HSAC Health Services Assessment Collaboration

A systematic review of the literature

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Systematic review of systems of palliative care

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Review Team

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The Palliative Care Advisory Group provided clinical and advisory input to the review (see Appendix A for membership). The systematic review of the evidence will ultimately be used by the Advisory Group to inform policy decision making in conjunction with other information. The content of the review alone does not constitute clinical advice or policy recommendations.

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Executive Summary

Introduction

The purpose of this systematic review (SR) is to review the existing published evidence relating to the effectiveness of systems or programs of palliative care provision possible for implementation at a national, state or provincial level. The review focuses on interventions that are comprehensive and multifaceted, with an emphasis on the structural/organisational aspects of service provision.

To address these issues, the review is structured in three parts:

1. A review of SRs of palliative care systems/programs
2. An SR of individual palliative care systems/programs.
3. A brief discussion of the feasibility of conducting a New Zealand-focused economic evaluation based on the information available

The review is intended to inform the development of a funding model for a structured palliative care system in New Zealand (NZ). If the outcome data contained within this report is considered to be reliable and applicable to NZ, it may be used to underpin a future economic evaluation. However it is beyond the scope of the current project to proceed to the conduct of that economic evaluation.

Methods

The clinical question to be answered by this review was defined by the Palliative Care Advisory Group in conjunction with the reviewers. In general, the aim of this review was to evaluate the effectiveness of different models of care of palliative care service delivery, with the longer term goal of developing a funding model for a structured palliative care system in NZ.

The primary research question to be addressed by this review was:

What is the effectiveness of different of systems or programs of palliative care provision for adult patients with advanced illness?

Part 1 presents the results of a literature search that is limited to existing systematic reviews of palliative care models, programs or systems. Details about each eligible citation were recorded in data extraction forms and this information was used to determine the extent to which the identified systematic reviews were able to satisfactorily answer the clinical question.

In **Part 2** of the review, the search was expanded to include published reports of individual palliative care programs. Although it was preferred that included studies should have a randomised controlled trial (RCT) design, it is often practically difficult to execute such trials, especially when an intervention requires extensive changes in organisational structure and workflow. Therefore the eligible evidence includes RCTs, controlled clinical trials (CCTs) and pre-post comparisons. Studies without a parallel control or comparison group were excluded.

The evidence identified through **Part 1** and **Part 2** was used in **Part 3** of this review to consider whether or not it is potentially relevant to NZ, and the feasibility of using the available literature to underpin an economic evaluation. Meta-analytic pooling of data was not undertaken due to the diversity of interventions and outcomes reported in the included studies.

The report methodology included a full systematic review of all levels of the available evidence including existing SRs and clinical practice guidelines, as well as different types of original primary studies. The search encompassed a range of bibliographic databases, review databases and HTA websites. Due to the emphasis on interventions implemented at a national, state, provincial or area/district health service level, an extensive search of the grey literature was also undertaken for policy documents, research reports and program evaluations. Searches were limited to English language material published from <1966 onwards. The searches were conducted between 18 February, 2010 and 24 February, 2010. Therefore, studies published after 24 February, 2010 were not considered for inclusion. Separate searches were conducted for the review of SRs presented in **Part 1**, and the review of original primary studies presented in **Part 2**.

Systematic reviews (in **Part 1**) were eligible if they included palliative care populations and were focused on the assessment of 'models of care'. Original studies (in **Part 2**) were eligible if they met the aforementioned criteria, and were also comparative, enrolled more than 100 patients in the intervention study arm, and were published in 1990 or later. Consistent with the system-wide approach to care delivery, only studies relating to at least an entire hospital catchment population were considered (i.e. hospital, area health service/district health board, town/city, province, state, country). As discussed previously, the review focused on interventions that were comprehensive and multifaceted, with an emphasis on the structural/organisational aspects of service provision. Studies that evaluated the impact of only one component of comprehensive palliative care were consequently excluded. Studies in a non-Western setting were also excluded.

The results of eligible SRs and primary studies were recorded in data extraction forms and this information was used to determine the extent to which the identified studies were able to satisfactorily answer the primary clinical question. Eligible studies from the systematic reviews identified in the first stage of the review (**Part 1**) were also assessed in the second stage (**Part 2**). National Health and Medical Research Council (NHMRC) dimensions of evidence, levels of evidence and quality assessment criteria, were used to evaluate each included study.

In the palliative care literature, there is a lack of consensus on the most appropriate instruments to use and as a result, there is very little consistency across studies. The current review reports a range of outcomes which were classified under the following commonly reported headings:

1. Patient quality of life
2. Patient satisfaction
3. Symptom control
4. Caregiver satisfaction
5. Place of death
6. Survival
7. Utilisation of resources
8. Cost of care

Key results

Part 1: Review of systematic reviews

The search strategy identified a total of 671 citations. After consideration of titles and abstracts using the study selection criteria, 40 full papers were retrieved and scrutinised in detail for possible inclusion in the review. As a result 16 publications reporting 14 systematic reviews were ultimately included in the review. Generally, the quality of the SRs identified through the literature search was good, with most adopting a systematic approach towards searching the literature and the inclusion/exclusion of evidence. Nonetheless, they all noted difficulties in assessing and analysing individual studies because of heterogeneity in terms of study design, settings, objectives, eligible populations, interventions and outcome measures.

Overall, the SRs of models of palliative care were heterogeneous and reported inconsistent results. For the majority of outcomes (i.e. quality of life, patient satisfaction, home deaths, survival and resource use) there was little evidence to suggest a benefit in favour of the intervention. Nor did the SRs report that any one model of palliative care was consistently more effective than another. Caregiver satisfaction was one of the few outcomes for which consistent benefits in favour of the intervention were observed. For symptom control, there were also some small but consistent benefits in favour of the intervention in SRs of Palliative Care Teams (PCTs).

Part 2: Review of original primary studies

The search strategy identified 152 studies via the reference lists of SRs and 1,661 non-duplicate citations identified through the updated literature search. After consideration of titles and abstracts using the study selection criteria, 195 full papers were retrieved and scrutinised in detail for possible inclusion in the review. As a result 33 publications reporting 26 original studies were ultimately included in the review. The eligible studies include 13 RCTs, one Level III-1 quasi-randomised study, 12 Level III-2 studies (including pre-post and non-randomised comparative studies) and two Level III-3 retrospective cohort studies. Most of the studies were poor to fair in terms of study quality; however, it should be noted that the conduct of high quality palliative care studies is complex due to problems associated with recruitment, attrition, and the vulnerability of the patient group. Despite these

obstacles, the literature search identified a number of reasonably large, well-designed, eligible RCTs.

Overall, the original studies of models of palliative care were heterogeneous and reported inconsistent results. For patient quality of life and survival, there was little evidence to suggest any benefits in favour of the intervention. On the other hand, there appear to be more good-quality studies reporting improvements patient satisfaction (Level II), symptom control (Level II) and caregiver satisfaction (Level II) as a result of the intervention, than there are reporting no effect at all. The results regarding place of death were largely inconclusive. In terms of resource use and costs of care, it would seem that programs involving home-care are associated with a reduction in the need for acute hospital care (Level II). There is also evidence from some high-quality RCTs pointing to a reduction in costs for programs including home care with PCT support.

It is important to note that there is no evidence in any of the outcome categories suggesting that the introduction of a palliative care intervention worsens patient or caregiver outcomes. Given that there is some evidence pointing to a reduction in costs in programs that involve home care with the support of a PCT, this is a significant finding.

Part 3: Feasibility of an economic evaluation

The systematic reviews undertaken in **Part 1** and **Part 2** of this report found little consistent evidence regarding patient quality of life benefits for palliative care compared to usual care in the literature identified. Nor was there sufficient evidence to say that one model of care was superior to another in terms of this outcome. The same conclusion was made in the systematic reviews of home care programs, palliative care teams, specialist palliative care programs, specialist palliative day care and general palliative care models. Further, the results for patient satisfaction were mixed, and depended on the nature of the intervention. However, there was some evidence to suggest palliative care programs including a PCT-based intervention may provide patients with symptom control benefits. Additionally, it is known that palliative care patients generally express a preference for dying at home and many of these programs assist in supporting this wish. Finally, caregiver satisfaction was one of the few outcomes for which consistent benefits in favour of the intervention were observed.

With regard to cost, a number of US-based RCTs have shown that the introduction of home care plus interdisciplinary PCTs may result in reduced direct costs to the health care system when compared to usual care. These reductions in costs reached statistical significance in two trials, one of which was a good quality RCT (Brumley *et al.*, 2007; Gade *et al.*, 2008). While numerically lower, the differences were not statistically different in the comparison of hospital-based home care versus usual care in the trial by Cummings *et al*. (1985) and in the comparison of the Advanced Illness Coordinated Care Program and usual care in the trial by Engelhardt *et al.* (2006). Reductions in hospital based costs appeared to be important components of the cost savings reported in many of these trials.

In summary, while there were inconsistent benefits recorded in the palliative care literature, on balance, these programs appear to show potential benefits for patients

and their carers, with no evidence for negative effects. From a cost perspective there is some evidence to suggest that these programs may result in reduced total health care costs. If these programs were found to provide benefits for patients and carers at a reduced total cost to the health care system they would dominate usual care and this would provide a strong case for their adoption. However, given the mixed results of the analyses seen in this review, and limited health care resources, the costs of any such program should be carefully assessed to assure that the system provides appropriate use of health care resources to provide value for money for New Zealand citizens.

The cost-effectiveness of these programs may be improved by developing a single New Zealand-wide framework of home based interdisciplinary palliative care. This would assist in the sharing of common specialist and administrative resources to support any such program. Further, a nationwide system is likely to provide clearer career paths for health care providers in this sector and allow movement of healthcare providers from one jurisdiction to another with less disruption to services and loss of expertise. In addition, a single national approach is likely to provide patients and their carers with consistency of care across the country. Further, it would appear that the mix of responsibilities taken by clinicians, nurses and other staff in the interdisciplinary palliative care teams may play an important role in the overall costs associated with these programs.

While the research identified herein were largely US-based, it would not appear to be unreasonable to assume some of the patient and the carer benefits of home-based interdisciplinary palliative care programs could also be realised in New Zealand. To determine the cost or cost-effectiveness of such a program it would be important to select the program from the literature that most suited New Zealand paying particular attention to the availability of healthcare staff and resources in this country. In the absence of evidence specific to the New Zealand setting, the inherent assumption would be that the effectiveness observed in the selected intervention would hold in New Zealand. The costing of these programs would then need to be facilitated by experts in the field describing the appropriate composition of the home based interdisciplinary palliative care team, the intensity of patient follow up and the structure of the program to be implemented.

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List of Abbreviations and Acronyms

4C	Continuing community cancer care
AD	Advanced directive
ADL	Activities of daily living
AHRQ	Agency for Healthcare Research and Quality
AICCP	Advanced illness coordinated care program
AIDS	Acquired immune deficiency syndrome
AOR	Adjusted odds ratio
AUC	Area under curve
CCP	Collaborative care plan
CCT	Controlled clinical trials
CDS	Caregiver demands scale
CHAH	Cambridge hospital at home service
CHF	Congestive heart failure
CI	Confidence interval
CM	Case management
COPD	Chronic obstructive pulmonary disease
CPG	Clinical practice guideline
CPR	Cardiopulmonary resuscitation
C QoL-C	Caregiver QoL index-cancer
DHB	District health boards
EDS	ESAS Distress Scores
EOL	End of life
EORTC	European Organisation for Research and the Treatment of Cancer
ESAS	Edmonton Symptom Assessment Scale
E-STATS	Expanded support team assessment schedule
FAMCARE	Family satisfaction with advanced cancer care
FATE	Family assessment of treatment at end-of-life
GP	General Practitioner
GSF	Gold Standards Framework
HADS	Hospital anxiety and depression scale
HBHC	Hines Model of Care
HBPC	Home based primary care
HIV	Human Immunodeficiency Virus
HMO	Health maintenance organisations
HRQoL	Health-related quality of life
HSAC	Health services assessment collaboration
HTA	Health technology assessment
ICU	Intensive care unit
ICS	Irish cancer society
IES	Impact of event scale
IHPC	Interdisciplinary home palliative care
IPCS	Interdisciplinary palliative care service
ITT	Intention to treat
KCE	Belgian Health Care Knowledge Centre
KP	Kaiser Permanente
KPI	Karnofsky performance index
LCP	Liverpool Care Pathway

LDS	Leiden detachment scale
LOS	Length of stay
MPAC	Memorial pain assessment card
MQOL	McGill QoL questionnaire
MSAS	Memorial symptom assessment scale
NCP	National Consensus Project
NHMRC	National Health and Medical Research Council
NICE	National Institute for Health and Clinical Excellence
NIH	National Institutes of Health
NR	Not reported
NS	Not significant
NZ	New Zealand
OPCC	Oncology palliative care clinic
OR	Odds ratio
PCIP	Palliative Care Integration Project
PCT	Palliative care team
PEP	Palliative care evaluation project
PHCT	Palliative home care team
POS	Palliative care outcomes scale
QoL	Quality of life
RCT	Randomised controlled trial
SD	Standard deviation
SE	Standard error
SHPC	Specialised home palliative care
SR	Systematic review
TCPG	TriCentre Palliative Care
TDS	Total Distress Scores
TIME	Toolkit of Instruments to Measure End of Life Care
UC	Usual care
UK	United Kingdom
US	United States
VA	Veterans Administration
VOICES	Views of informal carers – evalution of services
WHO	World Health Organisation

Introduction

According to the World Health Organisation (WHO, 2002) palliative care is:

"an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual."

Given the broad scope of this definition, it is not surprising that the provision of comprehensive palliative care is a complex task requiring input from a range of organisations and healthcare providers. Different approaches to service delivery are often distinguished by the make-up of their palliative care teams (PCTs) and the settings in which different aspects of patient management take place. Most patients receive end-of-life care in at least one of the following settings: hospitals (acute or sub-acute); inpatient hospices or palliative care services; home/supported residential setting (Finlay *et al.*, 2002). In addition, patients can receive supportive care at various ambulatory settings e.g. community health centres and day programs. With so many participants and possible configurations, insufficient planning and coordination of services can easily produce a system that is inefficient, ineffective and difficult for patients and their carers to navigate. The provision of cost-effective palliative care services is therefore a significant challenge in public health, especially in the context of an aging population.

Early systematic reviews regarding the effectiveness of palliative care were inconclusive because of poor study methodology and lack of clarity about outcome measures (Hearn and Higgenson, 1998; Critchley *et al.*, 1999). More recent evidence suggests that palliative care may improve outcomes; however the results are mixed for some outcomes and the size of the effect is unclear (Lorenz *et al.*, 2004). Overall, evidence on the efficacy of specific service models remains limited. Assessment of the effectiveness and cost-effectiveness offered by palliative care models in different settings is therefore needed to facilitate evidence-based health care planning. Research needs to focus on the development of systems that improve quality of life and satisfaction for patients and carers, but are also practical and affordable.

The majority palliative care recipients are cancer patients, and there is a correspondingly large amount of literature devoted to the needs of this group. In New Zealand, the majority of people who access palliative care services have a cancer diagnosis and are aged over 60 (Ministry of Health, 2001). Other populations that frequently require palliative management include patients with organ failure (e.g. congestive heart failure) and those with late-stage dementia. A recent study from the Netherlands (van der Velden *et al.*, 2009) used death certificate data to estimate the incidence and causes of non-acute death over a period of ten years. The study found that a little over half of all deaths from chronic diseases in the Netherlands were caused by cancer (52%), followed by stroke (12%), dementia (10%), chronic obstructive pulmonary disease (COPD) (8%), heart failure (8%) and diabetes (4.5%). Other diseases that caused death at a lower rate of incidence were Parkinson's disease, chronic kidney or liver diseases, spinal muscular atrophy, multiple sclerosis,

neuromuscular disorders and acquired immune deficiency syndrome (AIDS). While this picture may not necessarily reflect the prevalence of chronic disease in the community or the level of palliative care resource use in different disease groups, it provides an indication of the range of conditions that may require palliative management at some point in time. With improvements in cancer treatment and increasing rates of age-related illnesses (e.g. dementia), it is likely that these patterns will change over time and palliative care services will become less heavily geared towards the management patients with cancer.

Palliative care in New Zealand

The New Zealand Palliative Care Strategy (2001) was designed to set in place a systematic and informed approach to the provision and funding of palliative care services across New Zealand. The strategy focuses predominantly on establishing palliative care services, and applies the following definition of palliative care:

Care for people of all ages with a life-limiting illness which aims to:

- *optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.*
- *support the individual's family, whanau, and other caregivers where needed, through the illness and after death.*

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.

It should be available wherever the person may be.

It should be provided by all heath care professionals, supported where necessary, by specialist palliative care services.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Maori, children and young people, immigrants, refugees, and those in isolated communities.

The strategy emphasises the need for palliative care to be provided across a range of agencies and involve a partnership between primary care and a specialist palliative care provider. According to the New Zealand Palliative Care Strategy (2001) "*generalist and specialist services need to be part of an integrated framework of care provision which may be facilitated through local and regional networks, with defined formal linkages to key services including community primary care, local acute hospitals, regional cancer centres, and other regional palliative providers*." Generalist palliative care is defined as palliative care provided for those affected by life-limiting illness as an integral part of standard clinical practice by any healthcare professional that is not part of a specialist PCT. Generalist care is delivered in the community by general practice teams, Maori health providers, allied health teams, district nurses, and residential care staff. In a hospital setting, generalist care can be

provided by general ward staff and disease specific teams (e.g. oncology). Specialist palliative care is defined as "palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals."

A number of District Health Boards (DHBs) have implemented pilot palliative care strategies based on the principles identified in the NZ Palliative Care Strategy (2001). Some of these local strategies are based on international models, e.g. the Gold Standards Framework (GSF) (Thomas, 2003) and the Liverpool Care Pathway for the Dying Patient (Ellershaw *et al.*, 1997; Ellershaw *et al.*, 2003), both developed in the UK. Other DHBs have developed their own models of service delivery, also with an emphasis on the provision of generalist palliative care. These include the "Palliative Care Partnership" model of integrated palliative care developed by the MidCentral DHB (Stewart *et al.*, 2006).

Despite the existence of several well-organised local programs, at a national level, end-of-life services in New Zealand are relatively fragmented and inconsistent. A survey included in the recently published Positioning Palliative Care in New Zealand report (Palliative Care Council, 2010) found there was a relatively poor understanding of the need for care and a lack of information on the services being provided. Information about the effectiveness and cost-effectiveness of specific programs could inform the development of a funding model for a more structured and consistent palliative care system that represents acceptable value-for-money.

Objective

The purpose of this systematic review (SR) is to review the existing published evidence relating to the effectiveness of systems or programs of palliative care provision possible for implementation at a national, state or provincial level. The review is intended to inform the development of a funding model for a structured palliative care system in NZ. If the outcome data contained within this report is considered to be reliable and applicable to NZ, it may be used to underpin a future economic evaluation. However it is beyond the scope of the current project to proceed to the conduct of that economic evaluation. To address these issues, the review is structured in three parts:

1. A review of systematic reviews (SRs) of palliative care systems/programs
2. An SR of individual palliative care systems/programs.
3. A brief discussion of the feasibility of conducting a NZ-focused economic evaluation based on the information available

General methods

The aim of this systematic review was to identify research investigating the health outcomes and costs associated with well-described palliative care systems or programs *in toto*. Due to the emphasis on interventions implemented at a national, state, provincial or area/district health service level, an extensive search of the grey literature was also undertaken for policy documents, research reports and program evaluations.

The report methodology includes a full systematic review of all levels of the available evidence including existing systematic reviews and clinical practice guidelines, as well as different types of original primary studies.

Part 1 presents the results of a literature search that is limited to existing systematic reviews of palliative care models, programs or systems. Details about each eligible citation were recorded in data extraction forms and this information was used to determine the extent to which the identified systematic reviews were able to satisfactorily answer the primary clinical question.

In **Part 2** of the review, the search was expanded to include published reports of individual palliative care programs. Although it was preferred that included studies should have an RCT design, it is often practically difficult to execute such trials, especially when an intervention requires extensive changes in organisational structure and workflow. Therefore the eligible evidence includes RCTs, controlled clinical trials (CCTs) and pre-post comparisons. Studies without a parallel control or comparison group were excluded. The results of individual studies were recorded in data extraction forms and this information was used to determine the extent to which the identified studies were able to satisfactorily answer the primary and secondary clinical questions. Eligible studies from the systematic reviews identified in the first stage of the review were also assessed in the second stage.

The evidence identified through **Part 1** and **Part 2** will be used in **Part 3** of this review to consider whether or not it is potentially relevant to NZ, and the feasibility of using the available literature to underpin an economic evaluation. Meta-analytic pooling of data was not undertaken due to the diversity of interventions and outcomes reported in the included studies.

Research questions

The clinical question to be answered by this review was defined by the Palliative Care Advisory Group in conjunction with the reviewers. In general, the aim of this review was to evaluate the clinical efficacy of different models of care of palliative care service delivery, with the longer term goal of developing a funding model for a structured palliative care system in NZ.

The primary research question to be addressed by this review was:

What is the effectiveness of different of systems or programs of palliative care provision for adult patients with advanced illness?

In order to ensure the relevance of this review to the target palliative care population and the goals of the NZ Palliative Care Strategy, it was critical that the components of the main clinical question were appropriately defined. Broadly, the evidence included in this review was required to fulfil the PICO criteria outlined in **Table 1**.

Table 1: Criteria for determining study eligibility

Patient population	Adult patients who are candidates for palliative care according to the definitions provided in the NZ Palliative Care Strategy (2001). Patients with advanced cancer are the most common recipients of palliative care; however the evidence base will not be limited to this group.
Intervention	The review will consider any international structures, programs, systems or models of palliative care *in toto*. Where evidence relates to an individual component of palliative care (eg. respite care alone), this will not be included – as these do not address the question of the effectiveness of the program or system as a whole.
Comparator	Any alternative structure, program, system or model of palliative care (including no structured program).
Outcomes	Patient quality of life Patient satisfaction Symptom control Caregiver satisfaction Place of death Survival Utilisation of resources Cost of care

These PICO criteria were defined according to the definitions of palliative care used in the NZ Palliative Care Strategy, and current literature on best practice in palliative care. A detailed rationale for the selection of each criterion is provided in the sections below.

Selection of PICO criteria

Defining the eligible population

Since the concept of 'end-of-life' is inherently vague, the definitions of palliative care used in the published literature are somewhat variable. George (2002) reviews the conceptual issues that influence the validity and generalisability of palliative care studies. The definition of 'dying' is identified as the single most difficult and poorly handled issue in end-of-life research. While some investigators may apply the term to a patient's last few days or hours (sometimes referred to as active dying), others may assume it relates to the part of life when a person is impaired with an eventually fatal condition, even if the prognosis is ambiguous. A large proportion of studies do not provide a direct or implicit definition of 'dying' or 'terminal illness'.

When defining a population of interest, some studies select eligible patients based on prognosis (e.g. heart failure); however, many patients with fatal conditions have some probability for survival, even in their last weeks of life (Knaus *et al.*, 1995). Furthermore, physician's survival predictions are often inaccurate and tend to be overly optimistic (Glare *et al.*, 2003). Asking clinicians "Would it be a surprise if this patient were to die within 6 months?" is another approach, but also has had no rigorous testing (Thomas, 2004). Due to these limitations, the National Health and Medical Research Council (NHMRC) guidelines for a palliative approach in residential aged care (NHMRC, 2006) recommend that this approach should not be used to determine when palliative care should be commenced. Other studies use the health care setting to define the relevant population e.g. patients who access care through a hospice or intensive care unit (ICU). This approach has advantages in its

simplicity, but it excludes patients with terminal diseases who do not access specific palliative care systems.

The definition of a palliative care population used in New Zealand Palliative Care Strategy (2001) is:

"…people of all ages with a life-limiting illness, with little or no prospect of cure, and in whom death is the likely outcome - be that hours, days, weeks, months or sometimes years away."

This broad definition of "end-of-life" has become more widely accepted in recent years (Lorenz *et al.*, 2008) and is consistent with the approach espoused by the World Health Organisation (WHO, 2002). It supersedes earlier WHO definitions of palliative care, which were mostly relevant to patients not responsive to curative therapy and in their last stages of care. The revised meaning recognises that palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness. In the presence of such an illness, there may be a gradual transition from curative care to the acceptance that palliation is the major goal of management. There can also be occasions when disease modifying treatment is required for symptom control.

The population eligible for consideration in this review includes any patient with a terminal illness requiring palliative treatment in a home, hospital or other setting. The application of this relatively broad definition was thought to be appropriate given the wide range of approaches adopted in the literature. It should also be noted that the search did not include studies in specific disease populations (e.g. patients with gastrointestinal cancer) unless the disease category was broad enough for the results to be applicable to a general palliative care population (e.g. studies in patients with terminal cancer). Studies that were not exclusively in a palliative care population were also ineligible.

Defining the intervention

Palliative care is differentiated from curative strategies in that its goal is to manage the symptoms and consequences of disease. Interventions should be focused on improving quality of life rather than prolonging survival or preventing disease progression. Based on this principle, the current review is limited to interventions that do not address the cause of an illness or attempt to cure it. Specifically, clinical trials of chemotherapy, radiotherapy, surgery and other remedial strategies were not eligible for inclusion, unless the interventions were assessed beyond their effects on the primary disease process. It is also important to note that palliative care is generally thought to be distinct from supportive care, which is an umbrella term for all services that may be required to support palliative care patients and those who care for them. It is not a response to a particular stage of disease, but is based on an assumption that people have needs for supportive care from the time that they are diagnosed (Gysels and Higginson, 2004).

The interventions assessed in this review are meant to be structures, programs, systems or models of palliative care. Davidson *et al.* (2006) described a model of care as an "overarching design for the provision of a particular type of health care service that is shaped by a theoretical basis, evidence based practice and defined standards. It

consists of defined core elements and principles and has a framework that provides the structure for the implementation and subsequent evaluation of care". Well-rounded palliative care programs also address mental health and spiritual needs. While the strategies recommended by Qaseem *et al.* (2008) have been shown to improve quality of life in palliative care patients, for the purpose of this systematic review, they are regarded as possible components of program-based interventions or models of care. Studies that evaluated the impact of only one component of comprehensive palliative care (e.g. advance care planning or an episode of respite care) were consequently excluded from this review.

In recent years, this comprehensive approach to palliative care has been applied to develop systemic approaches towards end-of-life care. These initiatives include programs such as the National End of Life Care Program (UK Department of Health, 2008), Gold Standards Framework in Care Homes (Badger *et al.*, 2007) and the Liverpool Care Pathway (LCP) (Ellershaw *et al.*, 1997; Ellershaw *et al.*, 2003). These clinical pathways for end-of-life care are used widely around the world and have been set as the main part of the End-of- Life Care Strategy by the Department of Health in the UK (UK Department of Health, 2008; Veerbeek *et al.*, 2006).

Interventions eligible for inclusion in this review should therefore be comprehensive and multifaceted, combining clinical evidence with the needs and preferences of communities, health professionals, policy makers, funding agencies and professional organisations. There should also be an emphasis on the structural/organisational aspects of service provision. Consistent with the system-wide approach to care delivery, the search will focus on studies relating to at least an entire hospital catchment population were considered (i.e. hospital, area health service/district health board, town/city, province, state, country).

Defining the comparator

To minimise confounding, all assessed interventions should include a comparator or control. Eligible study types may range from RCTs to pre-post comparisons (only if data representing the pre-intervention system is adequately reported). Due to the multifaceted nature of program interventions, and the heterogeneous manner in which palliative care is delivered in different jurisdictions, it is difficult to define a single "standard of care" to serve as a suitable comparator for this review. Therefore, any report describing an alternative structure, program, system or model of palliative care (including no structured program) could be considered eligible for inclusion. The wide range of comparator interventions will have to be taken into consideration when establishing the relative efficacy of different models of care.

Defining the outcomes

The development of clinically relevant and valid outcomes in palliative care has been hampered by a lack of clear definitions and concepts in the field. In order to establish some uniformly accepted standards, the National Consensus Project (NCP) for Quality Palliative Care in the United States has published an overview of domains that are relevant to end-of-life care (Ferrell, 2005). The representatives of the NCP defined the following eight domains covering the WHO definition of palliative care (WHO, 2002): (1) structure and process of care, (2) physical aspects of care, (3) psychosocial and psychiatric aspects of care, (4) social aspects of care, (5) spiritual, religious, and existential aspects of care, (6) cultural aspects of care, (7) care of the

imminently dying patient, and (8) ethical and legal aspects of care. The NCP stated that the next step should be the development, testing, and implementation of quality indicators to allow the quality of care to be assessed and improved.

A recent systematic review by Pasman *et al.* (2009) summarised the literature on quality indicators for palliative care. The review found that most sets of quality indicators for palliative care consisted of process indicators reflecting documentation of care, as opposed to outcome indicators. While process indicators are relatively easy to use (Rubin *et al.*, 2001), they cannot provide direct evidence that any specific interventions are better or more effective than other interventions.

Traditional outcomes used to measure the efficacy of health interventions, such as mortality and morbidity, can be unsuitable in a palliative care setting. Outcomes relating to end-of-life treatment need to address the primary of objective of palliative care: to improve the quality of life of patients and carers. Unfortunately, many well-validated quality of life instruments become progressively insensitive as a patient's disease status deteriorates (McMillan and Weitzner, 2003). This is due to the fact that quality of life scales often focus on the assessment of physical functioning, and were initially validated in patients in early stage illness, such as cancer or whilst undergoing chemotherapy or curative treatment. The measurement of treatment efficacy in palliative care is also subject to the practical difficulties of collecting information from patients with a terminal illness. Palliative care trials are thus typically fraught with missing data and patients that are lost to follow-up.

A systematic review undertaken by the Agency for Healthcare Research and Quality (AHRQ) on end-of life care and outcomes attempts to identify elements that are important in advance care planning; collaboration and consultation; and assessment and support for patients receiving end-of-life care (Lorenz *et al.*, 2004). One of the key questions addressed in the review was "what is the reliability and validity of specific instruments for measuring quality of life or quality of care at end-of-life". The AHRQ literature search identified one comprehensive systematic review of measures relevant to end-of-life care: The Toolkit of Instruments to Measure End of Life Care (TIME) project (Teno, 2001). Based on a review of over 928 articles published from 1967 to 2000, the Toolkit finally recommends 35 unique measures to assist in the evaluation of end-of-life care. The AHRQ report (Lorenz *et al.*, 2004) identified 48 new measures to supplement those already described in the Toolkit. Nonetheless, the AHRQ report concluded that the majority of outcomes used in palliative care are not supported by sufficient reliability and validity testing. Since patients at the end of life (EOL) often receive care in multiple settings, instruments that are useful longitudinally and in hospitals, intensive care, outpatient settings, nursing homes, and at home are essential for comprehensive evaluations, but most instrument evaluations were limited to a single setting. Furthermore, validity studies addressing different populations (e.g. patients with diseases other than cancer) were also very uncommon. While there are a small number of measures that were developed specifically for use in a palliative population, most commonly used instruments have not been evaluated in end-of-life populations. Even in those domains where validated instruments do exist (e.g. quality of life or satisfaction); there remains a lack of consensus on the most appropriate instruments to use and very little consistency across studies.

With a lack of widely accepted assessment tools in palliative care, studies tend to report a wide range of outcomes. For consistency and simplicity, in the current review, outcomes have been classified under the following commonly reported headings:

9. Patient quality of life
10. Patient satisfaction
11. Symptom control
12. Caregiver satisfaction
13. Place of death
14. Survival
15. Utilisation of resources
16. Cost of care

Literature search

A systematic method of literature searching and selection was employed in the preparation of this review. Searches were limited to English language material published from <1966 onwards. The searches were conducted between 18 February, 2010 and 24 February, 2010. Therefore, studies published after 24 February, 2010 were not considered for inclusion in this systematic review. Separate searches were conducted for the review of SRs presented in **Part 1**, and the review of original primary studies presented in **Part 2**. The following databases were searched in both literature reviews:

Bibliographic databases

- Embase
- Medline

Review databases

- Cochrane Database of Systematic Reviews (including Cochrane Reviews, Other Reviews and Technology Assessments)
- Cochrane Central Register of Controlled Trials
- Database of Abstracts of Reviews of Effectiveness
- Health Technology Assessment database
- NHS Economic Evaluation database

HTA Groups

- INAHTA website database: http://www.inahta.org/Search2/?pub=1
- MSAC: http://www.msac.gov.au/
- ANZHSN: http://www.horizonscanning.gov.au/
- NZHTA: http://nzhta.chmeds.ac.nz/
- NICE: http://www.nice.org.uk/
- AHRQ/USPSTF: http://www.ahrq.gov/
- CADTH: http://www.cadth.ca/
- SBU: http://www.sbu.se
- KCE: http://kce.fgov.be

Clinical Practice Guidelines

- National Guideline Clearing House database: http://www.guideline.gov/
- Guidelines International Network: http://www.g-i-n.net/

The reference lists of included papers were scanned to identify any peer-reviewed evidence that may have been missed in the literature search. Hand searching of journals, contacting of manufacturers, or contacting of authors for unpublished research was not undertaken in this review; however an extensive search of the grey literature was performed for potentially relevant policy documents, research reports and program evaluations.

Search terms were searched for as keywords, exploded where possible, and as free text within the title and/or abstract, in the Embase and Medline databases. Variations on these terms were used for Cochrane library and Health Technology Assessment (HTA) websites modified to suit their keywords and descriptors. The search terms and search strategies used in **Part 1** and **Part 2** are presented in the relevant sections of this report.

Assessment of study eligibility

Studies were selected for appraisal using a two-stage process. First, titles and abstracts (where available) identified from the search strategy were scanned and excluded as appropriate. Second, the full text articles were retrieved for the remaining studies and selected for inclusion and appraisal in the review if they fulfilled the study selection criteria outlined below. Double-checking of the eligibility of studies by a second reviewer was not undertaken.

Non-English publications were excluded at the database searching stage. The exclusion criteria for eligible studies were based on the PICO criteria described earlier in this report. The eligibility criteria used in the selection of SRs (**Part 1**) differed to those applied in the search for original primary studies (**Part 2**). This was done to account for the heterogeneity of published SRs in palliative care, and to ensure that the search for original primary studies was limited to the most relevant evidence. Specifically, the search for original primary studies was limited to reports comparing models of care in at least an entire hospital catchment population (i.e. hospital, area health service/district health board, town/city, province, state, country), while the search for SRs included all reviews of palliative care models.

The assessment of eligibility for each search is listed in each appropriate section.

Appraisal of included studies

Dimensions of evidence

The aim of this review was to find the highest quality evidence to answer the clinical question. According to NHMRC guidance, the strength of a piece of evidence should be evaluated based on a number of dimensions, including: level of evidence, quality, statistical precision, effect-size and relevance (see **Table 2**).

Table 2: Dimensions of evidence (NHMRC, 2000b)

Dimension	Definition
Strength of evidence	
Level	The study design used, as an indicator of the degree to which bias has been eliminated by design.
Quality	The methods used by the investigators to minimise bias within a study design.
Statistical precision	The p-value or alternatively, the precision of the estimate of the effect (as indicated by the confidence interval). It reflects the degree of certainty about the existence of a true effect.
Size of effect	The distance of the study estimate from the 'null' value and the inclusion of only clinically important effects in the confidence interval.
Relevance of evidence	The usefulness of the evidence in clinical practice, particularly the appropriateness of the outcome measures used.

The highest level of evidence available is a systematic review of randomised controlled trials, which are considered the study type least subject to bias. Individual randomised controlled trials also represent good evidence. However, comparative observational studies such as cohort and case-control studies or non-comparative case series may often be more readily available. Such studies are often conducted early in the development of a technology, or to detect rare outcomes or outcomes which develop long after an exposure (e.g. cancer, cardiovascular disease). Nevertheless, these lower levels of evidence remain subject to considerable bias.

Each study was also assigned a level of evidence in accordance with the NHMRC (2005) interim levels of evidence (see **Table 3**).

Table 3 NHMRC Interim Levels of Evidence (NHMRC 2005) for Evaluating Intervention Studies

Level	Intervention
I *	A systematic review of level II studies
II	A randomised controlled trial
III-1	A pseudorandomised controlled trial (i.e. alternate allocation or some other method)
III-2	A comparative study with concurrent controls: . Non-randomised, experimental trial [a] . Cohort study . Case-control study . Interrupted time series with a control group
III-3	A comparative study without concurrent controls: . Historical control study . Two or more single arm study [b] . Interrupted time series without a parallel control group
IV	Case series with either post-test or pre-test/post-test outcomes

* A SYSTEMATIC REVIEW WILL ONLY BE ASSIGNED A LEVEL OF EVIDENCE AS HIGH AS THE STUDIES IT CONTAINS, EXCEPTING WHERE THOSE STUDIES ARE OF LEVEL II EVIDENCE.

[A] THIS ALSO INCLUDES CONTROLLED BEFORE-AND-AFTER (PRE-TEST/POST-TEST) STUDIES, AS WELL AS INDIRECT COMPARISONS (I.E. UTILISE A VS B AND B VS C, TO DETERMINE A VS C).

[B] COMPARING SINGLE ARM STUDIES I.E. CASE SERIES FROM TWO STUDIES.

NOTE: WHEN A LEVEL OF EVIDENCE IS ATTRIBUTED IN THE TEXT OF A DOCUMENT, IT SHOULD ALSO BE FRAMED ACCORDING TO ITS CORRESPONDING RESEARCH QUESTION E.G. LEVEL II INTERVENTION EVIDENCE; LEVEL IV DIAGNOSTIC EVIDENCE; LEVEL III-2 PROGNOSTIC EVIDENCE.

SOURCE: NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL (2005)

Even within the levels of evidence stated above there is considerable variability in the quality of evidence. In accordance with NHMRC guidelines, it was necessary to consider the quality of each of the included studies. NHMRC quality checklists (1999) have been employed to appraise included articles (**Appendix B**). The characteristics and quality of each included study were assessed using a number of quality criteria, as shown in **Table 4**, with studies rated as good, fair or poor quality.

Table 4 Quality criteria for different levels of evidence (NHMRC, 2000b)

Study type	Quality criteria
Systematic review	Was a clinical question clearly defined? Was an adequate search strategy used? Were the inclusion criteria appropriate and applied in an unbiased way? Was a quality assessment of included studies undertaken? Were the characteristics and results of the individual studies appropriately summarised? Were the methods for pooling the data appropriate? Were sources of heterogeneity explored?
Randomised controlled trials	Was allocation to treatment groups concealed from those responsible for recruiting subjects? Was the study double-blinded? Were patient characteristics and demographics similar between treatment arms at baseline? Were all randomised participants included in the analysis? Were the statistical methods appropriate? Were any subgroup analyses carried out?
Screening articles (using diagnostic criteria)	Were patients selected consecutively? Is the decision to perform the reference standard independent of the test results? Was there a valid reference standard? Are the test and reference standard measured independently Has confounding been avoided? If the reference standard is a later event that the test aims to predict, is any intervention decision blind to the result?
Other trials	Has selection bias been minimised? Have adequate adjustments been made for residual confounding? Was follow-up for final outcomes adequate? Has measurement or misclassification bias been minimised?

ADAPTED FROM NHMRC (2000)

It should also be noted that the grading of evidence in palliative care programs requires some special considerations. Given the real-world and multidisciplinary nature of palliative care programs, it is rarely feasible to blind patients and randomise them to treatment. Furthermore, the difficulties in identifying, recruiting and retaining patients mean that study populations often comprise those who are best able to cope and least ill. These factors have implications for the generalisability of RCT evidence in the assessment of palliative care models. Therefore, very useful information about the effectiveness of palliative care interventions can be derived from non-randomised comparative studies and pre-post program evaluations. In patients who are in their last days of life, RCTs can also be considered inappropriate and unethical. In light of these issues, it is not surprising that most SRs identified in this review include a variety of study designs ranging from RCTs to observational studies and surveys.

Because of the multi-faceted nature of palliative care programs, many studies report qualitative outcomes that cannot be statistically analysed. The assessment of

"statistical precision" and "size of effect" is therefore inapplicable. In studies that attempt to quantitatively evaluate a model of care, the most commonly reported outcomes are quality of life (QoL) and satisfaction with care. The instruments used to collect this data vary widely between studies, and statistical pooling of results is rarely possible. Because of the vastly different settings in which studies are undertaken, it is also difficult to prevent confounding. As a result of these challenges, very few systematic reviews identified in this literature search conducted proper appraisal of included studies, or reported quantitative findings.

Data extraction

Data was extracted onto specifically designed data extraction forms, and included information on study design, patient characteristics, the intervention, relevant outcomes, study quality and relevant results.

Unless otherwise specified, the data that were most adjusted for confounders and/or multiple comparisons were reported. Subgroup analyses were reported if they were considered relevant. Completed data extraction forms containing detailed information regarding study characteristics and quality, together with a brief summary of study results, can be found in **Appendix B**.

Data synthesis

Meta-analytic pooling of data was not undertaken due to the diversity of interventions and outcomes reported in the included studies. The results of relevant SRs and studies were summarised, compared and discussed qualitatively and using descriptive statistics where applicable. **Part 3** of this report considers the relevance of the evidence, both with regard to the applicability of the patient population and the intervention, as well as the relevance to the New Zealand health care setting. These conclusions will inform the feasibility of conducting a NZ-focused economic evaluation based on the available data.

Limitations of the review methodology

This review used a structured approach to review the literature. However, there were some inherent limitations with this approach. All types of study are subject to bias, with systematic reviews, such as the one conducted here, being subject to the same biases seen in the original studies they include, as well as biases specifically related to the systematic review process. Reporting biases are a particular problem related to systematic reviews and include publication bias, time-lag bias, multiple publication bias, language bias and outcome reporting bias (Egger *et al.,* 2001). A brief summary of the different types of reporting bias is shown in **Table 5.** Other biases can result if the methodology to be used in a review is not defined *a priori* (i.e., before the review commences). Detailed knowledge of studies performed in the area of interest may influence the eligibility criteria for inclusion of studies in the review and may therefore result in biased results. For example, studies with more positive results may be preferentially included in a review, thus biasing the results and overestimating treatment effect.

Table 5 Reporting biases in systematic reviews*

Type of bias	Definition and effect on results of review
Publication bias	The publication or non-publication of research findings. Small, negative trials tend not to be published and this may lead to an overestimate of results of a review if only published studies are included.
Time-lag bias	The rapid or delayed publication of research findings. Studies with positive results tend to be published sooner than studies with negative findings and hence results may be overestimated until the negative trials 'catch up'.
Multiple publication bias	The multiple or singular publication of research findings. Studies with significant results tend to be published multiple times which increases the chance of duplication of the same data and may bias the results of a review.
Citation bias	The citation or non-citation of research. Citing of trials in publications is not objective so retrieving studies using this method alone may result in biased results. Unsupported studies tend to be cited often which may also bias results.
Language bias	The publication of research findings in a particular language. Significant results are more likely to be published in English so a search limited to English-language journals may result in an overestimation of effect.
Outcome reporting bias	The selective reporting of some outcomes but not others. Outcomes with favourable findings may be reported more. For example, adverse events have been found to be reported more often in unpublished studies. This may result in more favourable results for published studies.

* ADAPTED FROM EGGER *ET AL.* (2001).

Some of these biases are potentially present in this review. In addition, the search was limited to English-language publications only so language bias is also potential problem. Outcome reporting bias and inclusion criteria bias are unlikely as the reviewers had no detailed knowledge of the topic literature, and the methodology used in the review and the scope of the review was defined *a priori.*

The review scope was developed with the assistance of Ministry of Health staff to support policy and purchasing relevant to New Zealand. The majority of studies included in this review were conducted outside New Zealand, and therefore, their generalisability to the New Zealand population and context may be limited and needs to be considered. This review was confined to an examination of the efficacy and safety of the interventions and did not consider ethical or legal considerations associated with those interventions.

The studies were initially selected by examining the abstracts of these articles. Therefore, it is possible that some studies were inappropriately excluded prior to examination of the full text article. However, where detail was lacking, ambiguous papers were retrieved as full text to minimise this possibility. Reasons for exclusion for every article included in the review are presented in **Appendix C** for transparency. Data extraction, critical appraisal and report preparation was performed by one reviewer and double-checked by another.

For a detailed description of interventions and evaluation methods, and results used in the studies appraised, the reader is referred to the original papers cited.

Part 1: Review of systematic reviews

Methods

Part 1 of this report is based on a review of systematic reviews. This choice of this methodology allows a high-level assessment of the quality and quantity of evidence available regarding the organisation of palliative care. The review also provides a comprehensive overview of diversity in palliative care models, and evidence on the effectiveness of these models in different health care settings. This search will also be used to help identify individual studies that may be eligible for inclusion in **Part 2** of this report.

Literature search for systematic reviews

Search terms were searched for as keywords, exploded where possible, and as free text within the title and/or abstract, in the Embase and Medline databases. Variations on these terms were used for the Cochrane library and other review databases to suit their keywords and descriptors. The search terms, search strategy and citations identified are presented in **Table 6**.

Table 6: Search strategy for systematic reviews

Database	Date searched	Search no.	Search terms	Citations
Embase + Medline	< 1966 – 18 February 2010	#1	'palliative therapy'/exp OR 'palliative therapy' OR 'terminal care'/exp OR 'terminal care' OR 'terminally ill'/exp OR 'terminally ill' OR 'terminal illness'/exp OR 'terminal illness' OR terminal* NEAR/2 ill* OR 'terminal disease'/exp OR 'terminal disease' OR palliat* OR 'EOL' OR 'dying'/exp OR 'dying' OR 'hospice'/exp OR 'hospice' OR limited NEAR/2 life* OR imminent NEAR/2 death OR incurabl* NEAR/2 ill*	122,630
		#2	'model of care' OR 'models of care' OR patient NEAR/2 manag* OR care NEAR/2 organisation* OR care NEAR/2 organisation* OR'integrated care' OR 'shared care' OR 'managed care'/exp OR 'managed care' OR care NEAR/2 delivery OR service NEAR/2 model OR 'multidisciplinary care' OR 'multi-disciplinary care' OR care NEAR/2 coordination OR 'health system':ab,ti OR 'health service':ab,ti OR'health care system':ab,ti OR program*:ab,ti OR 'policy':ab,ti OR 'policies':ab,ti OR 'patient care team':ab,ti	2,374,223
		#3	'meta analysis'/exp OR 'meta analysis' OR 'systematic review'/exp OR 'systematic review' OR 'pooled analysis' OR ('review'/exp OR 'review' AND ('meta analysis'/exp OR 'meta analysis' OR systemat* OR pool*))	110,291
		#4	#1 AND #2 AND #3	581
		#5	#4 AND [english]/lim	530
Cochrane library	18 February 2010	#1	Palliative care (title, abstract and keyword search, Cochrane Reviews and Other	162

			Reviews)	
HTA websites	24 February 2010	#1		3
CPG websites	24 February 2010	#1		0
Bibliographies of included studies and other sources				0
Total citations identified				695
Total citations after removal of duplicate citations				668

ABBREVIATIONS: CPG, CLINICAL PRACTICE GUIDELINE; EOL, END OF LIFE; HTA, HEALTH TECHNOLOGY ASSESSMENT

Assessment of review eligibility

SRs were selected for appraisal using a two-stage process. First, titles and abstracts (where available) identified from the search strategy were scanned and excluded as appropriate. Second, the full text articles were retrieved for the remaining SRs and selected for inclusion and appraisal in the review if they fulfilled the study selection criteria outlined below. Double-checking of the eligibility of studies by a second reviewer was not undertaken. As mentioned earlier, non-English publications were excluded at the database searching stage. The exclusion criteria for systematic reviews were based on the PICO criteria described earlier in this report, and are listed below:

1. Not a systematic review, including narrative reviews that were non-systematic.
2. The review did not deal with adult patients with a terminal illness requiring palliative treatment.
3. The review did not assess structures, programs, systems or models of palliative care.
4. The studies included in the review were not comparative.
5. The review reported results relating to at least one of the previously identified outcomes of interest.
6. The majority of studies included in the review were in a non-Western setting.

There were 668 non-duplicate studies identified by the search strategy described in **Table 6**. The application of exclusion criteria to identify eligible citations is presented in **Table 7**. All excluded articles are presented in **Appendix C**, annotated by reason for exclusion.

After screening the titles and abstracts of identified citations, 40 full text articles were eligible for retrieval. Following the full-text review, eight citations were excluded because they were narrative reviews or Cochrane protocols that are yet to be completed (Curivale *et al.*, 2007; Gomes *et al.*, 2009; Ream *et al.*, 2009). In addition, the search identified one recent Cochrane review on end-of-life care pathways (Chan et al., 2010) in which no studies were found to fulfil the eligibility criteria.

Seven studies were excluded on the basis that they did not include patients in appropriate study populations. As discussed previously, the search did not allow studies in specific disease populations (e.g. patients with gastrointestinal cancer) unless the disease category was broad enough for the results to be applicable to a general palliative care population (e.g. studies in patients with terminal cancer). Studies that were not exclusively in a palliative care population were also ineligible. Based on this eligibility criterion, the full text review excluded a number of papers in Human Immunodeficiency Virus/ Aquired Imune Deficiency Syndrome (HIV/AIDS)

patients (Harding *et al.*, 2005) and populations with dementia or persistent mental illness (Woods *et al.*, 2008 and Roberts *et al.*, 2000).

Many of the SRs that were subject to full text review allowed a broad range of study designs, including some original primary studies that were not comparative (Davies *et al.*, 2005; Francke *et al.*, 2000; Higginson *et al.*, 2003; Finlay *et al.*, 2002; Gysels and Higginson, 2004; Salisbury *et al.*, 1999; and Wilkinson *et al.*, 1999). In this review of SRs, those studies that included some studies with comparative study designs were considered to be eligible for inclusion. Two SRs in which none of the included studies were comparative were excluded (Agren Bolmsjo *et al.*, 2008; Evans *et al.*, 2003).

The reviews were also heterogeneous in terms of the assessed interventions. Some assessed specific models of palliative care such as the use of PCTs (Higginson *et al.*, 2003); homecare interventions (Smeenk *et al.*, 1998); or specialised palliative care services (Zimmermann *et al.*, 2003). Other reviews (Critchley *et al.*, 1999; Garcia-Perez *et al.*, 2009; Thomas *et al.*, 2006; and Wadhwa and Lavizzo-Mourey, 1999) included any SR that addressed the organisation of end-of-life care. It should be noted that these reviews used different definitions of a 'model of care' to select eligible studies. Critchley *et al.* (1999) included studies if they assessed "ways of providing care" to palliative care patients, while Wadhwa and Lavizzo-Mourey (1999) identified ten specific models of health care delivery in their literature search. Given the broad scope of the subject area, the interpretation of these definitions was necessarily associated with a degree of subjectivity and was highly dependent on the use of appropriate search terms. This review of SRs adopts an inclusive approach, whereby all studies claiming to assess models or organisational aspects of palliative care were included, regardless of the definitions or search terms used. Applying this approach, two SRs were excluded because they did not assess structures, programs, systems or models of palliative care (George *et al.*, 2002 and Mitchell *et al.*, 2002). The search also identified a review of SRs, commissioned by the National Institutes of Health (NIH) and undertaken by ARHQ (Lorenz *et al.*, 2004; Lorenz *et al.*, 2005; Lorenz *et al.*, 2008 and Dy *et al.*, 2008). Since many of the publications included in the ARHQ review reported the effectiveness of specific interventions (such as advance care planning), the results of this report were not considered relevant to the main research question (i.e. the effectiveness of different models of care). Four citations associated with the ARHQ report (Dy *et al.*, 2008, Lorenz *et al.*, 2004, Lorenz *et al.*, 2005 and Lorenz *et al.*, 2008) were excluded from the current review. Altogether, six citations were therefore excluded because they did not describe models of care.

Table 7: Application of selection criteria to citations

Exclusion criteria	Number
Total citations	668
Title/abstract (first pass):	668
Not a systematic review, including narrative reviews that were non-systematic and studies that were incomplete (e.g. protocols).	13
The review dealt with adult patients with a terminal illness requiring palliative treatment.	466
The review did not assess structures, programs, systems or models of palliative care.	149
The studies included in the review were not comparative.	0
The studies included in the review were in a non-Western setting.	0
Full papers reviewed:	40
Not a systematic review, including narrative reviews that were non-systematic and studies that were incomplete (e.g. protocols).	9 [a]
The review dealt with adult patients with a terminal illness requiring palliative treatment.	7
The review did not assess structures, programs, systems or models of palliative care.	6
The studies included in the review were not comparative.	2
The studies included in the review were in a non-Western setting.	0
Total included citations	16
Total included original SRs	14 [b]

[A] INCLUDES ONE COCHRANE REVIEW ON END-OF-LIFE CARE PATHWAYS (CHAN *ET AL*., 2010) IN WHICH NO STUDIES WERE FOUND TO FULFIL THE ELIGIBILITY CRITERIA. ALSO INCLUDES THREE COCHRANE REVIEW PROTOCOLS THAT ARE AS YET, INCOMPLETE (CURIVALE *ET AL*., 2007; GOMES *ET AL*., 2009; REAM *ET AL*., 2009)

[B] INCLUDES TWO REVIEWS OF SYSTEMATIC REVIEWS (KEIRSE *ET AL*., 2009 AND GARCIA-PEREZ *ET AL*., 2009)

ABBREVIATIONS: SR, SYSTEMATIC REVIEW

Following the application of selection criteria to all citations identified in the literature search, 16 published reports were found to be eligible for inclusion in this review. These citations report the results of 14 original SRs.

The publications by Salisbury *et al.* (1999) and Wilkinson *et al.* (1999) report the results of the same SR. The report by Salisbury *et al.* (1999) concentrates on quality of life outcomes, while the report by Wilkinson *et al.* (1999) presents outcomes relating to patient and carer preference and satisfaction. The publications by Higginson *et al.* (2003) and Finlay *et al.* (2002) also report the results of a single SR; however, the paper by Higginson also includes a meta-analysis and meta-synthesis of outcomes. Note that the National Institute for Health and Clinical Excellence (NICE) review by Higginson *et al.* (2003) differs from the SR by Higginson *et al.* (2003) and Finlay *et al.* (2002) since it includes all specialist palliative care services, not just team-based interventions. The publication by Higginson *et al.* (2002) presents a subset of the data included in the review of PCTs reported by Higginson *et al.* (2003), but focuses on palliative teams operating in hospitals. Because the two reviews report different results based on different (albeit not mutually exclusive) data sets, they are treated as separate studies in the current report. The review of palliative day care services by Davies et al (2005) was an update of a chapter in the NICE review by Gysels and Higginson (2004), but since it includes new evidence, this paper will be regarded as a separate study in the review.

The final list of eligible SRs also includes two recently published reviews of SRs (Keirse et al, 2009; and Garcia-Perez *et al.*, 2009). The review by Keirse *et al.* (2009)

was undertaken by the Belgian Health Care Knowledge Centre (KCE) as part of a report on the organisation of palliative care in Belgium. The KCE report specifically addressed the effectiveness of different models of palliative care, and was therefore considered highly relevant to the current review. The review by Garcia-Perez *et al.* (2009) included SRs or clinical studies in which at least two different specialised palliative care programs were compared.

The details of the 16 eligible SRs and their corresponding studies are provided in **Table 8** below.

Table 8: Included systematic reviews for models of palliative care

Study ID	Citation (s)
Smeenk *et al*., 1998	Smeenk FWJ, Van Haastregt JCM, De Witte LP, and Crebolder HFJ. (1998) Effectiveness of home care programs for patients with incurable cancer on their quality of life and time spent in hospital: Systematic review. British Medical Journal 316:1939-1944.
Wadhwa and Lavizzo-Mourey, 1999	Wadhwa S and Lavizzo-Mourey R. (1999) Tools, methods, and strategies. Do innovative models of health care delivery improve quality of care for selected vulnerable populations? A systematic review. The Joint Commission journal on quality improvement 25:408-433.
Francke *et al*., 2000	Francke AL. (2000) Evaluative research on palliative support teams: a literature review. Patient Education and Counseling 41:83-91.
Hearn and Higginson, 1998	Hearn J and Higginson IJ. (1998) Do specialist PCTs improve outcomes for cancer patients? A systematic literature review. Medicine 12:317-332.
Higginson *et al*., 2003; Finlay *et al*., 2002	Higginson IJ, Finlay IG, Goodwin DM, Hood K, Edwards AGK, Cook A, Douglas HR, and Normand CE. (2003) Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? Journal of Pain and Symptom Management 25:150-168. Finlay IG, Higginson IJ, Goodwin DM, Cook AM, Edwards AGK, Hood K, Douglas HR, and Normand CE. (2002) Palliative care in hospital, hospice, at home: Results from a systematic review. Annals of Oncology 13:257-264.
Higginson *et al*., 2002	Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AGK, Douglas HR, and Norman CE. (2002) Do hospital-based palliative teams improve care for patients or families at the end of life? Journal of Pain and Symptom Management 23:96-106.
Garcia-Perez *et al*., 2009	Garcia-Perez L, Linertova R, Martin-Olivera R, Serrano-Aguilar P, and itez-Rosario MA. (2009) A systematic review of specialised palliative care for terminal patients: Which model is better? Medicine 23:17-22.
Gysels and Higginson., 2004 (NICE guideline – specialist palliative care services)	Gysels M and Higginson I. (2004) Improving Supportive and Palliative Care for Adults with Cancer. Research Evidence Manual.
Salisbury et al., 1999; Wilkinson et al., 1999	Salisbury C, Bosanquet N, Wilkinson EK, Franks PJ, Kite S, Lorentzon M, and Naysmith A. (1999) The impact of different models of specialist palliative care on patients' quality of life: A systematic literature review. Medicine 13:3-17. Wilkinson EK, Salisbury C, Bosanquet N, Franks PJ, Kite S, Lorentzon M, and Naysmith A. (1999) Patient and carer preference for, and satisfaction with, specialist models of palliative care: A systematic literature review. Medicine 13:197-216.

Table 8: Included systematic reviews for models of palliative care *cont.*

Zimmermann *et al*., 2008	Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, and Tannock I. (2008) Effectiveness of specialized palliative care: A systematic review. JAMA - Journal of the American Medical Association 299:1698-1709.
Davies *et al*., 2005	Davies E and Higginson IJ. (2005) Systematic review of specialist palliative day-care for adults with cancer. Supportive Care in Cancer 13:607-627.
Critchley *et al*., 1999	Critchley P, Jadad AR, Taniguchi A, Woods A, Stevens R, Reyno L, and Whelan TJ. (1999) Are some palliative care delivery systems more effective and efficient than others? A systematic review of comparative studies. Journal of Care 15:40-47.
Thomas *et al*., 2006	Thomas RE, Wilson D, and Sheps S. (2006) A literature review of randomised controlled trials of the organisation of care at the end of life. Canadian Journal on Aging 25:271-293.
Keirse *et al*., 2009	Keirse E, Beguin C, Desmedt M, Deveugle M, Menten J, Simoens S, Wens J, Borgermans L, Kohn L, Spinnewijn B, Cardinael A, Kutten B, Vandenberghe P, and Paulus D. (2009) Organisation of palliative care in Belgium - supplement. Health Services Research.

Results

Overview

Methodological information and results extracted from eligible SRs are presented below. More detailed information is available in **Appendix B** or in the original papers. Only data relevant to the current review is presented.

Systematic reviews: characteristics

As discussed above, the search identified 15 eligible SRs, including two reviews of SRs (Keirse *et al.*, 2009 and Garcia-Perez *et al.*, 2009). Study characteristics of the included SRs are presented in **Table 9** below. More detailed information is available in **Appendix B** or in the original papers. Only data relevant to the current review is presented.

All of the included reviews were in adult populations with end-stage or terminal conditions. Quality of life, satisfaction with care, and symptom-control were some of the most frequently reported patient-relevant outcomes. Some reviews had a broader focus, and also included outcomes that were relevant to carers, the families of palliative care patients (Francke *et al.*, 2000; Gysels and Higginson, 2004; Hearn and Higginson, 1998; Higginson *et al.*, 2003; and Higginson *et al.*, 2002) or the health care system as a whole (Critchley *et al.*, 1999; Davies *et al.*, 2005; Francke *et al.*, 2000; Zimmermann *et al.*, 2008 and Keirse *et al.*, 2009). Given the heterogeneity of included studies, many reviews did not define the required outcomes *a priori*.

Although all of the reviews assessed the efficacy of palliative care models, there was considerable heterogeneity in the assessed interventions. Some reviews were limited to specific types of palliative care models; for example, the review by Smeenk *et al.* (1998) investigated the use of comprehensive home care programs in palliative care. Wadhwa and Lavizzo-Mourey (1999) investigated three 'innovative' models of care in terminally ill patients: multidisciplinary teams, home care and case management. A large amount of literature was focused on the effectiveness of PCTs (Finlay *et al.* 2002; Franke *et al.*, 2000; Hearn and Higginson, 1998; Higginson *et al.*, 2003; and Higginson *et al.*, 2002). Other reviews included studies in which the primary intervention was any specialist palliative care service (Garcia-Perez *et al.*. 2009; Gysels and Higginson, 2004; Salisbury *et al.*, 1999; Wilkinson *et al.*, 1999 and Zimmermann *et al.*, 2008). Davies *et al.* (2005) reviewed the effectiveness of specialist palliative day-care services. A specialist intervention was generally defined as one in which care is provided by professionals trained in palliative care. Note that some (but not all) specialist interventions can also be classified as team-based interventions (Hearn and Higginson, 1998; Higginson *et al.*, 2003; and Higginson *et al.*, 2002). Another group of reviews were less specific in their eligibility criteria, and included a broad range of palliative care models, organisational interventions or programs (Critchley *et al.*, 1999; Thomas *et al.*, 2006; and Keirse *et al.*, 2009).

The eligible reviews were also varied in terms of the number and quality of included studies. Three of the reviews only included RCTs (Critchley *et al.*, 1999, Thomas *et al.*, 2005 and Zimmermann *et al.*, 2008), while others were limited to comparative studies (Garcia-Perez *et al.*, 2008; Higginson *et al.*, 2003; Higginson *et al.*, 2002; Salisbury *et al.*, 1999; Smeenk *et al.*, 1998; Wilkinson *et al.*, 1999; and Wadhwa and

Lavizzo-Mourey, 1999). There were also a number of reviews that included a mix of comparative and non-comparative studies (Davies *et al.*, 2005; Francke *et al.*, 2000; Gysels and Higginson, 2004 and Hearn and Higginson, 1998).

The report published by Keirse *et al.* (2009) was a review of SRs; however, the results were actually based on an analysis of individual studies within the eligible SRs. These individual studies were deemed eligible for inclusion if they reported the results of a trial or intervention study, and contained sufficient information about study methodology. Similarly, the review of SRs by Garcia-Perez *et al.* (2009) focused on the results of four studies that were included as evidence in the eligible SRs.

Table 9: Systematic review characteristics

Author & year [Level of evidence]	Research question/aims	Type of included studies	Population	Intervention	Comparator	Outcomes of relevance
Smeenk *et al.*, 1998 [Level I/IV [a]]	To investigate whether for patients with incurable cancer comprehensive home care programs are more effective than standard care in maintaining the patients' quality of life and reducing their "readmission time" (percentage of days spent in hospital from start of care till death).	Clinical trials, cohort studies, case-control studies, comparative studies with historical controls, within group comparison studies, economic evaluations and high quality systematic reviews. **Includes 9 studies**	Patients with incurable cancer	Comprehensive home care program. Studies of specific home care interventions aimed at just one aspect of care (such as home parenteral nutrition or pain treatment) were excluded	The control group had to have received standard available (home) care; studies in which the control group received only hospital care were excluded	The dependent variables in the study included at least one dimension of quality of life or the readmission rate of patients.
Wadhwa and Lavizzo-Mourey, 1999 [Level I/IV [a]]	To determine whether multidisciplinary teams, outreach or home care and case management improve the quality of care in two vulnerable populations: the terminally ill and mentally ill.	Prospective comparative studies containing a group receiving conventional care. **Includes 7 studies**	The study population fell into one of the two vulnerable population categories: the terminally ill and mentally ill.	One or a combination of the three innovative models of care i.e. multidisciplinary teams, outreach or home care and case management.		The outcomes measured were clinical outcomes or a quality measure.
Francke *et al.*, 2000 [Level I/IV [a]]	1. What evaluative methods and instruments have been used in evaluative studies of palliative support teams? 2. What evaluative outcomes were reported with respect to physical, psychosocial, spiritual problems of patients and relatives as well as consumption and cost of health care?	Evaluative studies focusing on the outcomes of a palliative support team on patients, relatives or consumption/cost of care **Includes 16 studies, 6 of which had a comparator study arm**	The team evaluated should provide advice or support to terminal patients, relatives or care providers	Palliative support teams, defined as teams that give advice about palliative care and often also practical help to patients and/or care providers		Any outcomes related to the patients, their family members, health care providers or the health care system.

Table 9: Systematic review characteristics *cont.*

Author & year [Level of evidence]	Research question/aims	Type of included studies	Population	Intervention	Comparator	Outcomes of relevance
Hearn and Higginson, 1998 [Level I/IV [a]]	To determine whether teams providing specialist palliative care improve the health outcomes of patients with advanced cancer and their families or carers when compared to conventional services	RCTs and comparative or observational studies **Includes 18 studies**	Patients with advanced cancer and their families were included. Those studies focusing on one cancer site, for example, breast cancer, were not included	Specialist teams caring for advanced cancer patients and their families.		Not specifically described
Higginson *et al.*, 2003; Finlay *et al.*, 2002 [Level I/IV [a]]	Do PCTs achieve their aims and improve outcomes for patients or caregivers, or reduce costs? Which model(s) were most effective in delivery?	Comparative studies. Anecdotal and case reports or studies without measured outcomes were excluded **Includes 44 studies**	Study populations were patients with a progressive life threatening illness and their caregivers (defined as family, friends, or significant others)	Palliative care or hospice teams containing two or more health care workers, at least one of whom had specialist training or worked principally in palliative or hospice care	Usual care was routine community and general hospital/oncology services	Outcomes were classified as: pain and symptom control, quality of life and death; patient and family satisfaction/morbidity pre- and post-bereavement.
Higginson *et al.*, 2002 [Level I/IV [a]]	A systematic literature review of evaluations of hospital based teams to determine whether they affect care in hospital	Comparative studies. Anecdotal and case reports or studies without measured outcomes were excluded **Includes 13 studies**	The subjects of the research were defined as those patients with a progressive life-threatening illness, and their family, carers, or close friends	PCTs working in hospitals. Such teams were defined as: two or more health care workers, at least one of whom had specialist training or worked principally in palliative care	Usual care included routine community and general hospital/oncology services, and isolated professionals who have undertaken limited training in palliative care	Pain; control of other specific symptoms such as nausea, anorexia, tiredness; improved quality of life and quality of death; patient satisfaction and carer satisfaction pre-bereavement; carer morbidity pre- and post-bereavement.

Table 9: Systematic review characteristics *cont.*

Author & year [Level of evidence]	Research question/aims	Type of included studies	Population	Intervention	Comparator	Outcomes of relevance
Garcia-Perez *et al*., 2009 [Level I/IV [a]]	To determine the effectiveness and cost-effectiveness of different organisational models of specialised palliative care	Studies were excluded unless they compared at least two different specialised palliative care programs. **Includes 6 SRs, 3 studies on effectiveness and one cost study.**	Adults (18 years and older) with terminal illness included in a palliative care programs	Specialised palliative care programs (i.e. care provided by professionals trained in palliative care)		Control of pain and other symptoms, psychological symptoms, HRQoL, well-being, functional state, satisfaction, place of death, number of patients cared, number of home visits and number of days at hospital
Gysels and Higginson., 2004 (NICE guideline – specialist palliative care services) [Level I/III [a]]	To determine the effectiveness of different interventions, targeted at health care professionals or the structure in which health care professionals deliver their care, to improve the supportive and palliative care for those affected by cancer.	RCTs, controlled clinical trials, controlled before and after studies, interrupted time series and observational studies and SRs **Includes 54 original studies.**	Any person involved in the delivery of supportive and palliative care for those affected by cancer in a hospital, home or community setting	Any intervention strategies to improve the supportive and palliative care for those affected by cancer, specifically 1. Professional interventions 2. Organisational interventions		Objectively measured health professional performance or patient outcomes in a clinical setting and self report measures with known validity and reliability
Salisbury *et al*., 1999; Wilkinson *et al*., 1999 [Level I/IV [a]]	To evaluate the impact of alternative models of palliative care on quality of life or symptom control (Salisbury *et al*., 1999) To evaluate the impact of specialist models of palliative care on consumer satisfaction, opinion and preference	Comparative studies which evaluated a model of specialist palliative care, and used quality of life as an outcome measure. **Includes 22 descriptive studies and 27 comparative studies** (the latter being the main subject of the study).	Studies measuring the impact of palliative care on the quality of life of carers were excluded. Studies on quality of life of cancer patients who were not terminally ill were not included unless a specific reference to terminally ill patients was included.	At least two different specialised palliative care programs.		Quality of life, including formal measures of quality of life and measures of pain control, symptom control or general well-being.

Table 9: Systematic review characteristics *cont.*

Author & year [Level of evidence]	Research question/aims	Type of included studies	Population	Intervention	Comparator	Outcomes of relevance
Zimmermann *et al*., 2008 [Level I/IV [a]]	To examine systematically the evidence for effectiveness of specialised palliative care in improving quality of life, satisfaction with care, and economic cost.	RCTs evaluating a specialised palliative care service. **Includes 22 RCTs**	Not described	Studies including a specialised palliative care service in either arm.		Quality of life, satisfaction with care, or economic cost were eligible.
Davies *et al*., 2005 [Level I/IV [a]]	A list of review questions for the role of specialist palliative day-care was devised addressing service structure, care processes, and outcomes of care	Studies including the outcome measures of interest published in English (not including historical reviews, personal views, expert consensus and case studies of single patients) **Includes 12 comparative and non-comparative studies**	Patients aged 18 years or over enrolled in specialist palliative day-care services	Specialist palliative day-care services		Funding, organisation and management of services Staff skill mix and interventions offered to patients and relatives Referral, allocation of places to patients and discharge Uptake of interventions by patients and relatives Patient or relative satisfaction with care Patient outcomes including symptom control, HRQoL and social and psychological support
Critchley *et al*., 1999 [Level I/IV [a]]	To conduct a systematic review of comparative studies looking at the effectiveness of different models to provide palliative care services	Comparative studies of any methodological design **Only four of the 41 studies that were initially selected provided information on all clinically relevant elements selected *a priori***	Patients of any age described as palliative, or as having end-stage or terminal conditions	'Ways of providing care' in the eligible population		Any outcomes related to the patients, their family members, health care providers or the health care system
Thomas *et al*., 2006 [Level I/IV [a]]	To identify and analyse RCTs that focus on the organisation of EOL care provided to persons who are terminally ill, near death, or dying	RCTs **Includes 23 RCTs**	Not specifically described	Not specifically described	Not specifically described	Not specifically described

Table 9: Systematic review characteristics *cont.*

Author & year [Level of evidence]	Research question/aims	Type of included studies	Population	Intervention	Comparator	Outcomes of relevance
Keirse *et al*., 2009 [Level I/IV]	What types of care models do exist for patients who need palliative care and what evidence is available on the diversity and effectiveness of these models?	SRs and individual studies from SRs **Includes 11 SRs representing 59 individual studies**	Patients who need palliative care, aged 18 or over.	A comprehensive approach to care that evaluated structural and/or organisational aspects and/or outcomes of palliative care. Studies that evaluated (the impact of) only one component of comprehensive palliative care on only 1 aspect of quality of life (e.g. impact of pain medication on pain) were excluded.		During review, outcomes measures were grouped in four categories: 1. Biological outcomes 2. Psycho-social outcomes 3. Economic outcomes 4. Other outcomes

ABBREVIATIONS: EOL, END OF LIFE; HRQOL, HEALTH-RELATED QUALITY OF LIFE; NICE, NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE; PCT, PALLIATVE CARE TEAM; RCT, RANDOMISED CONTROLLED TRIAL; SR, SYSTEMATIC REVIEW;

Systematic reviews: results

Key conclusions of the included SRs are presented in the tables below. Given the heterogeneity of included interventions and assessed outcomes, very few of the SRs performed meta-analytic pooling or reported quantitative results. The only study that performed any form of data analysis was the systematic review undertaken by NICE (Gysels and Higginson, 2004). It combined three methods of data analysis. A meta-analysis, following Cochrane methods assessed specific outcomes, such as pain, symptom control etc, a meta-regression, using all the outcome data, and exploring factors, such as team composition, which may have affected the outcomes, and a qualitative meta-synthesis, combining all studies. Funnel plots indicated slight publication bias.

The range of studies included in the SRs varied due to differences in the interventions, inclusion criteria (e.g. eligible study types) and dates of publication. Nonetheless, some studies appear in more than one SR and there may therefore be a degree of duplication when the results of SRs are compared to one another.

Since the original studies incorporated a wide range of assessment tools, most of the SRs classify results in several broad categories of outcomes. For consistency, in the current review, outcomes have been grouped into the following commonly reported categories:

- Patient quality of life
- Patient satisfaction
- Symptom control
- Caregiver satisfaction
- Place of death
- Survival
- Utilisation of resources
- Cost of care

Results pertaining to the aforementioned outcomes are presented in detail in the tables below. As discussed above, many of the reviews differed in their inclusion criteria for eligible interventions. Some reviews were limited to specific types of palliative care models (Smeenk *et al.*, 1998; Wadhwa and Lavizzo-Mourey, 1999; and Davies *et al.*, 2005), while a number of studies focused on the effectiveness of PCTs, most of which focused on specialist teams (Franke *et al.*, 2000; Hearn and Higginson, 1998; Higginson *et al.*, 2003; and Higginson *et al.*, 2002). Another group of reviews included studies in which the primary intervention was any specialist palliative care service (Garcia-Perez *et al.*. 2009; Gysels and Higginson, 2004; Salisbury *et al.*, 1999; Wilkinson *et al.*, 1999 and Zimmermann *et al.*, 2008). Other reviews had broad eligibility criteria, including a wide range of palliative care models, organisational interventions or programs (Critchley *et al.*, 1999; Thomas *et al.*, 2006; and Keirse *et al.*, 2009). Where applicable, reviews assessing similar interventions are discussed together.

Most SRs noted that the primary included studies were generally of poor methodological quality, and should therefore be interpreted with caution. Many SRs

also highlighted the need for further trials, using a standardised palliative care interventions and measures constructed specifically for this population.

Systematic review results: Patient quality of life

Results pertaining to quality of life are presented in **Table 10** below. In their review of comprehensive home care programs compared to standard care, Smeenk *et al.* (1998) found a significantly positive influence on physical dimensions of quality of life in three out of seven studies.

Of the studies focusing on PCTs, only the review of hospital-based teams found a small but non-significant effect in favour of the intervention (Higginson *et al.*, 2002). The most recent and comprehensive review of PCTs by Higginson *et al.* (2003) reported inconclusive results.

The reviews of specialised palliative care models (Garcia-Perez *et al.*, 2009; Gysels and Higginson., 2004; Salisbury *et al.*, 1999; Wilkinson *et al.*, 1999; and Zimmermann *et al.*, 2008) also failed to identify significant improvements in quality of life as a result of palliative care interventions. Nor did they find that any one intervention was superior to another. Of the reviews of specialised interventions, the review by Garcia-Perez *et al.* (2009) is the most recent. This SR reported no differences in health-related quality of life between a broad service provided by a team of referring specialists at hospital and telephonic support between specialised PCTs and the staff caring for the patient (Hanks *et al.*, 2002). Nor were there any differences between hospital-based hospices and home-based hospices (Greer *et al.*, 1986; Morris *et al.*, 1986). The SR by Zimmermann *et al.* (2008) only included RCTs of specialised palliative care programs, and therefore represents the highest level of evidence. This review found that all but four of 13 studies (Rummans *et al.*, 2006; Aiken *et al.*, 2006; Moore *et al.*, 2002; Hughes *et al.*, 2000) reported no significant differences in patient quality of life between randomised groups, and one study favoured the control (McCorkle *et al.*, 1989). Notably, most studies were underpowered to detect differences in quality of life, either due to inadequate initial sample size or to high levels of loss to follow-up. The SR by Davies *et al.* (2005) focused on the effectiveness of specialist palliative day care services. The review found a single prospective comparative study in which quality of life was assessed (Goodwin *et al.*, 2003). This study reported no benefit in terms of quality of life for patients receiving palliative day care.

The results reported in SRs of palliative care models were also equivocal. In their review of RCTs, Thomas *et al.* (2006) found six studies with some improvement in ratings of quality of life and perceived management of symptoms of patients through the provision of care by PCTs; however, it should be noted that this review did not make a distinction between quality of life, symptoms, pain, anxiety and depression. Keirse *et al.* (2009) did not make any conclusions specifically related to quality of life, but did state that "in all care models, the greatest effectiveness is reported for psychological outcome measures". The lack of reliable data led the authors of this review to conclude that there was insufficient evidence to show that "one particular model of care is superior to another care model in terms of (cost) effectiveness or efficiency of care".

Table 10: Systematic review results: Quality of life

Author & year	Intervention	Results
Smeenk *et al*., 1998	Comprehensive home care programs compared to standard care	A significantly positive influence on the outcome measures was seen in 3/7 studies measuring physical dimensions of quality of life.
Higginson *et al*., 2003; Finlay *et al*., 2002	Specialist palliative care teams compared to usual care (routine community and general hospital/oncology services)	Weighted mean effect size (SE) in overall study population = 0.20 (0.12, 95% CI: -0.04, 0.44). QoL was not included in the meta-analysis because the scales used were too varied for comparison. According to the meta-synthesis, data regarding QoL were inconclusive.
Higginson *et al*., 2002	Specialist palliative care teams compared to usual care (routine community and general hospital/oncology services)	Most studies reported a medium effect size for improvement in QoL.
Garcia-Perez *et al*., 2009	At least two different specialist palliative care services	There were no differences in HRQoL between a broad service provided by a team of referring specialists at hospital and telephonic support between specialised palliative care teams and the staff caring for the patient (Hanks *et al*., 2002). Nor were there any differences between hospital-based hospices and home-based hospices (Greer *et al*., 1986; Morris *et al*., 1986). Similar data were found in the studies by Viney *et al*., (1994) and Doolittle *et al.* (2000).
Gysels and Higginson., 2004 (NICE guideline)	Specialist palliative care services	A study by Jordhoy *et al.* (2001) showed no effect of a hospital based team on QoL with home care.
Salisbury *et al*., 1999; Wilkinson *et al*., 1999	At least two different specialist palliative care services	Limited research does not demonstrate that palliative home care teams, co-ordinating nurses, or advisory teams have an impact on the quality of life of patients dying at home (Dessloch *et al*., 1992; Parkes *et al*., 1984; Zimmer *et al*., 1984; Zimmer *et al*., 1985; Addington-Hall *et al*., 1992; Hughes *et al*., 1992).
Zimmermann *et al*., 2008	At least two different specialist palliative care services	All but 4 of the 13 studies (Rummans *et al*., 2006; Aiken *et al*., 2006; Moore *et al*., 2002; Hughes *et al*., 2000) reported no significant differences in patient quality of life between randomised groups, and 1 study favoured the control (McCorkle *et al*., 1989).
Davies *et al*., 2005	Specialist palliative day care services	A prospective comparative study found no difference in quality of life scores over time in those patients who could be followed up or between the patients receiving home care (Goodwin *et al*., 2003).
Thomas *et al*., 2006	Interventions involving organisation of EOL care	Six studies found some improvement in ratings of the quality of life and perceived management of symptoms of patients through the provision of care by palliative care teams.
Keirse *et al*., 2009	Interventions that include a comprehensive approach to care that evaluated structural and/or organisational aspects and/or outcomes of palliative care.	In all care models, the greatest effectiveness is reported for psychological outcome measures.

ABBREVIATIONS: CI, CONFIDENCE INTERVAL; EOL, END OF LIFE; HRQOL, HEALTH-RELATED QUALITY OF LIFE; NICE, NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE; QOL, QUALITY OF LIFE; SE STANDARD ERROR

Systematic review results: Patient satisfaction

Results for outcomes relating to patient satisfaction are presented in **Table 11** below. In their review of comprehensive home care programs compared to standard care, Smeenk *et al.* (1998) found a significantly positive influence on patient satisfaction in only two out of the five studies in which this outcome was reported. This led the study authors to conclude "the general belief that home care programs are effective for patients with terminal cancer is not supported scientifically". In contrast, the SR by Wadhwa and Lavizzo-Mourey (1999) found that innovative models did appear to improve patient satisfaction. One hospital-based hospice study demonstrated significantly improved patient satisfaction with alternative care, while two home-based hospice studies showed trends toward improved patient satisfaction. Only a case management study by Addington-Hall *et al.* (1992) failed to demonstrate either improved patient or caregiver satisfaction.

Similarly, the reviews focusing on specialised teams found that there was a benefit in terms of patient satisfaction in favour of the intervention (Hearn and Higginson, 1998; Higginson *et al.*, 2002; Higginson *et al.*, 2003). The most comprehensive and recent of these reviews (Higginson *et al.*, 2003) reported the results of a meta-analysis, which demonstrated a non-significant trend towards benefits for satisfaction. To include the results of qualitative studies, the authors also performed a meta-synthesis of study data. These results supported the results of the meta-analysis, and further demonstrated that greater satisfaction and improved outcomes in inpatient hospices.

The SRs that assessed different models of specialised palliative care had less consistent results. Garcia-Perez *et al.* (2009) concluded that there were no differences in satisfaction between a broad service provided by a team of referring specialists at hospital and telephonic support between specialised PCTs and the staff caring for the patient (Hanks *et al.*, 2002). Nor were there any differences between hospital-based hospices and home-based hospices (Greer *et al.*, 1986; Morris *et al.*, 1986). The NICE guidelines by Gysels and Higginson (2004) reported one early study (Zimmer *et al.*, 1985) showing that home care significantly increased patients' satisfaction with services and another co-ordinating service study (Addington-Hall *et al.*, 1992) in which few differences were found in satisfaction and psychological support. Note that the results of the coordinating service study by Addington Hall *et al*., (1992) were interpreted differently in different reviews. The review by Salisbury *et al.* (1999) and Wilkinson *et al.* (1999) reported that research findings from North America did not reveal any reliable or consistent trends, and this was due primarily to methodological flaws in the research. In the UK, consumers were more satisfied with all types of palliative care, whether provided by inpatient units or in the community, than with palliative care provided by general hospitals. It should be noted that the supporting evidence came from small-scale local studies which were mainly focused on a single hospice. The review of RCTs by Zimmermann *et al.* (2008) found that patients' satisfaction with care improved in the intervention groups four out of 10 studies (Brumley *et al.*, 2007; Engelhardt *et al.*, 2006; Moore *et al.*, 2002; Kane *et al.*, 1984). In the remaining studies, the results were not statistically significant. However, all of these studies were affected by substantial loss to follow-up and diminished statistical power.

Of the SRs that included a broad range of palliative care models, only the review by Thomas *et al.* (2006) reported outcomes specifically relating to patient satisfaction.

This review found one study (Kane *et al.*, 1984) with higher patient satisfaction among the patients receiving home/hospice care than among those receiving standard hospital-based end of life care. Another study by Hanks *et al.* (2002) found equal increases in satisfaction for patients who were randomised to a hospital PCT or just telephone support from the team. Two studies found no increase in patient satisfaction. As was the case for quality of life, the review by Keirse *et al.* (2009) found that there was insufficient evidence to make any conclusions specifically related to patient satisfaction.

Table 11: Systematic review results: Patient satisfaction

Author & year	Intervention	Results
Smeenk *et al.*, 1998	Comprehensive home care programs compared to standard care	A significantly positive influence on the outcome measures was seen in 2 out of the 5 studies measuring patients' satisfaction with care.
Wadhwa and Lavizzo-Mourey, 1999	One or a combination of the three innovative models of care i.e. multidisciplinary teams, outreach or home care and case management	A hospital-based hospice study demonstrated significantly improved patient satisfaction with alternative care (Kane *et al.*, 1984). The two home-based hospice studies showed trends toward improved patient satisfaction. A case management study by Addington-Hall *et al.* (1992) failed to demonstrate either improved patient or caregiver satisfaction.
Hearn and Higginson, 1998	Specialist PCTs compared to usual care (routine community and general hospital/oncology services)	Four of the five RCTs and the majority of the comparative studies found similar or improved outcomes in terms of patient satisfaction when specialist multi-professional care is compared to conventional care.
Higginson *et al.*, 2003; Finlay *et al.*, 2002	Specialist PCTs compared to usual care (routine community and general hospital/oncology services)	Effect size Weighted mean effect size (SE) in overall study population = 0.24 (0.14, 95% CI: -0.04, 0.52). Meta-analysis Meta-analysis demonstrated a non-significant trend towards benefits for satisfaction. Meta-synthesis The meta-synthesis further demonstrated that greater satisfaction and improved outcomes in inpatient hospices.
Higginson *et al.*, 2002	Specialist PCTs compared to usual care (routine community and general hospital/oncology services)	The one study that reported patient satisfaction (Addington-Hall *et al.* 1992) found a medium improvement in this outcome.
Garcia-Perez *et al.*, 2009	At least two different specialist palliative care services	There were no differences in satisfaction between the specialist palliative services compared to one another.
Gysels and Higginson., 2004 (NICE guideline)	Specialist palliative care services	One study found that home care increased patients' satisfaction with services significantly (Zimmer *et al.*, 1985). The co-ordinating service study (Addington-Hall *et al.*, 1992) reported that few differences were found in symptoms and symptom control, service provision and satisfaction, and psychological support.
Salisbury *et al.*, 1999; Wilkinson *et al.*, 1999	At least two different specialist palliative care services	In the UK, consumers are more satisfied with all types of palliative care, whether provided by inpatient units or in the community, than with palliative care provided by general hospitals.

Table 11: Systematic review results: Patient satisfaction *cont.*

Author & year	Intervention	Results
Zimmermann *et al*., 2008	At least two different specialist palliative care services	Four studies out of 10 showed significantly increased satisfaction in the intervention groups compared with the control groups (Brumley *et al*., 2007; Engelhardt *et al*., 2006; Moore *et al*., 2002; Kane *et al*., 1984). In all of the remaining studies, the results were not statistically significant.
Davies *et al*., 2005	Specialist palliative day care services	In one study, replies were received from 23 of 63 patients (37%), and indicated general satisfaction with care. Only 2% of patients reported disliking the day unit (Wilkes *et al*., 1978). Goodwin *et al.* found that most of 120 patients made positive comments about the day unit and three-quarters could identify no "downsides" to attending (Goodwin *et al*., 2002).
Thomas *et al*., 2006	Interventions involving organisation of EOL care	One study (Kane *et al*., 1984) found higher patient satisfaction among the patients receiving home/hospice care than among those receiving standard hospital-based EOL care. Another study by Hanks *et al.* (2002) found equal increases in satisfaction for patients who were randomised to a hospital PCT or just telephone support from the team. Two studies found no increase in patient satisfaction.
Keirse *et al*., 2009	Interventions that include a comprehensive approach to care that evaluated structural and/or organisational aspects and/or outcomes of palliative care.	In all care models, the greatest effectiveness was reported for psychological outcome measures.

ABBREVIATIONS: CI, CONFIDENCE INTERVAL; EOL, END OF LIFE; NICE, NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE; PCT, PALLIATIVE CARE TEAM; RCT, RANDOMISED CONTROLLED TRIAL; SE STANDARD ERROR; UK, UNITED KINGDOM

Systematic review results: Symptom control

Results for outcomes relating to symptom control (including pain) are presented in **Table 12** below. The review of innovative models of care (Wadhwa and Lavizzo-Mourey, 1999) found that none of the randomised studies demonstrated a significant improvement in symptom control as measured by scales for pain control, depression, morale, anxiety, cognition or functional independence. Furthermore, there were essentially no trends toward improved symptom control.

In contrast, most of the reviews of PCTs found small but consistent benefits in favour of the intervention. The most comprehensive and recent review by Higginson *et al.* (2003) presented a meta-analysis including 19 studies, which demonstrated a small significant benefit on patients' pain and other symptoms. The three RCTs (Addington-Hall *et al.*, 1992; Kane *et al.*, 1984; Grande *et al.*, 2000) showed equivocal results on patient outcomes, but the quasi-experimental and observational/retrospective studies showed positive effects of a PCT on pain. Other SRs of PCTs came to similar conclusions about the effects of the intervention on symptom control (Francke *et al.*, 2000; Hearn and Higginson, 1998; and Higginson *et al.*, 2002).

In those studies that focused on specialised palliative care interventions, the results were mixed and depended on the nature of the intervention. Garcia-Perez *et al.* (2009) reported no differences in symptom control between a broad service provided by a team of referring specialists at hospital and telephonic support between specialised PCTs and the staff caring for the patient (Hanks *et al.*, 2002). Nor were there any differences between hospital-based hospices and home-based hospices (Greer *et al.*, 1986; Morris *et al.*, 1986). The NICE guideline by Gysels and Higginson (2004) reported one study in which there were better outcomes in symptom distress and independence in the intervention group (McCorckle *et al.*, 1989) and another co-ordinating service study (Addington-Hall *et al.*, 1992) in which there were few differences were found in symptoms and symptom control. The review by Salisbury *et al.* (1999) and Wilkinson *et al.* (1999) reported that there is evidence that inpatient specialist palliative care results in better pain control compared with home care or conventional hospital care (Parkes, 1979; Parkes, 1978; Greer *et al.*, 1996; Morris *et al.*, 1986; Seale, 1991). However, this conclusion is however based on research which is methodologically weak, and has not been supported in all studies (Kate *et al.*, 1985). There is limited evidence from non-experimental research that support teams can improve pain control for patients dying in hospital (Ellershaw *et al.*, 1995; McQuillan *et al.*, 1996). Similarly, Davies *et al.* (2005) found little evidence for improved symptoms in comparative studies of specialist palliative day care versus usual care.

In the broader reviews of palliative care models, Critchley et al (1999) reported one study where pain relief and symptom control was marginally better in hospices with beds (Greer *et al.*, 1986). Thomas et al (2006) identified six studies that found some improvement in quality of life and perceived management of symptoms of patients through the provision of care by PCTs, and three RCTs that found no improvement in symptoms. Keirse *et al.* (2009) found that palliative care interventions improved biological outcome measures in only 22% of the studies that measured relevant outcomes.

Table 12: Systematic review results: Symptom control

Author & year	Intervention	Results
Wadhwa and Lavizzo-Mourey, 1999	One or a combination of the three innovative models of care i.e. multidisciplinary teams, outreach or home care and case management	None of the randomised studies demonstrated a significant improvement in symptom control. There were no trends toward improved symptom control.
Francke *et al.*, 2000	Palliative support teams	Most studies in which pain and physical complaints were determined found that symptoms improved upon referral to a palliative support team. The one exception was an RCT by McWhinney *et al.* (1994) which found no changes in pain and nausea. This was attributed to a high drop-out rate.

Table 12: Systematic review results: Symptom control *cont.*

Author & year	Intervention	Results
Higginson *et al.*, 2002	Specialist hospital-based PCTs compared to usual care (routine community and general hospital/oncology services)	Most studies reported a medium effect size for improvement in pain. One study reported a large improvement, and another reported a small benefit in favour of the team intervention. One study reported a large improvement in other symptoms, two reported a medium effect size, one reported a small improvement, and one study found a small deterioration.
Higginson *et al.*, 2003 Finlay *et al.*, 2002	Specialist PCTs compared to usual care (routine community and general hospital/oncology services)	For pain and other symptoms, there was a small significant benefit of the PCT. Meta-analysis (19 studies) demonstrated small benefit on patients' pain (OR: 0.38, 95% CI: 0.23–0.64) and other symptoms (OR: 0.51, CI: 0.30–0.88).
Garcia-Perez *et al.*, 2009	At least two different specialist palliative care services	There were no differences in symptom control between a broad service provided by a team of referring specialists at hospital and telephonic support between specialised PCTs and (Hanks *et al.*, 2002). Nor were there any differences between hospital-based hospices and home-based hospices (Greer *et al.*, 1986; Morris *et al.*, 1986).
Gysels and Higginson., 2004 (NICE guideline)	Specialist palliative care services	McCorckle *et al.* (1989) showed better outcomes in symptom distress and independence than the control group. The co-ordinating service study (Addington-Hall *et al.*, 1992) reported that few differences were found in symptoms and symptom control.
Salisbury *et al.*, 1999; Wilkinson *et al.*, 1999	At least two different specialist palliative care services	There was evidence that inpatient specialist palliative care results in better pain control compared with home care or conventional hospital care (Parkes, 1979; Parkes, 1978; Greer *et al.*, 1996; Morris *et al.*, 1986; Seale, 1991). This conclusion was however based on research which is methodologically weak, and has not been supported in all studies (Kate *et al.*, 1985).
Davies *et al.*, 2005	Specialist palliative day care services	In one study where replies were received from 65 out of 140 bereaved relatives, 71% reported that the patient had symptom relief due to their attendance. In a comparative study (Goodwin *et al.*, 2002; Goodwin *et al.*, 2003), patients receiving usual care scored lower on symptom control at the second interview than those in day care, but worse for practical matters addressed at the final interview. These findings were limited by baseline differences between the two groups.
Critchley *et al.*, 1999	Models of care in palliative populations	Pain relief and symptom control was marginally better in hospices with beds (Greer *et al.*, 1986).
Thomas *et al.*, 2006	Interventions involving organisation of EOL care	Six studies found some improvement in ratings of the quality of life and perceived management of symptoms of patients through the provision of care by PCTs. Three RCTs found no improvement in symptoms.
Keirse *et al.*, 2009	Interventions that include a comprehensive approach to care that evaluated structural and/or organisational aspects and/or outcomes of palliative care.	Effectiveness on biological outcome measures was shown in only 22% of the studies that applied this outcome measure.

ABBREVIATIONS: EOL, END OF LIFE; NICE, NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE; PCT, PALLIATIVE CARE TEAM; RCT, RANDOMISED CONTROLLED TRIAL

Systematic review results: Caregiver satisfaction

Results for outcomes relating to caregiver satisfaction are presented in **Table 13** below. In the review by Wadhwa and Lavizzo-Mourey (1999) three out of four trials

showed higher caregiver satisfaction and lower caregiver anxiety rates with alternative care. Only the case management study by Addington-Hall *et al.* (1992) failed to demonstrate either improved patient or caregiver satisfaction. Evidence for caregiver satisfaction was demonstrated in hospice studies and studies of home care/multidisciplinary teams. Similarly, in the reviews of specialised teams where this outcome was reported, it was generally observed that there was a small to medium sized benefit in terms of carer satisfaction in favour of the intervention (Hearn and Higginson, 1998; Higginson *et al.*, 2002; Higginson *et al.*, 2003). A meta-analysis included in the largest and most thorough of these reviews (Higginson *et al.*, 2003) found a small but significant effect size, although it should be noted that this result was based on only three clinical studies.

The SRs that assessed different models of specialised palliative care had similar results. The most comprehensive and recent review by Zimmermann *et al.* (2008) found that assessments of caregiver satisfaction showed a statistically significant benefit for caregivers in the intervention group in seven of the 10 studies (Casarett *et al.*, 2005; Hughes *et al.*, 2000; Connors *et al.*, 1995; Hughes *et al.*, 1992; Zimmer *et al.*, 1985; Kane *et al.*, 1984; Ringdal *et al.*, 2002) but not in 3 studies (Hanks *et al.*, 2002; Addington-Hall *et al.*, 1992; Grande *et al.*, 2000). The NICE guideline by Gysels and Higginson (2004) reported consistent results for caregiver satisfaction.

The review of RCTs on the organisation of end of life care by Thomas *et al.* (2006) found three studies where caregiver satisfaction was significantly better in the intervention group (Zimmer *et al.*, 1985; Hughes *et al.*, 1992; and Ringdal *et al.*, 2002). The number of studies with non-significant findings for this outcome was not reported.

Table 13: Systematic review results: Caregiver satisfaction

Author & year	Intervention	Results
Wadhwa and Lavizzo-Mourey, 1999	One or a combination of the three innovative models of care i.e. multidisciplinary teams, outreach or home care and case management	Three out of four trials showed higher caregiver satisfaction and lower caregiver anxiety rates with alternative care. Only the case management study by Addington-Hall *et al.* (1992) failed to demonstrate either improved patient or caregiver satisfaction.
Hearn and Higginson, 1998	Specialist PCTs compared to usual care (routine community and general hospital/oncology services)	When specialist multi-professional care is compared to conventional care, four of the five RCTs and the majority of the comparative studies found similar or improved outcomes in terms of family satisfaction and family anxiety.
Higginson *et al.*, 2003	Specialist PCTs compared to usual care (routine community and general hospital/oncology services)	Only three studies reporting caregiver satisfaction could be included in the meta-analysis (Addington-Hall *et al.*, 1992; Seale *et al.*, 1991; Wakefield *et al.*, 1993). All indicated a small benefit from the team (OR: 0.17, CI: 0.03–0.96).
Higginson *et al.*, 2002	Specialist hospital-based PCTs compared to usual care (routine community and general hospital/oncology services)	The one study that reported carer satisfaction (Addington-Hall *et al.* 1992) found a medium improvement in this outcome.
Gysels and Higginson., 2004 (NICE guideline)	Specialist palliative care services	One study found that home care increased carers' satisfaction with services significantly (Zimmer *et al.*, 1985). Another reported that the patients' relatives in the intervention group were significantly more satisfied with

Author & year	Intervention	Results
		care than those in the control group, particularly in terms of information, availability of physicians, pain relief, and symptom assessment (Ringdal *et al*., 2002).

Table 13: Systematic review results: Caregiver satisfaction *cont.*

Author & year	Intervention	Results
Zimmermann *et al*., 2008	At least two different specialist palliative care services	Assessments of caregiver satisfaction showed a statistically significant benefit for caregivers in the intervention group in 7 of the 10 studies (Casarett *et al*., 2005; Hughes *et al*., 2000; Connors *et al*., 1995; Desbiens *et al*., 1996; Baker *et al*., 2000; Hughes *et al*., 1992; Zimmer *et al*., 1985; Kane *et al*., 1984; Ringdal *et al*., 2002) but not in 3 studies (Hanks *et al*., 2002; Addington-Hall *et al*., 1992; Grande *et al*., 2000).
Davies *et al*., 2005	Specialist palliative day care services	In only one study were the views of relatives or carers sought, and 45% of bereaved relatives (65/140) responded. The majority had found care "excellent" or "good" and were "greatly helped" by their day off. Otherwise attempts to recruit relatives to studies have been unsuccessful (Goodwin *et al*., 2002).
Thomas *et al*., 2006	Interventions involving organisation of EOL care	Three studies found increased caregiver satisfaction.

ABBREVIATIONS: CI, CONFIDENCE INTERVAL; EOL, END OF LIFE; NICE, NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE; OR, ODDS RATIO; PCT, PALLIATIVE CARE TEAM; RCT, RANDOMISED CONTROLLED TRIAL

Systematic review results: Place of death

Results for studies reported place of death are presented in **Table 14** below. In studies of PCTs, the results regarding home deaths were inconclusive. The large SR by Higginson *et al.* (2003) reported that data regarding home deaths were equivocal, while the earlier SR by Higginson *et al.* (2002) identified three studies with small to medium changes in the number of home deaths. Zimmermann *et al.* (2008) identified five studies that assessed death at home. Of these, three studies reported that more patients in the intervention group died at home than patients in the control group, while the remaining two studies showed no statistically significant differences between study arms.

Critchley *et al.* (1999) reported one study in which a higher proportion of patients who received services in the home died at home. Home care services did not decrease the length of a terminal hospital stay if a patient had to be admitted (Ward, 1987). The results reported by Keirse *et al.* (2009) were mixed, with one study reporting an increased likelihood of dying at home in a nursing home intervention, and another study finding no change in the likelihood of dying at home with a hospital at home palliative care service.

Table 14: Systematic review results: Place of death

Author & year	Intervention	Results
Higginson *et al.*, 2003; Finlay *et al.*, 2002	Specialist PCTs compared to usual care (routine community and general hospital/oncology services)	Data regarding home deaths were equivocal.
Higginson *et al.*, 2002	Specialist hospital-based PCTs compared to usual care (routine community and general hospital/oncology services)	Three studies found small to medium changes in the proportion of patients dying at home.
Zimmermann *et al.*, 2008	At least two different specialist palliative care services	Five studies assessed death at home. Three studies reported that more patients in the intervention group died at home than patients in the control group (United States, 71% vs 51%; p< .001; United Kingdom, 40% vs 23%; p=0.04; Norway, 25% vs 15%; p<.05). The remaining two studies showed no statistically significant differences between study arms.
Critchley *et al.*, 1999	Models of care in palliative populations	A higher proportion of patients who received services in the home died at home. Home care services did not decrease the length of a terminal hospital stay if a patient had to be admitted (Ward, 1987)
Thomas *et al.*, 2006	Interventions involving organisation of EOL care	Grande, Todd, Barclay, and Farquhar (1999) found the likelihood of dying at home did not change with a hospital at home palliative care service. Jordhøy *et al.* (2000) found that 25 per cent of deaths were at home compared to 15 per cent for the control group (p=0.02); and fewer of the deaths (9%) occurred in nursing homes compared to the control group (21%, p < 0.01).

ABBREVIATIONS: EOL, END OF LIFE; PCT, PALLIATIVE CARE TEAM

Systematic review results: Survival

Results for the studies reporting survival are presented in **Table 15** below. The review of innovative models of palliative care by Wadhwa and Lavizzo-Mourey (1999) did not report survival time, but found that the mortality rates were not different between intervention and control groups in the four studies. The review by Thomas *et al.* (2006) reported the results of a single study (Jordhøy *et al.*, 2000) in which patients cared for by a PCT had a median survival of 99 days compared to 125 for the control group.

Table 15: Systematic review results: Survival

Author & year	Intervention	Results
Wadhwa and Lavizzo-Mourey, 1999	One or a combination of the three innovative models of care i.e. multidisciplinary teams, outreach or home care and case management	Mortality rates were not different between intervention and control groups in the four studies.
Thomas *et al.*, 2006	Interventions involving organisation of EOL care	Jordhøy *et al.* (2000) found that patients cared for by a PCT had a median survival of 99 days compared to 125 for the control group.

ABBREVIATIONS: EOL, END OF LIFE; PCT, PALLIATIVE CARE TEAM

Systematic review results: Utilisation of services

Results for outcomes relating to the utilisation of services are presented in **Table 16** below.

The review of home care programs by Smeenk *et al.* (1998) found a significantly positive influence on outcome measures in two out of five studies measuring readmission time. Wadhwa and Lavizzo-Mourey (1999) reported that in the home care programs, two of the trials showed reductions in hospitalisations and hospital days.

In the reviews of PCTs, Higginson *et al.* (2003) found a trend towards the increased use of therapeutic interventions in patients receiving the intervention, although this did not reach significance. The NICE review of specialist palliative care services (Gysels and Higginson., 2004) identified one study Italian study in which a palliative home care team reduced days in hospital and allowed patients to spend more time at home (Costantini *et al.*, 2003). The differences were most marked in the last month of life, and disappeared among those patients who were in care for more than 120 days (throughout the course of their illness). The review also reported the results of an evaluation of a palliative home care team in Catalonia, which found reduced hospitalisation and costs in the last month of life (Serra-Prat *et al.*, 2001).

The review by Zimmermann *et al.* (2008) identified only one study in which there was a significant reduction in the utilisation of health care services in the intervention group. Another study reported reduced length of stay in an acute care centre for the intervention group (Hughes *et al.*, 1992). The review by Thomas et al (2006) reported the results of one study (Jordhøy *et al.*, 2000) which found that there were no differences in hospital use in patients receiving palliative care compared to usual care.

Table 16: Systematic review results: Utilisation of services

Author & year	Intervention	Results
Smeenk *et al.*, 1998	Comprehensive home care programs compared to standard care	A significantly positive influence on the outcome measures was seen in 2 out of 5 studies measuring readmission time.
Wadhwa and Lavizzo-Mourey, 1999	One or a combination of the three innovative models of care i.e. multidisciplinary teams, outreach or home care and case management	In the home care programs, two of the trials showed reductions in hospitalisations and hospital days (one of which had a statistically significant result).
Higginson *et al.*, 2003; Finlay *et al.*, 2002	Specialist PCTs compared to usual care (routine community and general hospital/oncology services)	Weighted mean effect size (SE) in overall study population (therapeutic interventions) = 0.43 (0.23, 95% CI: -0.01, 0.87).
Gysels and Higginson., 2004 (NICE guideline)	Specialist palliative care services	Evidence from a recent study (Costantini *et al.*, 2003) showed that a palliative home care team reduced days in hospital and allows patients to spend more time at home. An evaluation of a home care team in Catalonia reported a reduction in hospitalisation and costs in the last month of life (Serra-Prat *et al.*, 2001).

Table 16: Systematic review results: Utilisation of services *cont.*

Author & year	Intervention	Results
Zimmermann *et al*., 2008	At least two different specialist palliative care services	Only one of the studies assessing utilisation of health care services found consistently significant differences in favour of the intervention group. Another study reported reduced length of stay in an acute care centre for the intervention group (mean inpatient days, 9.94 vs 15.86; p=0.03) (Hughes *et al*., 1992).
Thomas *et al*., 2006	Interventions involving organisation of EOL care	Jordhøy *et al.* (2000) found that there were no differences in hospital use.

ABBREVIATIONS: CI, CONFIDENCE INTERVAL; EOL, END OF LIFE; NICE, NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE; PCT, PALLIATIVE CARE TEAM; SE, STANDARD ERROR

Systematic review results: Cost of care

Results for outcomes relating to cost of care are presented in **Table 17** below. The review by Wadhwa and Lavizzo-Mourey (1999) found that in three out of four studies, the costs of alternative care were not significantly different from those of conventional care. The reviews of PCTs reported mixed results for cost of care and resource use. The most comprehensive and recent SR by Higginson *et al.* (2003) identified 14 studies that contained some economic analysis alongside clinical effectiveness studies. The studies were heterogeneous and poorly reported, thereby excluding detailed meta-analysis. Nonetheless, the authors concluded that there was some evidence to suggest substitution effects between hospital and home care (Cummings *et al.*, 1990; Hughes *et al.*, 1992; McCusker *et al.*, 1987) reducing the number of inpatient days, and hence costs of health care. Differences in length of hospitalisation explained most of the variance in cost. Three studies (Kane *et al.*, 1984; Greer *et al.*, 1986; Dunt *et al.*, 1989) failed to find anticipated savings. Only one study (Raferty *et al.*, 1996) was reported in a way that met published guidelines for economic evaluation.

The results of reviews of specialised palliative care programs were generally inconsistent, with some included studies finding an increase in costs, some finding no differences in costs and others finding lower costs as a result of specialised palliative care. The most recent review by Zimmermann *et al.* (2008) found one recent RCT with significant findings for cost (Brumley *et al.*, 2007). In this study, overall costs were significantly lower for patients receiving in-home palliative care than for patients in the usual care group, even after adjusting for the significantly shorter survival of the intervention group. Results from other studies reported in this review insignificant or contradictory. Similarly, the SRs that included a broad range of palliative care models (Thomas *et al.*, 2006 and Keirse *et al.*, 2009) found some evidence for decreased resource use (especially for hospice care), but overall there was limited evidence for the economic benefits of palliative care models.

Table 17: Systematic review results: Cost of care

Author & year	Intervention	Results
Wadhwa and Lavizzo-Mourey, 1999	One or a combination of the three innovative models of care i.e. multidisciplinary teams, outreach or home care and case management.	In three out of four studies, costs of alternative care were not significantly different from those of conventional care (Kane *et al*., 1984; Hughes *et al*., 1992; Cummings *et al*., 1990). One the National Hospice Study (Mor *et al*., 1988) reported a significant increase in costs as a result of the intervention.
Francke *et al*., 2000	Palliative support teams	Three studies (Campbell, 1996; Carlson *et al*., 1988; and Field *et al.* 1996) found that a support team enabled patients to be transferred from intensive care units to less intensive wards and use fewer diagnostic/medical interventions. Lonberger *et al.* (1997) came to similar conclusions. One study by Bennett and Corcoran (1994) found the introduction of a support team increased consumption of care.
Hearn and Higginson, 1998	Studies which considered the use of specialist teams caring for advanced cancer patients and their families	Those studies which examined costs (Addington-Hall *et al*., 1992; Hughs *et al*., 1992; Wales *et al*., 1983; Zimmer *et al*., 1984; Mor *et al*., 1988; Ventafridda *et al*., 1989) showed a tendency for a reduction in hospital inpatient days, more time spent at home, and equal or lower costs.
Higginson *et al*., 2003; Finlay *et al*., 2002	Specialist PCTs compared to usual care (routine community and general hospital/oncology services	There was some evidence to suggest substitution effects between hospital and home care (Cummings *et al*., 1990; Hughes *et al*., 1992; McCusker *et al*., 1987) reducing the number of inpatient days, and hence costs of health care. Differences in length of hospitalisation explained most of the variance in cost. Three out of 14 studies (Kane *et al*., 1984; Greer *et al*., 1986; Dunt *et al*., 1989) failed to find anticipated savings.
Gysels and Higginson., 2004 (NICE guideline)	Specialist palliative care services	Zimmer et al (1985) showed that home care can be both cost-effective and desirable for those who wish it. As in the other studies having a cost component McCusker & Stoddard (1987) found that cost containment occurs for home care users due to decreasing hospital days and the reduced mean daily cost of hospitalisation. Kane *et al.* (1984) showed no substantial differences in cost or effectiveness between the study and the control group, but the patients and their families appreciated the qualitative differences in hospice care.
Salisbury *et al*., 1999; Wilkinson *et al*., 1999	At least two different specialist palliative care services	Three studies showed that an increase in costs results from using palliative care. Two studies found no differences in costs and two studies found lower costs for palliative care.
Zimmermann *et al*., 2008	At least two different specialist palliative care services	The only US study with significant findings for cost was a recent trial of in-home palliative care (Brumley *et al*., 2007). Overall costs were significantly lower for intervention patients than for patients in the usual care group (average cost per day, $95.30 vs. $212.80; p=0.02), even after adjusting for the significantly shorter survival of the intervention group (196 days vs. 242 days). Results from remaining studies were insignificant or contradictory.

Table 18: Systematic review results: Cost of care *cont.*

Author & year	Intervention	Results
Critchley *et al.*, 1999	Models of care in palliative populations	Traditional home care services were more expensive during the last 24 weeks of life than hospice home care or conventional care (Brooks, 1989). Hospice groups used fewer interventional therapies and diagnostic tests compared with conventional care (Greer *et al.*, 1986)
Keirse *et al.*, 2009	Interventions that include a comprehensive approach to care that evaluated structural and/or organisational aspects and/or outcomes of palliative care.	There is limited evidence with regard to the effectiveness of care models in economic terms: only 3 out of 10 studies provided positive outcomes for these measures.

ABBREVIATIONS: NICE, NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE; PCT, PALLIATIVE CARE TEAM; US, UNITED STATES

Summary and conclusions

Generally, the quality of the SRs identified through the literature search was good, with most adopting a systematic approach towards searching the literature and the inclusion/exclusion of evidence. Nonetheless, they all noted difficulties in assessing and analysing individual studies because of heterogeneity in terms of study design, settings, objectives, eligible populations, interventions and outcome measures.

For patient quality of life, evidence supporting the effectiveness of palliative care compared to usual care was weak. Nor was there sufficient evidence to say that one model of care was superior to another in terms of this outcome. The same conclusion was made in SRs of home care programs, PCTs, specialist palliative care programs, specialist palliative day care and general palliative care models.

The results for patient satisfaction were mixed, and depended on the nature of the intervention. The strongest evidence for improved patient satisfaction was found in those reviews that concentrated on PCTs (Hearn and Higginson, 1998; Higginson *et al.*, 2002; Higginson *et al.*, 2003). The results of the most comprehensive and recent of these reviews (Higginson *et al.*, 2003) demonstrated a non-significant trend towards greater satisfaction, especially in inpatient hospices. The SRs that assessed different models of specialised palliative care had less consistent results. Some non-comparative studies reported high satisfaction as a result of palliative care interventions; however, none of the reviews identified specific models of care that were superior to others. The review by Salisbury *et al.* (1999) and Wilkinson *et al.* (1999) reported that in the UK, consumers were more satisfied with all types of palliative care, whether provided by inpatient units or in the community, than with palliative care provided by general hospitals. Evidence for the benefits of home care programs (Smeenk *et al.*, 1998) and specialist day care services (Davies *et al.*, 2005) was weak.

For symptom control, there were some small but consistent benefits in favour of the intervention in SRs of PCTs. The meta-analysis by Higginson *et al.* (2003) including 19 studies, demonstrated a small significant benefit on patients' pain and other symptoms. It should be noted that while quasi-experimental and observational/retrospective studies showed positive effects of a PCT on pain, results

from RCTs were equivocal. In those studies that focused on specialised palliative care interventions, the results were mixed and depended on the nature of the intervention. Salisbury *et al.* (1999) and Wilkinson *et al.* (1999) reported that there is evidence that inpatient specialist palliative care results in better pain control compared with home care or conventional hospital care; however, this conclusion was based on research which is methodologically weak, and has not been supported in all studies. Evidence for the efficacy of other models of care (e.g. specialist palliative day care services and home care programs) was either weak or lacking altogether.

Caregiver satisfaction was one of the few outcomes for which consistent benefits in favour of the intervention were observed. Reviews of PCTs all demonstrated a small to medium sized benefit, and the meta-analysis by Higginson *et al.* (2003) found a small but significant effect size, although it should be noted that this result was based on only three clinical studies. The SRs that assessed specialised models palliative care had similar results. The review of RCTs by Zimmermann *et al.* (2008) found that satisfaction was significantly improved for caregivers in the intervention group in seven of the 10 studies.

Most people, when asked, indicate that they would prefer to die at home. Therefore, the proportion of home deaths is frequently used in the evaluation of palliative care programs. The SRs included in the current review reported mixed results for the effect of palliative care interventions on home deaths. Furthermore, the results are based on a small sample of studies in which this outcome was measured. The SR of PCTs by Higginson *et al.* (2003) found equivocal results in terms of home deaths, while the review of RCTs by Zimmermann *et al.* (2008) found that three out of five studies reported positive results for this outcome.

Survival was not often reported in the SRs of palliative care models, as by definition, palliative care does not set out to improve survival. The review by Wadhwa and Lavizzo-Mourey (1999) didn't not report survival time, but found that the mortality rates were not different between intervention and control groups in the four studies. Thomas *et al.* (2006) reported the results of one study (Jordhøy *et al.*, 2000) in which patients cared for by a PCT had a median survival of 99 days compared to 125 for the control group.

The goal of palliative care is to maximise quality of life for patients and carers; however, it is important that patient management also incorporates effective resource and service utilisation. Overall, SRs of palliative care models suggest that the provision of palliative care has an uncertain effect on resource use. Reviews of PCTs (Higginson *et al.*, 2003) and specialist PCTs (Gysels and Higginson, 2004) suggest decreased utilisation of services as a result of the intervention. The review of RCTs by Zimmermann *et al.* (2008) however, found only one study in which there was a significant reduction in resource use in the intervention group.

The results of reviews reporting cost outcomes were generally inconsistent. The SRs that included a broad range of palliative care models (Thomas *et al.*, 2006 and Keirse *et al.*, 2009) found some evidence for decreased resource use (especially for hospice care), but overall there was limited evidence for the economic benefits of palliative care models. For interventions involving PCTs, Higginson *et al.* (2003) reported some evidence to suggest substitution effects between hospital and home care reducing the

number of inpatient days, and hence costs of health care. The SRs of specialised palliative care programs reported some studies finding an increase in costs, some finding no differences in costs and others finding lower costs as a result of an intervention.

Overall, the SRs of models of palliative care are heterogeneous and report inconsistent results. For the majority of outcomes (i.e. quality of life, patient satisfaction, home deaths, survival and resource use) there is little evidence to suggest a benefit in favour of the intervention. Nor do the SRs report that any one model of palliative care is consistently more effective than another. Caregiver satisfaction was one of the few outcomes for which consistent benefits in favour of the intervention were observed. For symptom control, there were also some small but consistent benefits in favour of the intervention in SRs of PCTs.

Part 2: Review of original primary studies

Methods

Literature search for original studies

Part 1 of this report is based on a review of SRs. The review was used to provide a high-level assessment of the quality and quantity of evidence available regarding the organisation of palliative care. **Part 2** of this report examines the results of individual studies comparing the efficacy of different models of palliative care. There is a vast amount of literature available on this topic, so in order to keep the review to a manageable size, the literature search for original studies was conducted in three stages.

Firstly, eligible original studies were identified from the reference lists of the SRs presented in **Part 1** of this report. Collectively, the SRs identified in **Part 1** of this report had a total of 152 unique references. The studies reported in each eligible SR are listed in the data extraction forms in **Appendix B** of this review. All of these studies were assessed for eligibility through an initial review of titles and abstracts, followed by a review of full text articles.

The second phase of the literature search involved an extensive search of the grey literature for policy documents, research reports and program evaluations. This search focused on information contained in websites for palliative care organisations (e.g. www.caresearch.com.au).

The final stage of the literature search involved undertaking an updated search of electronic databases to identify studies published after the literature search date of the most recent SR. The most recently published review identified in **Part 1** was the review by Zimmermann *et al.* (2008). This SR included studies published prior to January 2008. Therefore, the updated literature search presented below includes literature published between January 2008 and February 2010. As noted previously, the SRs of palliative care models were heterogeneous in terms of the studies populations and interventions, so it is possible that some studies published prior to January 2008 may not appear in the SR reference lists. To address these potential gaps, the reference lists of eligible original studies were also manually searched for relevant citations.

In the updated literature search, search terms were searched for as keywords, exploded where possible, and as free text within the title and/or abstract, in the Embase and Medline databases. Variations on these terms were used for the Cochrane library and other review databases to suit their keywords and descriptors. The search terms, search strategy and citations identified are presented in **Table 19**. As noted previously, the SRs of palliative care models were heterogeneous in terms of the studies populations and interventions, so it is possible that some studies published prior to January 2008 may not appear in the SR reference lists. To address this issue, the reference lists of eligible original studies were also manually searched for relevant citations.

Table 19: Search strategy for systematic reviews

Database	Date searched	Search no.	Search terms	Citations
Embase + Medline	< 1 January 2008 – 18 February 2010	#1	'palliative therapy'/exp OR 'palliative therapy' OR 'terminal care'/exp OR 'terminal care' OR 'terminally ill'/exp OR 'terminally ill' OR 'terminal illness'/exp OR 'terminal illness' OR terminal* NEAR/2 ill* OR 'terminal disease'/exp OR 'terminal disease' OR palliat* OR 'EOL' OR 'dying'/exp OR 'dying' OR 'hospice'/exp OR 'hospice' OR limited NEAR/2 life* OR imminent NEAR/2 death OR incurabl* NEAR/2 ill*	122,630
		#2	'model of care' OR 'models of care' OR patient NEAR/2 manag* OR care NEAR/2 organisation* OR care NEAR/2 organisation* OR'integrated care' OR 'shared care' OR 'managed care'/exp OR 'managed care' OR care NEAR/2 delivery OR service NEAR/2 model OR 'multidisciplinary care' OR 'multi-disciplinary care' OR care NEAR/2 coordination OR 'health system':ab,ti OR 'health service':ab,ti OR 'health care system':ab,ti OR program*:ab,ti OR 'policy':ab,ti OR 'policies':ab,ti OR 'patient care team':ab,ti	2,374,223
		#3	assess* OR evaluat* OR outcome*	4,189,567
		#4	#1 AND #2 AND #3	16,199
		#5	#4 NOT ([animal cell]/lim OR [animal experiment]/lim OR [animal model]/lim OR [animal tissue]/lim)	16,071
		#6	#5 NOT ([conference abstract]/lim OR [conference paper]/lim OR [conference review]/lim OR [editorial]/lim OR [erratum]/lim OR [letter]/lim OR [note]/lim OR [review]/lim OR [short survey]/lim)	11,350
		#7	#6 NOT ([embryo]/lim OR [fetus]/lim OR [newborn]/lim OR [infant]/lim OR [preschool]/lim OR [school]/lim OR [child]/lim OR [adolescent]/lim)	9,589
		#8	#7 AND [english]/lim	7,180
		#9	#8 AND [2008-2010]/py	1,628
Cochrane library	2008 – 21 July 2010	#1	Palliative care (title, abstract and keyword search, Clinical trials)	1,735
HTA websites	24 February 2010	#1		107
Total citations identified				1,735
Total citations excluding duplicates				1,661

ABBREVIATIONS: HTA, HEALTH TECHNOLOGY ASSESSMENT

Assessment of study eligibility

The 152 studies identified via the reference lists of SRs and the 1,661 non-duplicate citations identified through the updated literature search were combined into a single database of 1,813 citations. From the combined database, eligible studies were selected for appraisal using a two-stage process. First, titles and abstracts (where available) identified from the search strategy were scanned and excluded as appropriate. Second, the full text articles were retrieved for the remaining studies and selected for inclusion and appraisal in the review if they fulfilled the study selection criteria outlined below. Double-checking of the eligibility of studies by a second reviewer was not undertaken.

The exclusion criteria for studies were based on the PICO criteria described earlier in this report, and are listed below:

1. Not a an original study
2. The study did not deal with adult patients with a terminal illness requiring palliative treatment.
3. The study did not assess structures, programs, systems or models of palliative care in at least an entire hospital catchment population (i.e. hospital, area health service/district health board, town/city, province, state, country) with more than 100 patients enrolled in the intervention study arm.
4. The study was not comparative.
5. The study does not report at least one of the previously identified outcomes of interest.
6. The study reports an intervention that occurred in a non-Western setting.
7. The study report was published prior to 1990

Unlike the exclusion criteria applied in the selection of eligible SRs in **Part 1** of this report, the search for primary evidence was limited to adequately powered studies (studies in which at least 100 patients received the intervention) in at least an entire hospital catchment population (i.e. hospital, area health service/district health board, town/city, province, state, country). This is consistent with the system-wide approach to care delivery. To ensure that the evidence is applicable to current health care systems, only studies published in the last 20 years were eligible for inclusion.

The application of exclusion criteria to identify eligible citations is presented in **Table 20**. All excluded articles are presented in **Appendix C**, annotated by reason for exclusion.

Table 20: Application of selection criteria to citations

Exclusion criteria	Number
Total citations (including citations from SR reference lists and updated literature search)	1,661
Title/abstract (first pass):	1,661
Not a an original study	5
The study did not deal with adult patients with a terminal illness requiring palliative treatment.	1273
The study did not assess structures, programs, systems or models of palliative care in at least an entire hospital catchment population (i.e. hospital, area health service/district health board, town/city, province, state, country) with more than 100 patients enrolled in the intervention study arm.	309
The study was not comparative.	17
The study does not report at least one of the previously identified outcomes of interest.	9
The study reports an intervention that occurred in a non-Western setting.	5
The study report was published prior to 1990	0
Full papers reviewed:	195
Not a an original study	11
The study did not deal with adult patients with a terminal illness requiring palliative treatment.	13
The study did not assess structures, programs, systems or models of palliative care in at least an entire hospital catchment population (i.e. hospital, area health service/district health board, town/city, province, state, country) with more than 100 patients enrolled in the intervention study arm.	46
The study was not comparative.	45
The study does not report at least one of the previously identified outcomes of interest.	1
The study reports an intervention that occurred in a non-Western setting.	0
The study report was published prior to 1990	46
Total included publications	33
Total included original studies	26

Following the application of selection criteria to the titles and abstracts of identified citations, 195 full text articles were eligible for retrieval. Following the full-text review, 162 citations were excluded because they met one or more of the exclusion criteria described above. The remaining 33 publications reported the results of 26 original clinical studies, all of which were comparative and included more than 100 patients receiving the palliative care intervention.

An extensive search of grey literature identified a large number of reports evaluating the implementation of palliative care programs at a regional level; however, the vast majority of these were not comparative, and were therefore ineligible for inclusion in this review. Only one report by Brumley *et al.* (2003) was identified in the grey literature search as eligible for inclusion in the current review. The lack of relevant studies has been observed previously in a study on the efficiency of searching the grey literature in palliative care (Cook *et al.*, 2001).

Table 21 below presents the 27 eligible studies and their 34 associated publications, identified through searching the reference lists of systematic reviews and through an updated literature search.

Table 21: Included original studies for models of palliative care

Study ID	Citation (s)
Identified from SR reference lists	
Cummings *et al*., 1990	Cummings JE, Hughes SL, Weaver FM, Manheim LM, Conrad KJ, Nash K, Braun B, and Adelman J. (1990) Cost-effectiveness of Veterans Administration hospital-based home care. A randomised clinical trial. *Archives of Internal Medicine* 150:1274-1280.
Ventafridda *et al*., 1990	Ventafridda V, De Conno F, Ripamonti C, Gamba A, and Tamburini M. (1990) Quality-of-life assessment during a palliative care program. *Annals of Oncology* 1:415-420.
Addington-Hall *et al*., 1992	Addington-Hall JM, MacDonald LD, Anderson HR, Chamberlain J, Freeling P, Bland JM, and Raftery J. (1992) Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. *British Medical Journal* 305:1317-1322. Raftery JP, ddington-Hall JM, MacDonald LD, Anderson HR, Bland JM, Chamberlain J, and Freeling P. (1996) A randomised controlled trial of the cost-effectiveness of a district co-ordinating service for terminally ill cancer patients. *Palliative Medicine* 10:151-161.
Hughes *et al*., 2000	Hughes SL, Weaver FM, Giobbie-Hurder A, Manheim L, Henderson W, Kubal JD, Ulasevich A, and Cummings J. (2000) Effectiveness of team-managed home-based primary care: A randomised multicenter trial. *Journal of the American Medical Association* 284:2877-2885.
Aristides and Shiell, 1993	Aristides M and Shiell A. (1993) The effects on hospital use and costs of a domiciliary palliative care nursing service. *Australian health review : a publication of the Australian Hospital Association* 16:405-413.
Connors *et al*., 1995	Connors J, Dawson NV, Desbiens NA, Fulkerson J, Goldman L, Knaus WA, Lynn J, Oye RK, Bergner M, Damiano A, Hakim R, Murphy DJ, Teno J, Virnig B, Wagner DP, Wu AW, Yasui Y, Robinson DK, and Kreling B. (1995) A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Journal of the American Medical Association* 274:1591-1598. Baker R, Wu AW, Teno JM, Kreling B, Damiano AM, Rubin HR, Roach MJ, Wenger NS, Phillips RS, Desbiens NA, Connors AF, Knaus W, and Lynn J. (2000) Family satisfaction with end-of-life care in seriously ill hospitalized adults. *Journal of the American Geriatrics Society* 48:S61-S69.
Higginson *et al*., 1997	Higginson IJ and Hearn J. (1997) A multicenter evaluation of cancer pain control by palliative care teams. *Journal of Pain and Symptom Management* 14:29-35.
Edmonds *et al*., 1998	Edmonds PM, Stuttaford JM, Penny J, Lynch AM, and Chamberlain J. (1998) Do hospital palliative care teams improve symptom control? Use of a modified STAS as an evaluation tool. *Palliative Medicine* 12:345-351.
Grande *et al*., 1999	Grande GE, Todd CJ, Barclay SIG, and Farquhar MC. (1999) Does hospital at home for palliative care facilitate death at home? Randomised controlled trial. *British Medical Journal* 319:1472-1475. Grande GE, Todd CJ, Barclay SIG, and Farquhar MC. (2000) A randomised controlled trial of a hospital at home service for the terminally ill. *Palliative Medicine* 14:375-385.
Doolittle *et al*., 2000	Doolittle GC. (2000) A cost measurement study for a home-based telehospice service. *Journal of telemedicine and telecare* 6 Suppl 1:S193-S195.
Jordhoy *et al*., 2000	Jordhoy MS, Fayers P, Saltnes T, hlner-Elmqvist M, Jannert M, and Kaasa S. (2000) A palliative-care intervention and death at home: A cluster randomised trial. *Lancet* 356:888-893. Jordhoy MS, Fayers P, Loge JH, Ahlner-Elmqvist M, and Kaasa S. (2001) Quality of life in palliative cancer care: Results from a cluster randomised trial. *Journal of Clinical Oncology* 19:3884-3894. Ringdal GI, Jordhoy MS, and Kaasa S. (2002) Family satisfaction with end-of-life care for cancer patients in a cluster randomised trial. *Journal of Pain and Symptom Management* 24:53-63.

Table 21: Included original studies for models of palliative care *cont.*

Hanks *et al*., 2002	Hanks GW, Robbins M, Sharp D, Forbes K, Done K, Peters TJ, Morgan H, Sykes J, Baxter K, Corfe F, and Bidgood C. (2002) The imPaCT study: A randomised controlled trial to evaluate a hospital palliative care team. *British Journal of Cancer* 87:733-739.
Costantini *et al*., 2003	Costantini M, Higginson IJ, Boni L, Orengo MA, Garrone E, Henriquet F, and Bruzzi P. (2003) Effect of a palliative home care team on hospital admissions among patients with advanced cancer. *Palliative Medicine* 17:315-321.
Goodwin *et al*., 2003	Goodwin DM, Higginson IJ, Myers K, Douglas HR, and Normand CE. (2003) Effectiveness of palliative day care in improving pain, symptom control, and quality of life. *Journal of Pain and Symptom Management* 25:202-212.
Engelhardt *et al*., 2006	Engelhardt JB, Clive-Reed KP, Toseland RW, Smith TL, Larson DG, and Tobin DR. (2006) Effects of a Program for Coordinated Care of Advanced Illness on patients, surrogates, and healthcare costs: A randomised trial. *American Journal of Managed Care* 12:93-100.
McMillan *et al*., 2006	McMillan SC, Small BJ, Weitzner M, Schonwetter R, Tittle M, Moody L, and Haley WE. (2006) Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomised clinical trial. *Cancer* 106:214-222. McMillan SC and Small BJ. (2007) Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: a clinical trial. *Oncology nursing forum* 34:313-321.
Brumley *et al*., 2007	Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, McIlwane J, Hillary K, and Gonzalez J. (2007) Increased satisfaction with care and lower costs: Results of a randomised trial of in-home palliative care. *Journal of the American Geriatrics Society* 55:993-1000.
Identified from updated literature search	
Casarett *et al*., 2008	Casarett D, Pickard A, Bailey FA, Ritchie C, Furman C, Rosenfeld K, Shreve S, Chen Z, and Shea JA. (2008) Do palliative consultations improve patient outcomes? *Journal of the American Geriatrics Society* 56:593-599.
Dudgeon *et al*., 2008	Dudgeon DJ, Knott C, Eichholz M, Gerlach JL, Chapman C, Viola R, Van Dijk J, Preston S, Batchelor D, and Bartfay E. (2008) Palliative Care Integration Project (PCIP) Quality Improvement Strategy Evaluation. *Journal of Pain and Symptom Management* 35:573-582. Dudgeon DJ, Knott C, Chapman C, Coulson K, Jeffery E, Preston S, Eichholz M, Van Dijk JP, and Smith A. (2009) Development, Implementation, and Process Evaluation of a Regional Palliative Care Quality Improvement Project. *Journal of Pain and Symptom Management* 38:483-495.
Gade *et al*., 2008	Gade G, Venohr I, Conner D, McGrady K, Beane J, Richardson RH, Williams MP, Liberson M, Blum M, and Penna RD. (2008) Impact of an inpatient palliative care team: A randomised control trial. *Journal of Medicine* 11:180-190.
Hanson *et al*., 2008	Hanson LC, Usher B, Spragens L, and Bernard S. (2008) Clinical and Economic Impact of Palliative Care Consultation. *Journal of Pain and Symptom Management* 35:340-346.
Veerbeek *et al*., 2008	Veerbeek L, van der Heide A, de Vogel-Voogt E, De Bakker R, Der Rijt DV, Swart SJ, Van Der Maas PJ, and Van Zuylen L. (2008) Using the LCP: Bereaved relatives' assessments of communication and bereavement. *American Journal of and Medicine* 25:207-214.
Follwell *et al*., 2009	Follwell M, Burman D, Le LW, Wakimoto K, Seccareccia D, Bryson J, Rodin G, and Zimmermann C. (2009) Phase II study of an outpatient palliative care intervention in patients with metastatic cancer. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology* 27:206-213.
Kusajima *et al*., 2009	Kusajima E, Kawa M, Miyashita M, Kazuma K, and Okabe T. (2009) Prospective evaluation of transition to specialized home palliative care in japan. *American Journal of and Medicine* 26:172-179.
Spettell *et al*., 2009	Spettell CM, Rawlins WS, Krakauer R, Fernandes J, Breton MES, Gowdy W, Brodeur S, MacCoy M, and Brennan TA. (2009) A comprehensive case management program to improve palliative care. *Journal of Medicine* 12:827-832.

Table 21: Included original studies for models of palliative care *cont.*

Bakitas *et al*., 2009	Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC, Seville J, Hull JG, Li Z, Tosteson TD, Byock IR, and Ahles TA. (2009) Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The project ENABLE II randomised controlled trial. *Journal of the American Medical Association* 302:741-749. Bakitas M, Lyons KD, Hegel MT, Balan S, Barnett KN, Frances C, Byock IR, Hull JG, Li Z, McKinstry E, Seville JI, and Ahles TA. (2009) The project ENABLE II randomised controlled trial to improve palliative care for rural patients with advanced cancer: Baseline findings, methodological challenges, and solutions. *Palliative and Supportive Care* 7:75-86.
Identified through grey literature search	
Brumley *et al*., 2003	Brumley, R., Enguidanos, S., & Hillary, K. (2003). The palliative care program. The Permanente Journal, 7(2), 7-13.

ABBREVIATIONS: SR, SYSTEMATIC REVIEW

It should be noted that some large studies were ineligible for inclusion in this review due to the fact that they were published prior to 1990 (Kane *et al.*, 1984; More *et al.*, 1988; Parkes *et al.*, 1979). The largest and most widely reported of these was the National Hospice Study (Morris *et al.*, 1986; Wallston *et al.*, 1988; Goldberg *et al.*, 1986; Greer *et al.*, 1986; Greer and Mor, 1986; Mor *et al.*, 1985; Mor *et al.*, 1988), which was a quasi-experimental US study comparing home hospice, inpatient hospice and conventional care. The study identified some differences between groups: the percentage of patients in persistent pain at the last measure prior to death was significantly higher in the home-based hospice group (13%) than in the hospital-based hospice (5%). The investigators did not find differences in other measure such as quality of life, patient and carer satisfaction, and symptom control.

There are also a few well-known and widely-used palliative care programs that have not been included in this review due to insufficient outcomes reporting in the published evaluations. The most notable of these is the GSF (Thomas, 2007), which is a systematic approach to improve the care for the end-of-life patients in the community. Originally developed for primary care and supported by a multidisciplinary reference group of specialists and generalists, it aims to improve the care provided in the community by the patient's usual community care team. Starting as a pilot program with 12 practices in one locality in 2000 (Mundy *et al.*, 2007) the GSF has been disseminated throughout the UK through a phased approach. There are a number of reports in the grey literature in which the implementation of the GSF program has been evaluated. These reports were found to be ineligible for inclusion in this review due to the fact that they were non-comparative, and focused on outcomes relating to successful implementation, rather than patient or carer-centred outcomes. Similarly, the LCP has been quite extensively evaluated; however very few reports provide comparative data or outcomes that reflect the patient or carer perspective. The literature search only identified one eligible study (Veerbeek *et al.*, 2008) that investigated the effect of using the LCP on communication during the last three days of life and on the level of bereavement in relatives after the patient's death. This study does not strictly report caregiver satisfaction, but does provide a caregiver perspective on communication prior to death, and levels of bereavement after death.

Results

Overview

Methodological information and results extracted from eligible studies are presented below. More detailed information is available in **Appendix B** or in the original papers. Only data relevant to the current review is presented.

Original primary studies: characteristics

The search identified 28 eligible primary research studies. Study characteristics are described in **Table 22**.

The eligible studies include 13 RCTs, one Level III-1 quasi-randomised study (Costantini *et al.*, 2003), 12 Level III-2 studies (including pre-post and non-randomised comparative studies) and two Level III-3 retrospective cohort studies. Most of the studies were poor to fair in terms of study quality; however, it should be noted that the conduct of high quality palliative care studies is complex due to problems associated with recruitment, attrition, and the vulnerability of the patient group. In RCTs, due to the nature of the intervention, it is also often difficult to maintain adequate blinding of subjects and investigators. Therefore, the evidence base for palliative care interventions only contains a small number of high quality RCTs.

As noted in other SRs of palliative care models, the included studies were heterogeneous in terms of the types of interventions employed, settings (e.g. home or hospital) and study populations. Several studies involved the delivery of in-home palliative care through the use of an interdisciplinary team (Brumley *et al.*, 2007; Cummings *et al.*, 1990; Hughes *et al.*, 2000; Gade *et al.*, 2008; Costantini *et al.*, 2003; Brumley *et al.*, 2003; Follwell *et al.*, 2009; Kusajima *et al.*, 2009), although the make-up of these teams differed between studies. For example, the RCT by Hughes *et al.* (2000) included a primary care manager and 24-hour contact for patients. By comparison, the consultant team working in the Palliative Medicine Unit described by Jordhøy *et al.* (2000) included two palliative-care nurses, a social worker, a priest, a nutritionist, a part time physiotherapist and three fulltime physicians. The team worked only daytime hours. Other studies assessed the efficacy of hospital-based PCTs (Edmonds *et al.*, 1998), or PCT interventions that were available to patients at home or in the hospital (Hanks *et al.*, 2002; Jordhøy *et al.*, 2000, Jordhøy *et al.*, 2001 and Ringdal *et al.*, 2002; Higginson and Hearn, 1997; Ventafridda *et al.*, 1990).

Other interventions were broadly classified as: coordination of care (Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996; Engelhardt *et al.*, 2006); hospital at home (Grande *et al.*, 1999; Grande *et al.*, 2000); hospital or home care with the assistance of a specially trained nurse (Connors *et al.*, 1995; Desbiens *et al.*, 1996; Baker *et al.*, 2000; Aristides and Shiell, 1993); hospice care with a nurse or coping skills intervention (McMillan *et al.*, 2007; McMillan *et al.*, 2006); home care plus a nurse-led phone intervention (Bakitas *et al.*, 2009; Bakitas *et al.*, 2009b); palliative day care (Goodwin *et al.*, 2002); inpatient consultations (Hanson *et al.*, 2008; Casarett *et al.*, 2008); case management (Spettell *et al.*, 2009); and a telehospice service (Doolittle, 2000). In addition, there were some studies that included interventions that could be better characterised as "care pathways" rather than "models of care". These include the Palliative Care Integration Project (Dudgeon *et al.*, 2008, Dudgeon *et al.*, 2009) and the LCP (Veerbeek *et al.*, 2008). Since the patient management guidelines described

in these studies necessitated some structural/organisational changes in the institutions where they were being implemented, they are considered to be eligible in the current review.

In most of the studies, usual or conventional care was the comparator; however, the definition of usual care differed considerably between studies and was highly influenced by the country and healthcare system in which they were undertaken. For example, a number of the US studies were undertaken by health maintenance organisations (HMOs) (Brumley *et al.*, 2003; Spetell *et al.*, 2009) or within Veterans Administration (VA) hospitals (Cummings *et al.*, 1990; Engelhardt *et al.*, 2006; Hughes *et al.*, 2000; Casarett *et al.*, 2008).

Table 22: Study characteristics: models of palliative care

Author & year	Study type Study quality	Population	Intervention	Comparator	Outcomes
Intervention Level II evidence					
Addington-Hall *et al*., 1992; Raferty *et al*., 1996	RCT UK Fair	Patients with cancer with a prognosis of less than one year n=203	All patients received routinely available services. Patients receiving the intervention also received the assistance of two nurse coordinators, whose role was to ensure that patients received appropriate and well coordinated services, tailored to their individual needs and circumstances **Home care + coordination of care** N=104	Routinely available services N=99	Outcome measures included presence and severity of physical symptoms, psychiatric morbidity, use of and satisfaction with services, and carers' problems.
Brumley *et al*., 2007	RCT USA Good	Homebound, terminally ill patients with a prognosis of approximately 1 year or less to live plus one or more hospital or emergency department visits in the previous 12 months. N=298	In-home palliative care plus usual care delivered by an interdisciplinary team providing pain and symptom relief, patient and family education and training, and an array of medical and social support services. The core care team consisting of the patient and family plus a physician, nurse, and social worker with expertise in symptom management and biopsychosocial intervention. Additional team members, including spiritual counsellor or chaplain, bereavement coordinator, home health aide, pharmacist, dietitian, volunteer, physical therapist, occupational therapist, and speech therapist were used on an as-needs basis. **Home care + PCT** N=155	Usual care consisted of standard care to meet the needs of the patients and followed Medicare guidelines for home healthcare criteria. N=115	Measured outcomes were satisfaction with care, use of medical services, site of death, and costs of care.

Table 22: Study characteristics: models of palliative care *cont.*

Author & year	Study type Study quality	Population	Intervention	Comparator	Outcomes
Cummings *et al.*, 1990	RCT USA Poor	Severely disabled or terminally ill patients admitted to a Veteran's Administration hospital between 1984 and 1987 N=419	A hospital-based home care program that provides care to patients using an interdisciplinary team directed by a physician. The comprehensive services provided include medical, nursing, social work, physical therapy and dietetic care. **Home care + PCT** N=208	Customary care N=211	Functional status, satisfaction with care and morale were measured at baseline and at 1 and 6 months after discharge from the hospital. Healthcare utilisation was tracked for 6 months.
Engelhardt *et al.*, 2006	RCT USA Fair	Patients had chronic COPD, CHF, or cancer diagnoses. Participants were recruited from 3 Department of Veterans Affairs medical centres, a home care organisation, and 2 managed care organisations n=275	The Advanced Illness Coordinated Care Program (AICCP) delivers care coordination and support through 6 functions: physician support, health literacy, care coordination, prevention of psychosocial concerns, and advance planning **Home care + team coordination** N=133	Usual care N=142	The AICCP was evaluated for effects on satisfaction with care, advance planning, consistency of care with patient preferences, and healthcare costs.
Grande *et al.*, 1999; Grande *et al.*, 2000	RCT UK Good	Patients with any diagnosis whose prognosis was two weeks or less, as estimated by clinicians and for respite care for patients with cancer, motor neurone disease, and AIDS. Patients were aged 16 years or above and residents of the former Cambridge health district. N=299	Hospital at home with practical home nursing care for up to 24 hours a day for up to two weeks. The service was used mainly during the last two weeks of life. The hospital at home team consisted of 6 qualified nurses, two nursing auxiliaries, and a nurse coordinator. Agency nurses were also used as required. **Hospital at home** N=186	Standard care comprised care in hospital or hospice or care with input from general practice, district nursing, Marie Curie nursing, Macmillan nursing, evening district nursing, social services, a flexible care nursing service or private care N=43	Demographic data and death certification, including place of death, were collected (Grande *et al.*, 1999). Perceived symptom control, adequacy of care and patients' ability to remain at home during their final 2 weeks. The impact on GP workload was also investigated (Grande *et al.*, 2000).

Table 22: Study characteristics: models of palliative care *cont.*

Author & year	Study type Study quality	Population	Intervention	Comparator	Outcomes
Hanks *et al*., 2002	RCT UK Good	Patients were inpatient referrals with palliative care needs. N=261	The full PCT service was the usual service delivered by a PCT, which comprised two clinical academic consultants, one specialist registrar and three clinical nurse specialists. The PCT had close links with a clinical psychologist, a local hospice and community based palliative care services and access to social workers, rehabilitation staff and the chaplaincy in the hospital **Hospital and home care + PCT** N=175	No direct contact between the PCT and the patient or their family. A telephone consultation took place between a senior medical member of the PCT and the referring doctor and also between a PCT nurse specialist and a member of the ward nursing staff directly involved with the patient. N=86	Symptom control and HRQoL were measured by EORTC QLQ-C30, visual analogue scales and the Memorial Pain Assessment Card (MPAC). Hospital stay Patient satisfaction using MacAdam's Assessment of Suffering Questionnaire. Carer satisfaction using the FAMCARE and Hospital Anxiety and Depression scale (HADS). Resource use from patient records and questionnaires
Hughes *et al*., 2000	RCT USA Good	Hospitalised patients were eligible if they had 2 or more activities of daily living (ADL) impairments or a prognosis of terminal illness, or patients who were homebound with a primary diagnosis of CHF or COPD. Note that 79.3% of patients enrolled in this study were not terminally ill. Subgroup analyses by terminal/non-terminal patient subgroup were provided. N=1966	A Veterans Affairs (VA) Team-Managed Home-Based Primary Care (TM/HBPC) program including a primary care manager, 24-hour contact for patients, prior approval of hospital readmissions, and HBPC team participation in discharge planning. **Home care + PCT** N=981	Patients in the control group could access any Veteran's Administration (VA) sponsored services for which they were eligible with the exception of HBPC, and non-VA post-acute services for which they were eligible, such as Medicare home health or hospice care. N=985	Patient functional status (Barthel Index), patient and caregiver HRQoL (SF-36) and satisfaction (Ware Satisfaction with Care scales), caregiver burden, hospital readmissions, and costs over 12 months.

Table 22: Study characteristics: models of palliative care *cont.*

Author & year	Study type Study quality	Population	Intervention	Comparator	Outcomes
Jordhøy *et al*., 2000, Jordhøy *et al*., 2001 and Ringdal *et al*., 2002	RCT Norway Good	Patients with advanced cancer N=434	The Palliative Medicine Unit has 12 inpatient beds, an outpatient clinic, and a consultant team that works in and out of the hospital, including two palliative-care nurses, a social worker, a priest, a nutritionist, a part time physiotherapist and three fulltime physicians. The team worked only daytime hours. **Hospital and home care + PCT** N=235	Conventional care N=199	Place of death and time spent in institutions in the last month of life (Jordhøy *et al*., 2000) Quality of life assessed using EORTC QLQ-C30 and Impact of Event scale (IES) (Jordhøy *et al*., 2001) Family satisfaction as measured by the FAMCARE Scale (Ringdal *et al*., 2002)
SUPPORT (Connors *et al*., 1995; Desbiens *et al*., 1996; Baker *et al*., 2000)	RCT USA Poor	Family members and other surrogate respondents for 767 seriously ill hospitalised adults who died. N=767	A specially trained nurse had multiple contacts with the patient, family, physician and hospital staff to elicit preferences, improve understanding of outcomes, encourage attention to pain control and facilitate advance care planning and patient-physician communication. **Hospital care + clinical nurse specialist**	Not reported	Caregiver satisfaction, timing of do-not-resuscitate order, patient-physician CPR choice, days in aggressive treatment, pain and hospital resource use.
Gade *et al*., 2008	RCT USA Fair	Eligible patients were 18 or more years of age, hospitalised with at least one life-limiting diagnosis, and whose attending physician indicated they "would not be surprised if the patient died within 1 year." N=517	The palliative care team included a palliative care physician and nurse, hospital social worker and chaplain. The team was available Monday through Friday. A palliative care physician was on call after hours **Home care + PCT** N=280	Usual hospital care N=237	The primary study outcomes were symptom control, levels of emotional and spiritual support, patient satisfaction, and total health services costs at 6 months post-index hospitalisation. Secondary measures included survival, number of advance directives (ADs) at discharge, and hospice utilisation.

Table 22: Study characteristics: models of palliative care *cont.*

Author & year	Study type Study quality	Population	Intervention	Comparator	Outcomes
McMillan *et al*., 2007; McMillan *et al*., 2006	RCT USA Good	Family caregivers of community dwelling hospice patients with advanced cancer. The population was drawn from consecutive admissions to a large non-profit community-based hospice in the south eastern United States. N=354	Patient/caregiver pairs were randomly divided into three groups, including a control group who received standard hospice care, a group who received standard hospice care plus three supportive visits from an intervention nurse, and a group who received standard care plus three visits to teach a coping skills intervention. **Hospice care + nurse or coping skills intervention** Hospice care + nurse =109 Hospice care + intervention =111	Caregivers in the control group received hospice standard care and participated in data collection. N=109	Caregiver QoL was assessed with the Caregiver Quality of Life Index-Cancer (CQoL-C) Burden associated with patient cancer symptoms was assessed with the Memorial Symptom Assessment Scale (MSAS). Caregivers completed the Caregiver Demands Scale (CDS), which has 46 items that assess burden and mastery. The impact of the interventions on coping responses was assessed using the Brief COPE.
Bakitas *et al*., 2009a, Bakitas *et al*., 2009b	RCT USA Good	Family caregivers of community dwelling hospice patients with advanced cancer. N=354	Project ENABLE II was a phone-based, nurse-led educational, care coordination palliative care intervention model. Intervention services were provided weekly for the first month and then monthly until death, including bereavement follow-up call to the caregiver. **Home care + nurse-led phone intervention** N=161	Participants assigned to usual care were allowed to use all oncology and supportive services without restrictions including referral to the institutions' interdisciplinary palliative care service. N=161	QoL was measured by the Functional Assessment of Chronic Illness Therapy for Palliative Care. Symptoms were measured by the Edmonton Symptom Assessment Scale. Mood was measured by the Centre for Epidemiological Studies Depression Scale. Intensity of service was measured as the number of days in the hospital and in the intensive care unit (ICU) and the number of emergency department visits.

Table 22: Study characteristics: models of palliative care *cont.*

Author & year	Study type Study quality	Population	Intervention	Comparator	Outcomes
Intervention Level III-1 evidence					
Costantini *et al.*, 2003	Quasi randomised prospective study Italy Fair	Patients with a diagnosis of advanced terminal cancer requiring palliative care and age at least 18 years. N=2,503	The palliative home care team (PHCT) is a free service comprising 12 physicians, seven registered nurses, three psychologists and 25 volunteers. **Home care + PCT** N=189	Patients not followed by the PHCT received usual care from hospitals, their general practitioners and other health services N=378 matched for primary tumour	The outcome measure was the number of days spent in hospital in the last 180 days before death, both before and after PHCT admission.
Intervention Level III-2 evidence					
Goodwin *et al.*, 2002	Prospective comparative study UK Fair	The day care patients were consecutive new referrals to five palliative day care centres. Comparison patients were identified from the home care nursing teams within each of the five palliative care services.	Five palliative day care centres in the UK provided facilities for medical and nursing assessment of all patients. The centres provided a variety of activities and often employed specialists, such as art therapists and aromatherapists. All patients received the usual palliative care services (home care, inpatient services, and outpatient services). **Palliative day care** N=120	All patients received the usual palliative care services (home care, inpatient services, and outpatient services), but the comparison group did not attend day care. N=53	Patients were assessed at 3 interviews (baseline, 6–8 weeks, and 12–15 weeks) using measures of health-related quality of life: McGill Quality of Life Questionnaire (MQOL) and Palliative Care Outcome Scale (POS).
Hanson *et al.*, 2008	Prospective observational study USA Good	Seriously ill hospitalised patients referred to the PCT between July 1, 2002 and June 30, 2005.	Enrolled palliative care patients received inpatient consultation from an interdisciplinary team consisting of an advance practice nurse and a physician. **Inpatient consultation + PCT** N=104	To test impact on costs, a one-year subset of cases with lengths of stay >4 days (n = 104) was compared to all available controls matched on diagnosis and mortality risk scores. N = 1,813	Only cost outcomes are eligible (due to presence of a control group).

Table 22: Study characteristics: models of palliative care *cont.*

Author & year	Study type Study quality	Population	Intervention	Comparator	Outcomes
Brumley *et al.*, 2003	Non-randomised experimental trial USA Fair	Patients with a diagnosis of COPD, CHF, or cancer; two or more emergency department visits or hospital admissions in the past year; and limited life expectancy. N=558	The Kaiser Permanente (KP) TriCentral Palliative Care (TCPC) Program is an interdisciplinary, home-based program for patients at the end of life. The program allows patients to retain their primary care physician while receiving home visits from the PCT and physician. **Home care + PCT** N=210	Usual care (KP home health patient) N=348	Data collected from the interviews included patients' rating of their illness severity, quality of life, and satisfaction with services. The Reid-Gundlach Satisfaction with Services instrument was used to measure patient satisfaction with services. Service utilization data were collected from KP administrative databases. The cost effectiveness of the TCPC model was evaluated using staff costs only.
Casarett *et al.*, 2008	Retrospective telephone survey USA Fair	Veterans had received inpatient or outpatient care from a participating VA in the last month of life. One family member completed each survey. N=524	The consultation service included physicians, nurse practitioners, or both, who contribute between 1.0 and 2.5 full time equivalents to the consultation service. They also include nurses, social workers, chaplains, volunteers, and other disciplines on an as-needed basis **Inpatient palliative consultations** N=296	Usual care (no inpatient palliative consultation) N=228	Interviews used the Family Assessment of Treatment at End-of-life (FATE) survey. The survey assessed the patient's well-being and dignity, adequacy of communication, respect for treatment preferences, emotional and spiritual support, management of symptoms, access to the inpatient facility of choice, care around the time of death, access to home care services, and access to benefits and services after the patient's death.

Table 22: Study characteristics: models of palliative care *cont.*

Author & year	Study type Study quality	Population	Intervention	Comparator	Outcomes
Dudgeon *et al.*, 2008, Dudgeon *et al.*, 2009	Pre-post program evaluation Canada Poor	Cancer patients in the palliative phase of their illness, and their carers Study includes 513 patients in 2001 increasing to 579 patients in 2003.	The Palliative Care Integration Project (PCIP) includes the development of collaborative care plans (CCPs), Symptom Management/Medical guidelines, the use of common, validated assessment tools, and application of the CCPs, medical guidelines and assessment tools in the different care settings in the region. **Integration project** Study includes 513 patients in 2001 increasing to 579 patients in 2003.	Pre-post design	Two cohorts of eligible patients and caregivers completed Edmonton Symptom Assessment Scales, Caregiver Reaction Assessment and FAMCARE Scales. Chart audits were also conducted.
Aristides and Shiell, 1993	Pre-post study Australia Fair	Terminally ill cancer patients N=123	The continuing community cancer care (4C) program provided after-hours and weekend nursing care. The program also funded a day centre, additional home care services and two new medical officer positions. **Home care + palliative care nursing service** N=123	Pre-post study design	The use of hospital bed-days and hospital costs incurred by patients during the last 90 days of their life was compared before and after the introduction of 4C.
Edmonds *et al.*, 1998	Pre-post prospective study UK Poor	All new patients referred to the hospital PCT between August 1996 and May 1997. N=352	The PCT consisted of two full time clinical nurse specialists and two part-time doctors (a consultant for two sessions and a senior registrar for five sessions). **Hospital-based PCT for inpatients and outpatients** N=352	Pre-post study design	The E-STAS is an extended version of the STAS, designed to evaluate interventions for the control of physical and psychological symptoms.

Table 22: Study characteristics: models of palliative care cont.

Author & year	Study type Study quality	Population	Intervention	Comparator	Outcomes
Higginson and Hearn, 1997	Pre-post prospective study UK Fair	Terminal cancer patients N=695	Multidisciplinary PCTs of hospital and home care organisations in Ireland and England. Two projects were involved: palliative care evaluation project (PEP) included five teams in the southeast of England, and the Irish Cancer Society (ICS) project included six teams in Ireland. **Hospital and home care + multidisciplinary PCTs** N=695	Pre-post study design	The Karnofsky Performance Index (KPI) was used as an indicator of functional status Pain was recorded and rated using the Support Team Assessment Schedule (STAS).
Ventafridda *et al*., 1990	Pre-post prospective study Italy Poor	All patients had originally been referred because of pain or other symptoms resulting from the progression of cancer that was no longer responsive to anti-cancer treatments N=115	Hospital team part of whole service, four hospital nurses (seven doctors and 100 volunteers worked across hospital and home care). **Hospital and home care + PCT** N=115	Pre-post study design	Pain, other symptoms (vomiting), QoL (felt sad or depressed).
Follwell *et al*., 2009	Pre-post prospective study Canada Fair	Eligible patients had metastatic cancer N=150	An oncology palliative care clinic (OPCC) where patients are seen by a nurse, physician, social worker and psychiatrists. All patients are given contact information for the nurse and physician and the number for the 24-hour on-call service staffed by palliative care physicians. **Home care + PCT**	Pre-post study design	Symptom control and patient satisfaction were assessed using the Edmonton Symptom Assessment Scale (ESAS) and patient-adapted Family Satisfaction with Advanced Cancer Care (FAMCARE).

Table 22: Study characteristics: models of palliative care cont.

Author & year	Study type Study quality	Population	Intervention	Comparator	Outcomes
Kusajima *et al*., 2009	Pre-post prospective study Japan Fair	The participants were terminal cancer patients and their families who had been referred to the specialised home palliative care service N=100	Specialised home palliative care (SHPC) service comprising palliative care physicians, nurses, caseworkers, and other care specialists. Each patient was visited at least once per week by a physician and at least 3 times per week by a nurse. If required, a visit was also carried out every day. **Home care + PCT** N=100	Pre-post study design	Quality of life: Self-reported health status by patients (EQ-5D). Families' health status and families' perception of patients' health status. Patient symptoms
Veerbeek *et al*., 2008	Pre-post study Netherlands Fair	Patients who received care at various institutions using the Liverpool Care Pathway (LCP) who died between November 2003 and February 2006. Includes 140 patients in the intervention period and 131 patients in the baseline period.	The LCP promotes clear communication around the dying and death of the patient, and it supports psychosocial and spiritual care to patients and their relatives, for example, by promoting adequate communication and support and giving relatives a brochure for bereavement after the death of the patient. **A guide for members of a multidisciplinary team** Includes 140 patients in the intervention period and 131 patients in the baseline period.	Pre-post study design	Levels of communication and bereavement using the Views of Informal Carers - Evaluation of Services (VOICES) questionnaire. Relatives were also asked to fill in the Leiden Detachment Scale (LDS), which includes 7 items about bereavement.

Table 22: Study characteristics: models of palliative care cont.

Intervention Level III-3 evidence					
Author & year	**Study type** **Study quality**	**Population**	**Intervention**	**Comparator**	**Outcomes**
Spettell *et al.*, 2009	Retrospective cohort design with three intervention groups, each matched to a historical control group. USA Fair	Patients with advanced illness and their families. Intervention groups were health plan enrollees who died after 2004: 3491 commercial enrollees with case management (CM); 387 commercial enrollees with CM and expanded hospice benefits; and 447 Medicare enrollees with CM.	The ''Compassionate Care Program'' included comprehensive case management services provided by health plan nurse case managers who received extensive training in palliative care. The 3 included interventions were: commercial enrollees with CM; commercial enrollees with CM and expanded hospice benefits; and Medicare enrollees with CM. **Case management**	Control groups consisted of enrollees who died in 2004 prior to the start of the palliative care CM program.	Primary outcomes were rates of hospice use and mean number of days in hospice; however, emergency visits, ICU stays, and acute inpatient stays were also reported.
Doolittle, 2000	Retrospective cost analysis USA Poor	Number and characteristics of patients not reported.	The service provided telephone-based videoconferencing equipment to link hospice providers with patients and families in their homes. The telehospice service included telemedicine visits provided by nurses and social workers. **Home care + telehospice**	Traditional hospice care including home visits.	Cost data and resource-use.

ABBREVIATIONS: 4C, CONTINUING COMMUNITY CANCER CARE; AD, ADVANCED DIRECTIVE; ADL, ACTIVITIES OF DAILY LIVING; AICCP, ADVANCED ILLNESS COORDINATED CARE PROGRAM; AIDS, ACQUIRED IMMUNE DEFICIENCY SYNDROME; CCP, COLLABORATIVE CARE PLAN; CDS, CAREGIVER DEMANDS SCALE; CHF, CONGESTIVE HEART FAILURE; COPD, CHRONIC OBSTRUCTIVE PULMONARY DISEASE; CM, CASE MANAGEMENT; CPR, CARDIOPULMONARY RESUSCITATION; C QOL-C, CAREGIVER QUALITY OF LIFE INDEX-CANCER; GP, GENERAL PRACTITIONER; EORTC, EUROPEAN ORGANISATION FOR RESEARCH AND THE TREATMENT OF CANCER; E-STAS, EXPANDED SUPPORT TEAM ASSESSMENT SCHEDULE; FAMCARE, FAMILY SATISFACTION WITH ADVANCED CANCER CARE; FATE, FAMILY ASSESSMENT OF TREATMENT AT END-OF-LIFE; HADS, HOSPITAL ANXIETY AND DEPRESSION SCALE; HBPC, HOME BASED PRIMARY CARE; HRQOL, HEALTH RELATED QUALITY OF LIFE; ICU, INTENSIVE CARE UNIT; ICS, IRISH CANCER SOCIETY; IES, IMPACT OF EVENT SCALE; KP, KAISER PERMANENTE; KPI, KARNOFSKY PERFORMANCE INDEX; LCP, LIVERPOOL CARE PATHWAY; LDS, LEIDEN DETACHMENT SCALE; MPAC, MEMORIAL PAIN ASSESSMENT CARD; MSAS, MEMORIAL SYMPTOM ASSESSMENT SCALE; MQOL, MCGILL QUALITY OF LIFE QUESTIONNAIRE; OPCC, ONCOLOGY PALLIATIVE CARE CLINIC; PCIP, PALLIATIVE CARE INTEGRATION PROJECT; PHCT, PALLIATIVE HOME CARE TEAM; PCT, PALLIATIVE CARE TEAM; POS, PALLIATIVE CARE OUTCOME SCALE; PEP, PALLIATIVE CARE EVALUATION PROJECT; QLQ-C30, QUALITY OF LIFE QUESTIONNAIRE C30; QOL, QUALITY OF LIFE; RCT, RANDOMISED CONTROLLED TRIAL; SHPC, SPECIALISED HOME PALLIATIVE CARE; STATS, SUPPORT TEAM ASSESSMENT SCHEDULE; TCPC, TRICENTRAL PALLIATIVE CARE; TM, TEAM-MANAGED; UK, UNITED KINGDOM; USA, UNITED STATES OF AMERICA; VA, VETERANS' ADMINISTRATION; VOICES, VIEWS OF INFORMAL CARERS – EVALUATION OF SERVICES

Original primary studies: results

Key conclusions of the included original studies are presented in the tables below. As was the case for the SRs discussed in **Part 1** of this report, the studies included a variety of interventions and assessed outcomes. To account for the wide range of assessment tools used in the studies, results were classified into the following broad categories of outcomes:

- Patient quality of life
- Patient satisfaction
- Symptom control
- Caregiver satisfaction
- Place of death
- Survival
- Utilisation of resources
- Cost of care

The classification of outcomes into the aforementioned categories was intended to provide convenient headings under which results could be qualitatively discussed, rather than a basis for meta-analysis. For certain outcomes, categorisation was associated with a degree of subjectivity, for example, functional assessment tools (such as Activities of Daily Living) have been classified as quality of life measures, even though they technically relate to different aspects of a patient's well-being. It is also important to note that there may be some outcomes reported in the included studies that were not thought to fit appropriately under any of the outcome headings. These outcomes have been excluded from the current review.

Original primary studies: Patient quality of life

Results pertaining to quality of life are presented in **Table 23** below. Overall, six RCTs reported outcomes relating to quality of life in patients receiving palliative care. Of these studies, only one reported a statistically significant improvement in the intervention arm (Bakitas *et al.*, 2009a and 2009b). This relatively high quality study (Project ENABLE II) was designed to assess a phone-based, nurse-led educational, care coordination palliative care intervention model. Intervention services were provided weekly for the first month and then monthly until death, including bereavement follow-up call to the caregiver. The study randomised 322 participants with cancers of the gastrointestinal tract, lung, genitourinary tract, or breast to the intervention or usual care. Quality of life was measured using a validated tool used specifically in palliative care populations: the Functional Assessment of Chronic Illness Therapy for Palliative Care (Lyons *et al.*, 2009). The estimated treatment effect (intervention minus usual care) for all participants was a mean of 4.6 for quality of life ($p=0.02$). While there is no universally accepted definition of a clinically meaningful difference in quality of life scores (Hays *et al.*, 2000), differences between groups of 4% for improvement or 9% for worsening have been cited as clinically meaningful differences using the Functional Assessment of Cancer Therapy tool (Cella *et al.*, 2002). Between-group differences of this magnitude were found in the RCT by Bakitas *et al.* (2009). It should be noted that this study differed from other RCTs of palliative care models, in that it was designed to test a palliative care intervention concurrent with oncology treatment. This approach is recommended in

international guidelines and consensus recommendations and was therefore considered appropriate by the authors (Ferris *et al.*, 2002; Mularski et al, 2007).

The remaining five RCTs found no differences between study arms in terms of anxiety, depression (Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996), functional status (Cummings *et al.*, 1990; Hughes *et al.*, 2000) or quality of life scores (Jordhøy *et al.*, 2000 and 2001; Ringdal *et al.*, 2002; Gade *et al.*, 2008). Two of these studies were relatively recent, high quality studies of home care plus a primary care team (Hughes *et al.*, 2000) and a Norwegian Palliative Care Unit including a PCT providing home and hospital care (Jordhøy *et al.*, 2000).

The results of Level III-2 studies were similarly inconclusive. A fair quality prospective comparative study by Goodwin *et al.* (2002) found that there was a statistically significant difference in 'practical matters addressed' ($p=0.026$), where the day care group had more severe/overwhelming scores. However, this was based on five outliers in the comparison group and when the outliers were removed the results were non-significant. A poor quality pre-post prospective study of a hospital and home-based PCT by Ventafridda *et al.* (1990) found some statistically significant improvements in specific quality of life domains, including difficulties at work, difficulties in visual free time activities, feeling sad or depressed, feeling anxious or scared and feeling nervous or insecure. However, there were many areas where no improvements were seen. Another pre-post prospective study by Kusajima *et al.* (2009) found no significant benefits for quality of life after the introduction of a PCT to patients receiving care at home.

Table 23: Original primary studies: Quality of life

Author & year	Intervention	Results
Intervention Level II evidence		
Addington-Hall *et al*., 1992; Raferty *et al*., 1996	Home care + coordination of care	The groups did not differ significantly in terms of quality of life, anxiety or depression.
Cummings *et al*., 1990	Home care + PCT	No group differences in Activities of Daily Living function or cognitive status were observed at either the 1- or 6-month post-test were detected.
Hughes *et al*., 2000	Home care + PCT	No difference was observed in functional status (Barthel Index) among terminal patients by treatment group. However, patients in the treatment group improved significantly vs. those in the control group in 6 of 8 HRQoL scales, including emotional role function, social function, bodily pain, mental health, vitality, and general health.
Jordhøy *et al*., 2000 and 2001 and Ringdal *et al*., 2002	Hospital and home care + PCT	For the AUC estimates, no statistically significant differences between the intervention and control groups were found, neither for psychologic distress, pain, physical and emotional functioning (p=0.1), or for any of the other EORTC QLQ-C30 scores. At later assessments and for scores that were made within 3 months before death, there was also no consistent tendency in favour of any treatment group on the main outcomes or other EORTC QLQ-C30 scales/items.
Gade *et al*., 2008	Home care + PCT	There were no differences between IPCS and UC for mean enrollment and discharge scores for the Physical, Emotional/Relationship, Spiritual Area composite scales or the Quality of Life scale.
Bakitas *et al*., 2009a and 2009b	Home care + nurse-led phone intervention	Longitudinal ITT analyses for the total sample revealed higher quality of life (mean p=0.02) (Functional Assessment of Chronic Illness Therapy for Palliative Care scores) in the intervention group compared with the usual care group.
Intervention Level III-2 evidence		
Goodwin *et al*., 2002	Palliative day care	At final interview, there was a statistically significant difference in the POS item 'practical matters addressed' (p=0.026), where the day care group had more severe/overwhelming scores. However, this was based on five outliers in the comparison group and when the outliers were removed the results were non-significant.
Ventafridda *et al*., 1990	Hospital and home care + PCT	Statistical improvements seen in difficulties at work, difficulties in visual free time activities, feeling sad or depressed, feeling anxious or scared and feeling nervous or insecure. There were many areas where no improvements were seen.
Kusajima *et al*., 2009	Home care + PCT	There were significant deteriorations in self-reported health status scores for mobility (p<0.001) and self-care (p=0.01). There were no significant deteriorations regarding the scores for pain/discomfort and anxiety/depression.

ABBREVIATIONS; AUC, AREA UNDER CURVE; COPD, CHRONIC OBSTRUCTIVE PULMONARY DISEASE; EORTCQLQ-C30, EUROPEAN ORGANISATION FOR RESEARCH AND TREATMENT OF CANCER QUALITY OF LIFE QUESTIONNNAIRE C30; HRQoL, HEALTH-RELATED QUALITY OF LIFE; IPCS, INTERDISCIPLINARY PALLIATIVE CARE SERVICE; ITT INTENTION TO TREAT; MQOL, MCGILL QUALITY OF LIFE QUESTIONNAIRE; PCT, PALLIATIVE CARE TEAM; POS, PALLIATIVE CARE OUTCOMES SCALE; UC, USUAL CARE;

Original primary studies: Patient satisfaction

Results for outcomes relating to patient satisfaction are presented in **Table 24**.

The six RCTs that included outcomes relating to patient satisfaction reported mixed results. A relatively high-quality study by Brumley *et al.* (2007) assessed the effects of an in-home palliative care service delivered by an interdisciplinary team and an array of medical and social support services. This study found statistically significant and sizeable improvements in satisfaction in the intervention group at 30 days (OR=3.37, 95% CI=1.42–8.10; p<0.006) and 90 days (OR=3.37, 95% CI=0.65–4.96; p<0.03) after enrollment. It should be noted that the study reported that 93% of those enrolled in the palliative care group very satisfied with care at 90 days after enrollment, compared with 81% of usual care patients, suggesting that satisfaction was relatively high in both groups. Two other fair quality RCTs reported increased patient satisfaction in patients receiving home care plus a team intervention (Engelhardt *et al.*, 2006; Gade *et al.*, 2008). A poor quality RCT by Cummings *et al.* (1990) also reported improved satisfaction in patients at one month; however, there were no significant benefits associated with the intervention at the six-month time point. In contrast, two good-quality RCTs of a hospital and home-based PCT (Hanks *et al.*, 2002) and home care plus a primary care team (Hughes *et al.*, 2000) found no differences between the study groups in terms of patient satisfaction. The results reported by Hughes *et al.* (2000) were based on an analysis that excluded non-terminal patients.

Both Level III-2 studies reporting patient satisfaction found benefits in favour of the intervention. A non-randomised prospective study by Brumley *et al.* (2003) on the effects of an interdisciplinary home-based program team found a significant increase in satisfaction scores for the intervention group after 60 days, while scores for the control group remained unchanged. Another pre-post prospective study of an oncology palliative care clinic (Follwell *et al.*, 2009) used the patient-adapted Family Satisfaction with Advanced Cancer Care (FAMCARE) assessment tool to measure patient satisfaction. The mean baseline total FAMCARE score was 34.7, with a mean improvement score of 6.1 (p<0.0001) at 1 week and 5.0 at 1 month (p<0.0002).

Table 24: Original primary studies: Patient satisfaction

Author & year	Intervention	Results
Intervention Level II evidence		
Brumley *et al.*, 2007	Home care + PCT	Patients randomised to in-home palliative care reported greater improvement in satisfaction with care at 30 and 90 days after enrollment ($p<0.05$)
Cummings *et al.*, 1990	Home care + PCT	At one month, HBHC recipients reported significantly higher satisfaction with care (0.1 on a three-point scale, $p<0.001$) than controls. There were no significant differences in satisfaction at the 6-month post-test.
Engelhardt *et al.*, 2006	Home care + team coordination	The AICCP patients reported significantly greater increases in satisfaction from pretest (mean=3.70, SD=0.74) to posttest (mean=4.07, SD=0.68) than usual care patients, whose pretest mean was 3.83 (SD=0.76) and whose posttest mean was 3.98 (SD=0.67; $p=0.03$). Effect size of AICCP on patient satisfaction was 0.18.
Hanks *et al.*, 2002	Hospital and home care + PCT	Patients in both treatment groups expressed high levels of satisfaction with their hospital care and there were no apparent differences between the groups
Hughes *et al.*, 2000	Home care + PCT	There was no difference in patient satisfaction with care among terminal patients during 12 months.
Gade *et al.*, 2008	Home care + PCT	The IPCS group reported higher mean satisfaction for both the Place of Care Environment scale (IPCS: 6.8; UC: 6.4, p< 001.) and the Doctors, Nurses/Other Health Care Providers Communication scale (IPCS: 8.3; UC: 7.2, $p<0.001$).
Intervention Level III-2 evidence		
Brumley *et al.*, 2003	Home care + PCT	No statistically significant difference in mean satisfaction scores was seen between intervention and comparison groups at baseline, although satisfaction at baseline was high for both groups. However, at 60 days after enrollment, the satisfaction score for the intervention group increased significantly from baseline ($p = .01$), whereas scores for the comparison group remained unchanged.
Follwell *et al.*, 2009	Home care + PCT	The mean baseline total FAMCARE score was 34.7, with a mean improvement score of 6.1 ($p<0.0001$) at 1 week and 5.0 at 1 month ($p<0.0002$). FAMCARE domains that showed the greatest improvement were "Information given about how to manage pain", "Doctor's attention to symptoms," "Pain relief,""How thoroughly the doctor assesses symptoms," and "Speed with which symptoms are treated" (all $p<0.0001$).

ABBREVIATIONS: AICCP, ADVANCED ILLNESS COORDINATED CARE PROGRAM; FAMCARE, FAMILY SATISFACTION WITH ADVANCED CANCER CARE HBHC, HINES MODEL OF CARE; IPCS, INTERDISCIPLINARY PALLIATIVE CARE SERVICE; PCT, PALLIATIVE CARE TEAM; SD, STANDARD DEVIATION; UC, USUAL CARE

Original primary studies: Symptom control

Results for outcomes relating to symptom control (including pain) are presented in **Table 25** below. Some of the studies measured symptom control using patient reports, while other studies asked carers to rate the symptoms of patients. In the current review, both types of assessments are discussed together.

Overall, there were six RCTs and eight Level III-2 studies reporting outcomes relating to symptom control.

One large well-designed trial of a phone-based, nurse-led palliative care intervention model (Bakitas *et al.*, 2009a and 2009b) found an almost significant trend toward lower symptom intensity (p=0.06) in the intervention group compared with the usual care group. Similarly, a good quality study of hospital at home during the last two weeks of life found that carers were more likely to give control patients higher ratings of pain compared with those in the intervention group (Grande *et al.*, 1999 and 2000). Differences between groups for other symptoms were non-significant. Another good quality RCT showed that patients receiving standard hospice care were just as likely to experience symptoms as those who also received three additional visits from an intervention nurse; however, a third group of patients who received a coping skills intervention experienced a significant improvement in symptom burden compared to usual care (McMillan *et al.*, 2006 and 2007). A UK study involving the use of two nurse coordinators found that patients in the intervention group were significantly less likely to experience vomiting, but there were no other significant differences in patient-reported symptoms (Addington-Hall *et al.*, 1992; Raftery *et al.*, 1996). Another poor quality RCT involving the introduction of a hospital-based nursing intervention reported no difference between the intervention and control groups in terms of symptom control (Connors *et al.*, 1995; Desbiens *et al.*, 1996; Baker *et al.*, 2000).

There was one RCT that measured the impact of a hospital and home-based PCT service on symptoms (Hanks *et al.*, 2002). This good quality study reported no difference between the intervention and control groups in terms of symptom control (Hanks *et al.*, 2002). The results of lower level studies of PCTs were more likely to suggest benefits in favour of the intervention study arm. There were five Level III-2 studies that assessed team interventions and also reported outcomes relating to symptom control. A pre-post prospective study in the UK found that an intervention involving an interdisciplinary PCT resulted in statistically significant improvements in the mean E-STAS score for all symptoms except depression (Edmonds *et al.*, 1998). Similarly, Higginson and Hearn (1997) found a significant reduction in the levels of pain experienced by patients receiving care from multidisciplinary PCTs after two weeks. Ventafridda *et al.* (1990) reported statistically significant improvements in pain, feeling weak, drowsiness and not feeling well; however, there were many areas where no improvements were seen. A recent pre-post prospective study of an oncology palliative care clinic found statistically significant improvements after one week for all symptoms except well-being, including pain, fatigue, nausea, anxiety, dyspnoea, and insomnia (all $p<0.0001$), as well as depression, drowsiness, and constipation (all $p<0.002$). In those patients who were assessable at one month, there was a significant improvement in Total Distress Scores (TDS) ($p<0.0001$) and

ESAS Distress Scores (EDS) ($p<0.0001$) and statistically significant improvement in symptom control for anxiety, insomnia, dyspnoea, depression, and pain (Follwell *et al.*, 2009). In their pre-post prospective study of a team-based home palliative care service Kusajima *et al.* (2009) found that after two weeks there were significant improvements in symptom scores of pain ($p= .02$), appetite loss ($p<0.001$), and constipation ($p<0.001$). Similarly, the number of moderate to extreme symptoms decreased significantly ($p=0.01$).

The three remaining Level III-2 studies involved inpatient consultations for palliative patients (Casarett *et al.*, 2008), a Palliative Care Integration Project (PCIP) (Dudgeon *et al.*, 2008 and 2009), and a study of palliative day care (Goodwin *et al.*, 2002). The retrospective telephone survey by Casarett *et al.* (2008) found that patients who received a consultation had better scores for pain (adjusted mean 2.15 vs. 1.88; $p=0.04$) and symptoms related to posttraumatic stress disorder (adjusted mean 1.92 vs. 0.77; $p=0.02$). There was no difference for confusion (adjusted mean 0.56 vs. 0.16; $P=0.17$) or dyspnoea (adjusted mean 1.03 vs. 0.87; $p=0.40$). The PCIP study by Dudgeon *et al.* (2008 and 2009) showed an increase in documentation of pain from 24.5% to 74.6% ($p<0.001$). There was also minimal change in the intensity of symptoms ($p=0.591$). Goodwin *et al.* (2002) reported that usual care was significantly worse than palliative day care at 6-8 weeks in terms of symptom control, but not at the other two time points in the study (baseline and 12-15 weeks).

Table 25: Original primary studies: Symptom control

Author & year	Intervention	Results
Intervention Level II evidence		
Addington-Hall *et al*., 1992; Raferty *et al*., 1996	Home care + coordination of care	Patients in the intervention group were significantly less likely to have experienced vomiting (p=0.05) but there were no other significant differences in the symptoms experienced in the 24 hours before the interview. The coordination group were also less likely to be concerned about itchy skin (p=0.02). Carers of the coordination group were more likely to report that the patient had a cough (p=0.04), less likely to rate the patient's difficulty in swallowing as severe (p=0.03), more likely to report effective treatment for constipation (p=0.01) and less likely to report effective treatment for anxiety (p=0.01).
Grande *et al*., 1999; Grande *et al*., 2000	Hospital at home	Carers were more likely to give patients in the control group high ratings of pain compared with those in the CHAH group (mean 3.00 versus 2.52, Z=1.971, p=0.049). All other comparisons were nonsignificant (p > 0.05)
Hanks *et al*., 2002	Hospital and home care + PCT	For symptom scores, there was a highly significant improvement in scores for all times in the both groups after one week. However, comparison of the mean scores at 1 week adjusted for baseline scores showed no statistically significant differences between the groups.
Connors *et al*., 1995; Desbiens *et al*., 1996; Baker *et al*., 2000	Hospital care + clinical nurse specialist	Reported pain increased for the 1677 intervention patients and surrogates interviewed in the second week, compared with the control group (adjusted ratio, 1.14; 95% CI, 1.00 to 1.33)
McMillan *et al*., 2007 and 2006	Hospice care + nurse or coping skills intervention	The results of this analysis indicated that the treatment group by time interactions were not statistically significant for the comparison between usual care and support condition for symptom burden. By contrast, for the comparison between the usual care group and the COPE intervention group, the group by time interactions for symptom burden were statistically significant (p<0.001). For symptom burden, significant improvements being seen in the COPE intervention group (p<0.001) but not for the usual care group.
Bakitas *et al*., 2009a and 2009b	Home care + nurse-led phone intervention	There was a trend toward lower symptom intensity (p=0.06) (ESAS scores) in the intervention group compared with the usual care group.
Intervention Level III-2 evidence		
Casarett *et al*., 2008	Inpatient palliative consultations	In ordinal logistic regression models, adjusting for propensity score, age, and ethnicity, patients who received a consultation had better scores for pain (adjusted mean 2.15 vs. 1.88; p=0.04) and symptoms related to posttraumatic stress disorder (adjusted mean 1.92 vs. 0.77; p=0.02). There was no difference for confusion (adjusted mean 0.56 vs. 0.16; p=0.17) or dyspnoea (adjusted mean 1.03 vs. 0.87; p=0.40)
Dudgeon *et al*., 2008, Dudgeon *et al*., 2009	Integration project	Audits of 53 charts pre-implementation and 63 post-implementation showed an increase in documentation of pain from 24.5% to 74.6% (p<0.001). There was minimal change in the intensity of symptoms (p=0.591)

Table 25: Original primary studies: Symptom control *cont.*

Author & year	Intervention	Results
Edmonds *et al.*, 1998	Hospital-based PCT for inpatients and outpatients	The change in mean E-STAS scores for each symptom in the 122 patients with a score ≥1 on first assessment and who completed three or more E-STAS forms showed that the PCT intervention resulted in statistically significant improvements in the mean E-STAS score for all symptoms except depression. These symptoms include pain, mouth discomfort, anorexia, nausea, vomiting, constipation, breathlessness and psychological distress.
Higginson and Hearn, 1997	Hospital and home care + PCT	After two weeks of care by the services, there was a significant reduction in the levels of pain (Wilcoxon signed-rank test, Z = -7.19; p<0.0001), and no patients experienced overwhelming pain. Presence of pain and severity were not associated with the Karnofsky score, or with the time in care before death or with place of care at referral.
Ventafridda *et al.*, 1990	Hospital and home care + PCT	Statistical improvements seen in pain, feeling weak, drowsiness and not feeling well. There were many areas where no improvements were seen.
Follwell *et al.*, 2009	Home care + PCT	In the 123 patients with 1-week follow-up data, there was a mean improvement of 8.8 in ESAS Distress Score (EDS) (9.8%; p< .0001) and of 10.8 in Total Distress Score (TDS) (9.8%; p< .0001). Statistically significant improvements occurred for all symptoms except well-being, including pain, fatigue, nausea, anxiety, dyspnea, and insomnia (all p<0.0001), as well as depression, drowsiness, and constipation (all p<0.002). More than 40% of the 150 patients enrolled had a reduction of symptom score by at least 1 point at 1 week for pain, fatigue, anxiety, and insomnia and more than 60% of those scoring 8 to 10 out of 10 had an improvement of at least 1 point for all symptoms except fatigue, appetite, and constipation. In the 88 patients who were assessable at 1 month, there was a significant improvement in TDS (p<0.0001) and EDS (p<0.0001) and statistically significant improvement in symptom control for anxiety, insomnia, dyspnea, depression, and pain.
Goodwin *et al.*, 2002	Palliative day care	There was a marginally significant baseline difference for the POS item 'pain control' (p=0.053), where the comparison group had more severe/overwhelming scores. The comparison group were also significantly worse at the second interview for the POS item 'symptom control' (p=0.025).
Kusajima *et al.*, 2009	Home care + PCT	There were significant improvements in symptom scores of pain (p= 0.02), appetite loss (p<0.001), and constipation (p<0.001). Similarly, the number of moderate to extreme symptoms decreased significantly (p=0.01). However, no significant improvement was observed in symptom score for dry mouth (p=0.003).

ABBREVIATIONS: CHAH, CAMBRIDGE HOSPITAL AT HOME SERVICE; CHF, CONGESTIVE HEART FAILURE; CI, CONFIDENCE INTERVAL; COPD, CHRONIC OBSTRUCTIVE PULMONARY DISEASE; EDS, ESAS DISTRESS SCORE; E-STAS, EXPANDED SUPPORT TEAM ASSESSMENT SCHEDULE ; POS, PALLIATIVE OUTCOMES SCALE; PCT, PALLIATIVE CARE TEAM; TDS, TOTAL DISTRESS SCORE

Original primary studies: Caregiver satisfaction

Results for outcomes relating to caregiver satisfaction are presented in **Table 26** below. Overall, there were seven RCTs and three Level III-2 studies that reporting outcomes relating to caregiver satisfaction. It should be noted that some of these studies reported caregiver responses on topics other than satisfaction with care (e.g. their views on communication and the patient's physical/psychological wellbeing). As such, there are some outcomes reported here that do not reflect caregiver satisfaction *per se*, but rather, caregiver perception of care.

The results of studies reporting outcomes relating to caregiver satisfaction for PCT interventions were generally mixed. In a large good quality RCT in a Norwegian Palliative Medicine Unit, caregivers of patients who received hospital or home care with the assistance of a PCT reported greater satisfaction with care in 16 out of 18 items. For 11 of these items, the difference between study groups was statistically significant (Jordhøy *et al.*, 2000 and 2001 and Ringdal *et al.*, 2002). Hughes *et al.* (2000) reported the results of a good quality study of team-managed home-based primary care (HBPC) including a primary care manager, 24-hour contact for patients and HBPC involvement in hospital admissions and discharges. This study also found that caregivers of terminal patients in the HBPC group showed significant health-related QoL (HRQoL) improvements ($p<0.05$ overall) compared with the control patients in all but 2 dimensions of the SF-36, the exceptions being vitality and general health. However, another good quality RCT of hospital and home-based PCTs (Hanks *et al.,* 2002) found that carers of patients in both treatment groups expressed high levels of satisfaction with their hospital care and there were no apparent differences between the groups. A poor quality RCT by Cummings *et al.* (1990) found that caregivers of patients receiving a hospital-based home care program were significantly more satisfied with care than patients receiving usual care at one month ($p=0.003$) and at six months ($p=0.04$). A Level III-2 pre-post study of a Specialised Home Palliative Service (Kusajima *et al.*, 2009) reported a significant improvement in caregiver anxiety regarding care at home ($p=0.002$). However, there were significant deteriorations in the frequency of night-time awakening for patient care ($p<0.001$) and in the physical status ($p=0.01$). The families' perception of patients' physical and psychological status did not change significantly.

Another good quality RCT showed that only caregivers of patients who received a coping skills intervention experienced improvements in quality of life over time (McMillan *et al.*, 2006 and 2007).

A fair quality UK RCT assessing the effects of care coordination using two nurse coordinators found no significant differences in the experience of carers (Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996). A poor quality study of another nursing intervention for palliative care patients found that the intervention was significantly associated with satisfaction with communication and decision-making (Connors *et al.*, 1995; Desbiens *et al.*, 1996; Baker *et al.*, 2000).

A Level III-2 pre-post program evaluation reported by Dudgeon *et al.* (2008 and 2009) found no change in the burden on the caregiver or caregiver satisfaction with care after the introduction of a Palliative Care Integration Project. In another pre-post study of the Liverpool Care Pathway, Veerbeek *et al.* (2008) found that

communication was evaluated similarly before and after the introduction of the intervention, except that in the intervention period more relatives (93%) found the information about the patient's situation and care comprehensible when compared with the baseline period (85%; p=0.05). However, it should be noted that these differences could largely be explained by place of death and the type of relationship between the patient and the relative. There was also a significantly lower bereavement level in relatives of patients in the intervention period.

Table 26: Systematic review results: Caregiver satisfaction

Author & year	Intervention	Results
Intervention Level II evidence		
Addington-Hall *et al*., 1992; Raferty *et al*., 1996	Home care + coordination of care	There were no significant differences in the experiences of carers.
Cummings *et al*., 1990	Home care + PCT	HBHC caregivers reported significantly lower satisfaction with care at baseline than control group caregivers. At 1 and 6 months, this finding was reversed. Experimental group caregivers were significantly more satisfied with care at both 1 month (0.1 on a three-point scale, p=0.003) and at 6 months (p=0.04).
Hanks *et al*., 2002	Hospital and home care + PCT	Carers of patients in both treatment groups expressed high levels of satisfaction with their hospital care and there were no apparent differences between the groups
Hughes *et al*., 2000	Home care + PCT	Caregivers of terminal patients in the HBPC group showed significant HRQoL improvements (p<0.05 overall) compared with the control patients in all but 2 dimensions of the SF-36, the exceptions being vitality and general health.
Jordhøy *et al*., 2000 and 2001 and Ringdal *et al*., 2002	Hospital and home care + PCT	Respondents related to the patients who had participated in the intervention group reported lowest scores, that is, highest satisfaction with care, on all items except item 6, “availability of a hospital bed,” and item 14, “Time required to make a diagnosis.” In total, 11 of the 18 negative differences in mean scores were statistically significant at the 0.05 level.
SUPPORT (Connors *et al*., 1995; Desbiens *et al*., 1996; Baker *et al*., 2000)	Hospital care + clinical nurse specialist	Sixteen percent of respondents reported dissatisfaction with patient comfort and 30% reported dissatisfaction with communication and decision-making. Factors found to be significantly associated with satisfaction with communication and decision-making were hospital site, whether death occurred during the index hospitalisation (adjusted odds ratio (AOR) 2.2, 95% CI, 1.3-3.9), and for patients who died following discharge, whether the patient received the SUPPORT intervention (AOR 2.0, 1.2-3.2).
McMillan *et al*., 2007 and 2006	Hospice care + nurse or coping skills intervention	For caregiver QoL, only the COPE intervention group showed statistically significant improvements in QoL ratings over time (p=0.033), whereas the usual care group experienced no significant change over time. None of the time effects for the usual care or COPE intervention group were statistically significant for the caregiving task burden measure; however, the source of interaction was likely due to the finding that the COPE group improved over time, whereas the usual care group exhibited increased burden scores.
Intervention Level III-2 evidence		
Dudgeon *et al*., 2008, Dudgeon *et al*., 2009	Integration project	There was no change in the burden on the caregiver (p=0.086) or caregiver satisfaction with care (p=0.942)

Table 26: Systematic review results: Caregiver satisfaction *cont.*

Author & year	Intervention	Results
Kusajima *et al*., 2009	Home care + PCT	There was a significant improvement in anxiety regarding care at home (p=0.002). However, there were significant deteriorations in the frequency of night-time awakening for patient care (p<0.001) and in the physical status (p=0.01). The families' perception of patients' physical and psychological status did not change significantly.
Veerbeek *et al*., 2008	A guide for members of a multidisciplinary team	Communication was evaluated similarly in both periods, except that in the intervention period more relatives (93%) found the information about the patient's situation and care comprehensible when compared with the baseline period (85%; p=0.05). However, place of death and the type of relationship between the patient and the relative largely explained the difference in comprehensibility of information between both periods. The sum score of the LDS was significantly lower in the intervention period when compared with the baseline period (p=0.01), indicating a significantly lower bereavement level in relatives of patients in the intervention period.

ABBREVIATIONS: AOR, ADJUSTED ODDS RATIO; HBHC, HINES MODEL OF CARE; HBPC, HOME BASED PALLIATIVE CARE; HRQOL, HEALTH-RELATED QUALITY OF LIFE; LDS, LEIDEN DETACHMENT SCALE; PCT, PALLIATIVE CARE TEAM; QOL, QUALITY OF LIFE

Original primary studies: Place of death

Results for studies reported place of death are presented in **Table 27** below. Overall, there were three RCTs and one Level III-2 study that reported outcomes relating to place death.

One relatively good quality RCT (Brumley *et al.*, 2007) found that patients randomised to in-home palliative care were more likely to die at home than those receiving usual care ($p<0.001$). The results of another good quality RCT on hospital at home with practical home nursing care were less conclusive (Grande *et al.*, 2000). While patients who were actually admitted to hospital at home were more likely to die at home than controls (78% vs. 58%), ITT analysis did not show that the patients allocated to hospital at home were more likely to die at home (67%) than patients allocated to standard care, and it may be that patients who were most suitable for remaining at home were also most likely to receive hospital at home care. A third RCT set in a Norwegian Palliative Medicine Unit did not report place of death, but found that the time spent at home was not significantly increased, although intervention patients spent a smaller proportion of time in nursing homes in the last month of life than did controls (7.2 vs. 14.6%, $p<0.05$). In a Canadian pre-post program evaluation, examination of administrative data showed a numeric decrease in the percentage of deaths in acute care from 43.1% to 35.7% ($p=0.133$) after the introduction of a Palliative Care Integration Project (Dudgeon *et al.*, 2008 and 2009).

Table 27: Original primary studies: Place of death

Author & year	Intervention	Results
Intervention Level II evidence		
Brumley *et al.*, 2007	Home care + PCT	Patients randomised to in-home palliative care were more likely to die at home than those receiving usual care ($p<0.001$).
Grande *et al.*, 1999; Grande *et al.*, 2000	Hospital at home	While patients who were actually admitted to hospital at home were more likely to die at home than controls (78% vs. 58%), these results do not lead to the conclusion that hospital at home enabled more patients to die at home. Intention to treat analysis did not show that the patients allocated to hospital at home were more likely to die at home (67%) than patients allocated to standard care, and it may be that patients who were most suitable for remaining at home were also most likely to receive hospital at home care. The results are therefore inconclusive in terms of causation, but suggestive of an effect associated with receipt of hospital at home. The study attained less statistical power than initially planned.
Jordhøy *et al.*, 2000 and 2001 and Ringdal *et al.*, 2002	Hospital and home care + PCT	The time spent at home was not significantly increased, although intervention patients spent a smaller proportion of time in nursing homes in the last month of life than did controls (7.2% vs. 14.6%, $p<0.05$).
Intervention Level III-2 evidence		
Dudgeon *et al.*, 2008, Dudgeon *et al.*, 2009	Integration project	Administrative data showed a decrease in the percentage of deaths in acute care from 43.1% to 35.7% ($p=0.133$).

ABBREVIATIONS: PCT, PALLIATIVE CARE TEAM

Original primary studies: Survival

Results for the studies reporting survival are presented in **Table 28** below. Overall there were seven RCTs that reported outcomes relating to patient survival, of which only one found a survival benefit in favour of the intervention. This fair quality study (Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996) reported that median survival in patients receiving home care plus a nursing intervention was 385 days, compared to 340 days in patients receiving usual care. This difference was assessed by Cox regression as just significant (p=0.05). The remaining RCTs showed no significant differences in survival time between study groups; however, it should be noted that increasing survival is not an objective of palliative care.

Table 28: Original primary studies: Survival

Author & year	Intervention	Results
Intervention Level II evidence		
Addington-Hall *et al*., 1992; Raferty *et al*., 1996	Home care + coordination of care	The median survival after study entry was 385 days in the study group and 340 days in the control group. This was assessed by Cox regression as just significant (p=0.05)
Brumley *et al*., 2007	Home care + PCT	Results of the Kaplan-Meier survival analysis did not show significant differences in survival time between study groups (log rank test=2.98; p=0.08), although subsequent analysis controlled for survival days due to the strong trend toward higher survival in the usual care group and its potential effect on use of medical services and costs of medical care.
Engelhardt *et al*., 2006	Home care + team coordination	No significant differences were found. Survival rates at 18 months post-enrollment were 43% for the AICCP group versus 42% for the UC group.
Cummings *et al*., 1990	Home care + PCT	Mean survival was similar in both groups at 124.6 (SD=91.44) for the HBHC and 128.2 (SD=70.12) for the control group.
Jordhøy *et al*., 2000 and 2001 and Ringdal *et al*., 2002	Hospital and home care + PCT	Median survival was 99 days (95% CI 79–119) in the intervention group and 127 days (88–166) in the control group (p=0.1, adjusted for diagnostic groups). 34 (14%) intervention patients and 35 (18%) controls died within 1 month of enrolment.
Gade *et al*., 2008	Home care + PCT	There was no difference in survival between IPCS and UC.
Bakitas *et al*., 2009a and 2009b	Home care + nurse-led phone intervention	Post hoc, exploratory analyses demonstrated no statistically significant differences in survival between the 2 groups.

ABBREVIATIONS: CI, CONFIDENCE INTERVAL; HBHC, HINES MODEL OF CARE; IPCS, INTERDISCIPLINARY PALLIATIVE CARE SERVICE; PCT, PALLIATIVE CARE TEAM; SD, STANDARD DEVIATION; UC, USUAL CARE

Original primary studies: Utilisation of services

Results for outcomes relating to the utilisation of services are presented in **Table 29** below.

The studies reporting utilisation of health services included 10 RCTs, one Level III-1 study, three Level III-2 studies and one Level III-3 study. In general the types of health services measured and reported varied across studies. Relevant outcomes included hospital/ICU/emergency department visits, length of hospitalisation, visits to General Practitioners (GPs) and other health care specialists and medication use.

The results of studies reporting utilisation of services for PCT interventions were mixed. In a good quality study by Brumley *et al.* (2007) it was found that 20% of patients receiving a PCT intervention went to the emergency department compared with 33% of patients receiving usual care (p=0.01). Similarly, 36% of those receiving the intervention were hospitalised, compared with 59% of those enrolled in usual care (p<0.001). In another good quality study of a Norwegian Palliative Medicine Unit, (Jordhøy *et al.*, 2000 and 2001 and Ringdal *et al.*, 2002), the proportion of time spent in nursing homes was higher for the control group for the entire observation period and in the last month before death. However, the proportion of hospital readmission time and overall time in institutions did not differ significantly between groups. Two other good quality RCTs reporting the effects of interventions involving the use of specialist teams did not report significant differences in the length of hospital stays, rates of readmission or resource use (Hanks *et al.*, 2002; Hughes *et al.*, 2000). A fair quality study reported by Gade *et al.* (2008) found that while the number of days from index hospital admission to study enrollment, days from enrollment to hospital discharge, and hospital length of stay did not differ between the intervention arm and patients receiving usual care, patients receiving the intervention had significantly fewer ICU stays on readmission (12 vs. 21, p=0.04). In contrast to these results, a poor quality study by Cummings *et al.* (1990) found that patients receiving a PCT intervention spent a greater proportion of their hospital stay on the intermediate care ward (3 days vs. 1.5 days, respectively; p<0.03) and less time on general care wards (8.5 days vs. 12.2 days, respectively; p<0.04) than control patients. However, patients in the PCT group had fewer outpatient clinic visits than their control group counterparts (1.33 visits vs. 3.39 visits, respectively; p<0.0001).

The evidence from lower level studies regarding the utilisation of health services in PCT-based interventions was generally more consistent. In a quasi-randomised prospective study, Costantini *et al.* (2003) found that after introducing the intervention, the percentage of days in hospital was significantly higher in the control group (30.3%; 95% CI: 26-34) than in cases (19.0%; 95% CI: 15-23). Similarly, a Level III-2 study by Brumley *et al.* (2003) reported that patients in the PCT group had fewer emergency department visits, inpatient days, skilled nursing days, and physician office visits than did the comparison group; however, the intervention group had more home care visits than did the comparison group.

An RCT of hospital at home compared to usual care showed that those receiving the intervention had fewer GP evening home visits (mean 0.17 vs. 0.61; p=0.022) and night visits (mean 0.04 versus 0.26; p=0.0003) in the penultimate week of life

compared to the control group (Grande *et al.*, 1999; Grande *et al.*, 2000). There was no difference in daytime visits or in night and evening visits in the last week of life.

In their RCT of a nurse-led phone intervention, Bakitas *et al.* (2009a and 2009b) reported no statistically significant differences between groups in the number of days in the hospital (6.6 vs. 6.5, respectively; p=0.14), number of days in the ICU (0.06 vs. 0.06; p=0.99), or in the number of emergency department visits (0.86 vs. 0.63; p=0.53).

A fair quality UK RCT assessing the effects of care coordination using two nurse coordinators found no difference in the type of analgesics taken, or in the proportions of patients taking antiemetics, laxatives, antidepressants, sedatives or anxiolytics. The two groups were equally likely to report having had contact with social service agencies, nursing services and general practitioners; however more patients in the intervention group reported contact with a chiropodist (p<0.02) (Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996). The SUPPORT trial (Connors *et al.*, 1995; Desbiens *et al.*, 1996; Baker *et al.*, 2000), which looked at the impact of a nursing intervention on family members, also found no difference in hospital resource use between the intervention and control arm (adjusted ratio, 1.05; 95% CI, 0.99 to 1.12). Another Level III-2 study of a palliative nursing service (Aristides and Shiell, 1993) reported no statistically significant difference in the proportion of patients admitted to hospital before and after the introduction of the program. Nor did the program have a significant impact on length-of-stay once a patient had been admitted to hospital.

One poor quality Level III-2 study evaluation of the Palliative Care Integration Project showed a decrease in the percentage of patients with at least one emergency room visit from 94.3% to 84.8% (p<0.001) and in the percentage of patients with at least one admission to the acute care hospital (p<0.001) (Dudgeon *et al.*, 2008, Dudgeon *et al.*, 2009). A case-controlled study of case management (Spettell *et al.*, 2009) reported that the percentage of patients using hospice more than doubled compared to its control group (p<0.0001) and the mean number of days in hospice care increased significantly for all of the intervention groups. The percentages of members with an acute inpatient stay or ICU admission after program enrollment were reduced for all three intervention groups compared to their respective control groups.

On balance, there is some evidence to suggest that there are reductions in health services utilisation as a result of palliative care interventions, including evidence from some high quality studies, such as those reported by Brumley et al. (2007) and Kane et al. (2008). However, it is important to note that many studies were poorly reported and the extra services required for the implementation of an intervention were sometimes not fully accounted for.

Table 29: Original primary studies: Utilisation of services

Author & year	Intervention	Results
Intervention Level II evidence		
Addington-Hall *et al*., 1992; Raferty *et al*., 1996	Home care + coordination of care	There were no differences in the type of analgesics taken, nor in the proportions of patients taking antiemetics, laxatives, antidepressants, sedatives or anxiolytics. The two groups were equally likely to report having had contact with social service agencies, nursing services and general practitioners; however more patients in the intervention group reported contact with a chiropodist ($p<0.02$).
Brumley *et al*., 2007	Home care + PCT	20% of palliative care members went to the emergency department, compared with 33% of usual care members ($p=0.01$; Cramer's $V=0.15$). Similarly, 36% of those receiving palliative care were hospitalised, compared with 59% of those enrolled in usual care ($p<0.001$; Cramer's $V=0.23$).
Cummings *et al*., 1990	Home care + PCT	The total number of VA hospital days did not differ significantly by group. However, patients receiving HBHC spent a greater proportion of their hospital stay on the intermediate care ward (3 days vs. 1.5 days, respectively; $p<0.03$) and less time on general care wards (8.5 days vs. 12.2 days, respectively; $p<0.04$) than control patients. A significant difference was observed in the use of outpatient care. Overall, patients in the HBHC group had fewer outpatient clinic visits than their control group counterparts (1.33 visits vs. 3.39 visits, respectively; $p<0.0001$).
Grande *et al*., 1999; Grande *et al*., 2000	Hospital at home	The CHAH group had fewer GP evening home visits (mean 0.17 vs. 0.61) and night visits (mean 0.04 versus 0.26) in the penultimate week of life compared to the control group ($Z=2.295$, $p=0.022$ and $Z=3.610$, $p=0.0003$, respectively). There was no difference in daytime visits or in night and evening visits in the last week of life ($p>0.05$)
Hanks *et al*., 2002	Hospital and home care + PCT	There was very little difference in the length of hospital stay or rates of readmission between the two groups. Hospital resource use (number of diagnostic images, diagnostic tests or visits from other hospital therapists) was very similar in the two groups.
Hughes *et al*., 2000	Home care + PCT	In the subgroup of terminally ill patients, no significant group differences were seen in number of hospital readmissions or the proportion of patients readmitted at 6 or 12 months.
Jordhøy *et al*., 2000 and 2001 and Ringdal *et al*., 2002	Hospital and home care + PCT	The proportion of time spent in nursing homes was higher for the control group for the entire observation period and in the last month before death. Overall, the proportion of hospital readmission time did not differ for the entire follow-up or for the last month. For the entire follow-up, the intervention and control patients spent a mean of 35% and 37% of time, respectively, in institutions ($p=0.6$). In the last month of life, the mean percentages were 52% and 59% ($p=0.06$).
SUPPORT (Connors *et al*., 1995; Desbiens *et al*., 1996; Baker *et al*., 2000)	Hospital care + clinical nurse specialist	There was no difference in hospital resource use between the intervention and control arm (adjusted ratio, 1.05; 95% CI, 0.99 to 1.12).

Table 29: Original primary studies: Utilisation of services *cont.*

Author & year	Intervention	Results
Gade *et al*., 2008	Home care + PCT	Number of days from index hospital admission to study enrollment, days from enrollment to hospital discharge, and hospital length of stay did not differ between the IPCS and UC patients. There was no difference in the number of hospital readmissions but IPCS patients had significantly fewer ICU stays on readmission (IPCS: 12; UC: 21, p=0.04).
Bakitas *et al*., 2009a and 2009b	Home care + nurse-led phone intervention	There were no statistically significant differences between groups in the number of days in the hospital (6.6 vs. 6.5, respectively; p=0.14), number of days in the ICU (0.06 vs. 0.06; p=0.99), or in the number of emergency department visits (0.86 vs. 0.63; p=0.53).
Intervention Level III-1 evidence		
Costantini *et al*., 2003	Home care + PCT	After admission to the PHCT, the percentage of days in hospital increased for both cases and controls. The percentage was significantly higher in the control group (30.3%; 95% CI: 26-34) than in cases (19.0%; 95% CI: 15-23). This corresponds to a relative reduction of 37%, and an absolute reduction of 11%, of days spent in hospital.
Intervention Level III-2 evidence		
Brumley *et al*., 2003	Home care + PCT	The intervention group had fewer emergency department visits, inpatient days, skilled nursing days, and physician office visits than did the comparison group, although the intervention group had more home care visits than did the comparison group.
Dudgeon *et al*., 2008, Dudgeon *et al*., 2009	Integration project	Administrative data showed a decrease in the percentage of patients with at least one emergency room visit from 94.3% to 84.8% (p<0.001) and in the percentage of patients with at least one admission to the acute care hospital (p<0.001).
Aristides and Shiell, 1993	Home care + palliative care nursing service	A higher proportion of patients were admitted at least once before the introduction of 4C than afterwards but the difference is not statistically significant at conventional levels. There was a shift in admissions away from the tertiary centre to non-tertiary hospitals. The average number of days spent in hospital by a patient once he or she had been admitted fell slightly following the introduction of 4C from 23.8 days to 22.9 days. The difference is not statistically significant, indicating that 4C was not successful in reducing length-of-stay once a patient had been admitted to hospital.

Table 29: Original primary studies: Utilisation of services *cont.*

Author & year	Intervention	Results
Intervention Level III-3 evidence		
Spettell *et al.*, 2009	Case management	For each group receiving CM, the percentage of members using hospice more than doubled compared to its control group (Enhanced Benefits CM 69.8% versus 27.9%, p<0.0001; CM 71.7% versus 30.8%, p<0.0001). The mean number of days with hospice increased from 21.4 days to 36.7 days (p<0.0001) for the Enhanced Benefits CM group, and from 15.9 days to 28.6 days (p<0.0001) for the CM group. The rate of use of hospice in the Medicare CM Group was 62.9%. The percentages of members with an acute inpatient stay after program enrollment were reduced for the Enhanced Benefits CM Group (16.8% versus 40.3%, p<0.0001), CM group (22.7% versus 42.9%, p<0.0001), and Medicare CM group (30.0% versus 88.4%, p<0.0001) compared to their respective control groups. The number of acute inpatient days was reduced for the Enhanced Benefits CM group (1549 versus 3986 days per thousand members, p<0.0001), CM Group (2311 versus 3858 days per thousand members, p<0.0001), and Medicare CM Group (2309 versus 15,217 per thousand members, p<0.0001) compared to their respective control groups. The proportion of members with ICU stays during an acute inpatient admission was significantly lower for all of the groups receiving CM compared to their respective control groups, as was ICU days per thousand member (Enhanced Benefits CM Group 899 versus 2542, p<0.0001, CM Group 1356 versus 2162, p<0.0001, Medicare CM Group; 1189 versus 9840, p<0.0001) compared to the control groups.

ABBREVIATIONS: CHAH, CAMBRIDGE HOSPITAL AT HOME SERVICE; CI, CONFIDENCE INTERVAL; CM, CASE MANAGEMENT; GP, GENERAL PRACTITIONER; HBHC, HINES MODEL OF CARE; ICU, INTENSIVE CARE UNIT; IPCS, INTERDISCIPLINARY PALLIATIVE CARE SERVICE; PCT, PALLIATIVE CARE TEAM; PHCT, PALLIATIVE HOME CARE TEAM; UC, USUAL CARE; VA, VETERAN'S ADMINISTRATION

Original primary studies: Cost of care

Results for outcomes relating to cost of care are presented in **Table 30** below.
Overall there were six RCTs, three Level III-2 studies and one Level III-3 study reporting outcomes relating to cost of care.

One good quality study (Brumley *et al.*, 2007) of in-home palliative care delivered by an interdisciplinary team found that there was a significant reduction in cost of care in the intervention study group (t= -3.63, p<0.001). Linear regression showed that overall costs of care for those receiving the intervention were 33% less than those receiving standard care (p=0.03; 95% CI= -$12,411 to -$780; R^2=0.16). Two less high quality RCTs of PCT interventions reported similar results (Cummings *et al.*, 1990; Gade *et al.*, 2008). Gade *et al.* (2008) found that total mean health costs for patients receiving home care plus a PCT intervention were lower by $6,766 per patient compared to usual care patients (p=0.001), and lower by $4,855 per patient once program staffing costs were taken into consideration. Cost savings were largely driven by a significant difference in the number of ICU stays on readmission for each group (p=0.04). In their study of a hospital-based home care program, Cummings *et al.* (1990) found that patients in the intervention study arm had significantly lower total hospital costs and private sector health care costs, but higher home care costs. Altogether, the average cost of care (institutional and community-based) was 13% lower in patients receiving the intervention than controls, although this difference was not statistically significant. The authors therefore conclude that the higher cost of home care for the intervention was offset by the savings achieved in institutional care. In contrast, a good quality RCT of team-managed home-based primary care (Hughes *et al.*, 2000) found that after 12 months, the total costs of public and private health care were 12.1% higher for the intervention group (p=0.005). However, it should be noted that these results apply to the full study population which included a large proportion of patients (79.3%) who were not terminally ill.

Both Level III-2 studies of PCT-based interventions reported cost reductions associated with the introduction of palliative care interventions. A prospective observational study of patients receiving an inpatient consultation from an interdisciplinary PCT (Hanson *et al.*, 2008) found that compared to matched controls without palliative care consultation, palliative care cases had lower cost per day ($897 vs. $1004, p< 0.03). Similarly, a non-randomised trial of a home-based PCT program found that per-patient costs for the intervention group averaged $6580 less than for the comparison group, a significant reduction of 45% (p <0. 001) (Brumley *et al.*, 2003).

An RCT of home care plus care coordination (Engelhardt *et al.*, 2006) found a 25% reduction in costs for the intervention compared to usual care ($12,123 vs. $16,295).

In their study of a palliative care nursing service, Aristides and Shiell (1993) found a reduction in hospital costs but an increase in overall per-patient costs as a result of the intervention. In a poor quality Level III-3 study by Doolittle *et al.* (2000) the introduction of a telehospice program was associated with an increase in cost; however any cost offsets as a result of decreased health service use were not measured.

In summary, a number of US-based RCTs have shown that the introduction of home care with the support of an interdisciplinary PCT may result in reduced direct costs to the health care system when compared to usual care. These reductions reached statistical significance in two trials (Brumley *et al*., 2007; Gade *et al*., 2008), one of which was a relatively large, good quality study (Brumley *et al*., 2007). In a number of studies, these reductions were partially driven by a decrease in the number/rate of acute hospital admissions.

Table 30: Original primary studies: Cost of care

Author & year	Intervention	Results
Intervention Level II evidence		
Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996	Home care + coordination of care	There were no significant differences between groups in terms of finance and benefits.
Brumley *et al.*, 2007	Home care + PCT	Significant differences between palliative and usual care members in cost of care (t= -3.63, p<0.001) were noted. Linear regression showed that overall costs of care for those enrolled in the IHPC program were 33% less than those receiving standard care (p=0.03; 95% CI= -$12,411 to -$780; R^2=0.16).
Cummings *et al.*, 1990	Home care + PCT	Total hospital costs were significantly lower (p=0.03) for the HBHC sample. Total hospital cost was $1200 less per person in the HBHC group than the control group, a cost savings of 29% (mean=$3000 vs. $4246, respectively). As a result, the total institutional costs also differed by group (p=0.052). The HBHC program saved $1154 or 26% in total institution costs compared with customary care. The average total cost of private sector health care services for control group subjects was more than double that of patients in the HBHC group ($1683 vs. $680, p=0.004). The cost of home care was 47% higher in the HBHC group than in the control group ($1206 vs. $640, respectively; p<0.0001). Although the average cost of care (institutional and community-based) for an individual receiving HBHC was not significantly lower than controls, it was 13% lower. Thus, the higher cost of home care for HBHC was offset by the savings achieved in institutional care.
Engelhardt *et al.*, 2006	Home care + team coordination	On average, AICCP costs per patient were $12,123 vs. $16,295 for usual care a $4172 (25%) difference, with an effect size of 0.18. This represents a statistically nonsignificant trend toward total lower cost from 6 months pre-enrollment to 6 months post-enrollment.
Hughes *et al.*, 2000	Home care + primary care team	At 6 months, VA hospital readmission costs for the TM/HBPC group were lower, but home-based care and nursing home care costs were significantly higher than the control group costs. Despite significantly lower private sector costs, total TM/HBPC costs were 6.8% higher than the total control group costs. At 12 months home care (p<0.001) and nursing home (p=0.02) costs were significantly higher for the TM/HBPC group than the control group, and only outpatient costs were significantly lower in the TM/HBPC group compared with the control group (p=0.02). As a result, total VA costs were 18.1% higher in the TM/HBPC group (p<0.001). This increase was partially offset by a 9% reduction in the TM/HBPC group for private sector or non-VA costs (p<0.001). However, total costs of VA and private sector care combined were 12.1% higher for the TM/HBPC group (p=0.005). This $3000 difference was approximately equal to the cost of the TM/HBPC intervention and amounted to a mean add-on of $282 per client per month. Results apply to the full study population which included a large proportion of patients (79.3%) who were not terminally ill.

Table 30: Original primary studies: Cost of care

Author & year	Intervention	Results
Gade *et al*., 2008	Home care + PCT	Total mean health costs for the IPCS group were lower by $6,766 per patient compared to UC patients (IPCS: $14,486; UC: $21,252, p=0.001). After subtracting the cost of staffing the IPCS ($1,911 per patient), the net savings was $4,855 per patient. Cost savings were largely driven by a significant difference in hospital readmission costs (IPCS: $6,421 per patient versus UC: $13,275 per patient, p= 0.009). There was no difference in the number of hospital readmissions but IPCS patients had significantly fewer ICU stays on readmission (IPCS: 12; UC: 21, p=0.04).
Intervention Level III-2 evidence		
Hanson *et al*., 2008	Inpatient consultation + PCT	Compared to controls, palliative care cases had no significant difference in variable costs across their entire hospitalisation ($16,748 vs. $15,926, p<0.0.78). Palliative cases and controls also did not differ significantly in total LOS (16.6 vs. 13.8 days, p=0.11), or ICU days (2.4 vs. 3.4 days, p=0.35). When daily costs were examined across the entire hospitalisation, as a measure of intensity of medical resource use, palliative care cases had significantly lower variable costs per day ($897 vs. $1004, p=0.03).
Brumley *et al*., 2003	Home care + PCT	For the TCPC group, per-patient cost reduction was seen across diagnoses (range $3514 to $8293) but was significant for patients who had cancer (p = .001) or COPD (p = .02). Per-patient costs for the intervention group averaged $6580 less than for the comparison group, a significant reduction of 45% (p <0. 001).
Aristides and Shiell, 1993	Home care + palliative care nursing service	The 4C program reduced average hospital costs per patient by $300, but the difference in cost before and after the introduction of 4C is not statistically significant. Over 550 patients registered with 4C during the 1991-1992 financial year and so the annual expenditure of the program translates into an approximate average cost per patient referred to the after-hours nursing service of $1000. The net average cost of the 4C program is therefore approximately $700 per patient.
Intervention Level III-3 evidence		
Doolittle, 2000	Home care + telehospice	For the first study period, costs were measured for traditional hospice home visits. During the second, expenses were monitored for traditional (in-person) and telehospice visits. For traditional care, the cost per visit was $126 and $141, for the first and second time periods, respectively. The average telehospice visit cost was $29.

ABBREVIATIONS: AICCP, ADVANCED ILLNESS COORDINATED CARE PROGRAM; CI, CONFIDENCE INTERVAL; COPD, CHRONIC OBSTRUCTIVE PULMONARY DISEASE; HBHC, HINES MODEL OF CARE; ICU; INTENSIVE CARE UNIT; IHPC, INTERDISCIPLINARY HOME PALLIATIVE CARE; IPCS, INTERDISCIPLINARY PALLIATIVE CARE SERVICE; LOS, LENGTH OF STAY; PCT; PALLIATIVE CARE TEAM; TCPC, TRICENTRAL PALLIATIVE CARE; TM/HBPC, TEAM-MANAGED HOME-BASED PRIMARY CARE; UC; USUAL CARE; VA, VETERANS' ADMINISTRATION

Summary and conclusions

The eligible studies include 13 RCTs, one Level III-1 quasi-randomised study, 12 Level III-2 studies (including pre-post and non-randomised comparative studies) and two Level III-3 retrospective cohort studies. Most of the studies were poor to fair in terms of study quality; however, it should be noted that the conduct of high quality palliative care studies is complex due to problems associated with recruitment, attrition, and the vulnerability of the patient group. Despite these obstacles, the literature search identified a number of reasonably large, well-designed, eligible RCTs.

The studies assessed a range of palliative care models, including interventions based around the use of PCTs, coordination of care, hospital at home, nurse-led strategies and case management. In addition, there were some studies that assessed interventions that could be better characterised as 'care pathways' rather than 'models of care'. These include the Palliative Care Integration Project (Dudgeon *et al.*, 2008, Dudgeon *et al.*, 2009) and the LCP (Veerbeek *et al.*, 2008).

The greatest amount of evidence pertained to interventions that involved home care with PCT support; however, the composition of the teams varies widely between studies. The majority of programs were relatively comprehensive, and included a range of health care specialists (e.g. nurses, physicians, social workers, physiotherapists, nutritionists and chaplains), but the exact differences in staffing and structure of service delivery were often difficult to elicit from the descriptions provided in the publications. As a result, it was difficult to draw conclusions about the efficacy of individual program components.

It should also be noted that many of the studies were conducted in the US, where a distinction is made between general palliative care (which is appropriate for anyone with a serious, complex illness) and hospice care (which delivers palliative care to those at the end of life). There are also differences between countries in the organisation and funding of palliative service delivery, which may affect the applicability of results to the NZ healthcare system. For example, a number of the US studies were undertaken by health maintenance organisations (HMOs) or within Veterans Administration (VA) hospitals.

A summary of the results of the original studies included in this review is provided in Table 31 below.

By and large, high quality (Level II) evidence suggests that most palliative care programs do not significantly improve patient quality of life. The exception to this was a single a phone-based, nurse-led educational, care coordination program in patients with terminal cancer (Bakitas *et al.*, 2009a and 2009b). There was no evidence from RCTs that home-care or PCT-based interventions had a positive effect on this outcome. The results of Level III-2 studies were similarly inconclusive. One poor quality pre-post prospective study of a hospital and home-based PCT by Ventafridda *et al.* (1990) found some statistically significant improvements in specific quality of life domains; however, there were many areas where no improvements were seen.

The evidence for increased patient satisfaction was more substantial than that for patient quality of life. Nonetheless, the included studies reported mixed results from which it is difficult to draw conclusions. For interventions that involved home-care plus a PCT there was evidence from a range of RCTs (Brumley *et al.*, 2007; Engelhardt *et al.*, 2006; Gade *et al.*, 2008; Cummings *et al.*, 1990) and lower level studies (Brumley *et al.*, 2003) showing that there were improvements associated with the intervention. Only one RCT of hospital care plus a PCT (Hanks *et al.*, 2002) reported no improvement at all in terms of patient satisfaction. An additional poor quality RCT (Cummings *et al.*, 1990) found improved satisfaction in patients at one month, but not six months. This raises the possibility that palliative care programs may be more effective in the short-term than in the long-term (i.e. six months or greater).

For symptom control, there were mixed results but a general trend towards small benefits in favour of the intervention. Improvements in symptom control were observed in RCTs of hospital at home (Grande *et al.*, 1999 and 2000), home care plus a nurse-led phone intervention (Bakitas *et al.*, 2009a and 2009b) and hospice care with a coping skills intervention (McMillan *et al.*, 2006 and 2007). An additional study of home care plus coordination of care reported improvements in only some of the measured symptoms. The SUPPORT study of hospital care with a clinical nurse specialist was the only RCT that reported worse pain in the intervention study arm compared with the control group. Of the non-randomised studies, most demonstrated some improvements in symptom control associated with the introduction of an intervention. There was substantial evidence in support of symptom control as a result of PCT-based interventions, with four studies reporting improvements in patient symptom (Edmonds *et al.*, 1998; Higginson and Hearn, 1997; Folwell *et al.*, 2009; Kusajima *et al.*, 2009) and one reporting mixed results (Ventafridda *et al.*, 1990). There were also mixed results from one study involving inpatient palliative consultations (Casasrett *et al.*, 2008) and an increase in pain in patients who were involved in the integration project reported by Dudgeon *et al.* (2008 and 2009).

The most consistent benefits in favour of the intervention were seen for outcomes relating to caregiver satisfaction. Improved satisfaction in caregivers was observed in three RCTs of PCT-based interventions, one RCT of hospital care plus a clinical nurse specialist (Connors *et al.*, 1995; Desbiens *et al.*, 1996; Baker *et al.*, 2000) and one study of a coping skills intervention in a hospice (McMillan *et al.*, 2007 and 2006). One RCT of coordinated home care (Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996) and another of a PCT in a hospital or home setting (Hanks *et al.*, 2002) identified no difference between study groups. In the Level III studies, one study of an integration project (Dudgeon *et al.*, 2008 and 2009) also showed no change in caregiver satisfaction after the introduction of the intervention, while another study of home care plus a PCT found mixed results. The study of the LCP reported by Veerbeek *et al.* (2008) did not directly report patient satisfaction, but did find that caregivers' perception of communication and levels of bereavement were improved during the intervention period. However, it should be noted that place of death and the type of relationship between the patient and the relative largely explained the difference in comprehensibility of information between both periods.

As discussed previously, palliative care patients often prefer to die at home. Therefore, the proportion of home deaths is frequently used in the evaluation of palliative care programs. There were three RCTs and one Level III-2 study reporting outcomes related to place death. A good quality RCT of home care plus a PCT found an increase in the proportion of patients dying at home, while the two other RCTs reported inconclusive results. One program evaluation of a palliative care integration project (Dudgeon *et al.*, 2008 and 2009) reported a decrease in the percentage of deaths in acute care.

There were seven RCTs that reported outcomes relating to patient survival, of which only one found a survival benefit in favour of the intervention. This fair quality study (Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996) reported that median survival in patients receiving home care plus a nursing intervention was 385 days, compared to 340 days in patients receiving usual care.

The results for the utilisation of resources were mixed. This is largely because usually a decrease in resource use in one area (e.g. hospitalisations) was offset by an increase in another type of resource use (e.g. time spent in nursing homes). Some RCTs that involved home care (with or without a PCT intervention) demonstrated reductions in time spent in acute care (Brumley *et al.*, 2007; Cummings *et al.*, 1990; Jordhøy *et al.*, 2000 and 2001 and Ringdal *et al.*, 2002; Gade *et al.*, 2008; Costantini *et al.*, 2003; Brumley *et al.*, 2003) while others showed no difference between study arms (Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996; Hanks *et al.*, 2002; Hughes *et al.*, 2000; Bakitas *et al.*, 2009a and 2009b; Aristides and Shiell, 1993). An RCT of hospital at home compared to usual care showed that those receiving the intervention had fewer GP evening home visits (Grande *et al.*, 1999; Grande *et al.*, 2000). A poor quality Level III-2 study evaluation of the Palliative Care Integration Project showed a decrease in the percentage of patients with at least one emergency room visit (Dudgeon *et al.*, 2008, Dudgeon *et al.*, 2009) and A case-controlled study of case management (Spettell *et al.*, 2009) reported that the percentage of patients using hospice more than doubled compared to its control group. It should be noted that there is considerable variability surrounding the measurement of this outcome. While a number of these studies show reductions in health services utilisation as a result of palliative care interventions, it is important to note that the extra services required for the implementation of an intervention were sometimes not accounted for.

On balance, there appears to be some evidence that PCT-based interventions can produce cost-savings. Two relatively recent, high quality RCTs of home care with a PCT reported decreased costs in patients receiving the intervention (Brumley *et al.*, 2007; Gade *et al.*, 2008). Two less well reported studies of coordinated home care found no significant differences between study groups (Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996; Engelhardt *et al.*, 2006); however, the study by Engelhardt *et al.* (2006) observed a trend towards lower costs in the intervention study arm. One RCT (Hughes *et al.*, 2000) found increased costs in the intervention study arm, although it should be noted that these results were for the full study population which included a large proportion of patients (79.3%) who were not terminally ill. The applicability of these results to a palliative care population is therefore questionable.

Both Level III-2 studies of PCT-based interventions reported cost reductions associated with the introduction of palliative care interventions (Hanson *et al.*, 2008;

Brumley *et al.*, 2003). In their study of a palliative care nursing service, Aristides and Shiell (1993) found a reduction in hospital costs but an increase in overall per-patient costs as a result of the intervention. In a poor quality Level III-3 study by Doolittle *et al.* (2000) the introduction of a telehospice program was associated with an increase in cost; however any cost offsets as a result of decreased health service use were not measured.

Overall, the original studies of models of palliative care are heterogeneous and report inconsistent results. For patient quality of life and survival, there is little evidence to suggest any benefits in favour of the intervention. On the other hand, there appear to be more good-quality studies reporting improvements patient satisfaction, symptom control and caregiver satisfaction as a result of the intervention, than there are reporting no effect at all. The results regarding place of death were largely inconclusive. In terms of resource use and costs of care, it would seem that programs involving home-care are associated with a reduction in the need for acute hospital care. There is also evidence from some high-quality RCTs pointing to a reduction in costs for programs including home care with PCT support.

It is important to note that there is no evidence in any of the outcome categories suggesting that the introduction of a palliative care intervention worsens patient or caregiver outcomes. Given that there is some evidence pointing to a reduction in costs in programs that involve home care with the support of a PCT, this is a significant finding.

Table 31: Original primary studies: Summary of results

Citation	Patient QoL	Patient satisfaction	Symptom control	Caregiver satisfaction	Place of death	Survival	Utilisation of resources	Cost of care
Intervention Level II evidence								
Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996	-	NR	↑ ↓	-	NR	↑	-	-
Brumley *et al.*, 2007	NR	↑	NR	NR	↑	-	↑	↑
Cummings *et al.*, 1990	-	↑ ↓	NR	↑	NR	-	↑ ↓	↑
Engelhardt *et al.*, 2006	NR	↑	NR	NR	NR	-		↑ ↓
Grande *et al.*, 1999; Grande *et al.*, 2000	NR	NR	↑	NR	↑ ↓	NR	↑ ↓	NR
Hanks *et al.*, 2002	NR	-	-	-	NR	NR	-	NR
Hughes *et al.*, 2000	↑ ↓	-	NR	↑	NR	NR	-	↓
Jordhøy *et al.*, 2000, Jordhøy *et al.*, 2001 and Ringdal *et al.*, 2002	NR	NR	NR	↑	-	-	↑ ↓	NR
SUPPORT (Connors *et al.*, 1995; Desbiens *et al.*, 1996; Baker *et al.*, 2000)	NR	NR	↓	↑	NR	NR	-	NR
Gade *et al.*, 2008	-	↑	NR	NR	NR	-	↑ ↓	↑
McMillan *et al.*, 2007; McMillan *et al.*, 2006	NR	NR	↑ (for COPE intervention only)	↑ (for COPE intervention only)	NR	NR	NR	NR

Table 31: Original primary studies: Summary of results *cont.*

Citation	Patient QoL	Patient satisfaction	Symptom control	Caregiver satisfaction	Place of death	Survival	Utilisation of resources	Cost of care
Bakitas *et al.*, 2009a, Bakitas *et al.*, 2009b	↑	NR	↑ (n.s.)	NR	NR	-	-	NR
Intervention Level III-1 evidence								
Costantini *et al.*, 2003	NR	NR	NR	NR	NR	NR	↑	NR
Intervention Level III-2 evidence								
Goodwin *et al.*, 2002	↑ ↓	NR	NR	NR	NR	NR	NR	NR
Hanson *et al.*, 2008	NR	NR	NR	NR	NR	NR	NR	↑ ↓
Brumley *et al.*, 2003	NR	↑	NR	NR	NR	NR	↑ ↓	↑
Casarett *et al.*, 2008	NR	NR	↑ ↓	NR	NR	NR	NR	NR
Dudgeon *et al.*, 2008, Dudgeon *et al.*, 2009	NR	NR	↓	-	↑	NR	↑	NR
Aristides and Shiell, 1993	NR	NR	NR	NR	NR	NR	-	↓
Edmonds *et al.*, 1998	NR	NR	↑	NR	NR	NR	NR	NR
Higginson and Hearn, 1997	NR	NR	↑	NR	NR	NR	NR	NR
Ventafridda *et al.*, 1990	↑ ↓	NR	↑ ↓	NR	NR	NR	NR	NR
Follwell *et al.*, 2009	NR	↑	↑	NR	NR	NR	NR	NR
Kusajima *et al.*, 2009	-	NR	↑	↑ ↓	NR	NR	NR	NR

Table 31: Original primary studies: Summary of results *cont.*

Citation	Patient QoL	Patient satisfaction	Symptom control	Caregiver satisfaction	Place of death	Survival	Utilisation of resources	Cost of care
Veerbeek *et al.*, 2008	NR	NR	NR	↑ ↓	NR	NR	NR	NR
Intervention Level III-3 evidence								
Spettell *et al.*, 2009	NR	NR	NR	NR	NR	NR	↑ ↓	NR
Doolittle, 2000	NR	NR	NR	NR	NR	NR	NR	↑

TABLE NOTES:

↑ ↓	RESULTS WERE MIXED OR INCONCLUSIVE
↑	BENEFIT IN FAVOUR OF THE INTERVENTION
↓	BENEFIT IN FAVOUR OF THE COMPARATOR
-	NO DIFFERENCE BETWEEN INTERVENTION AND COMPARATOR

ABBREVIATIONS: NR, NOT REPORTED; NS, NOT SIGNIFICANT; QOL, QUALITY OF LIFE

As mentioned previously, a number of NZ DHBs have implemented pilot palliative care strategies based on the principles identified in the NZ Palliative Care Strategy (2001). A number of evaluations for these programs were identified in the search for grey literature, but were subsequently excluded from the review because they were not comparative and did not report relevant clinical outcomes. Nonetheless, reports describing the implementation and success of these programs are highly applicable to the delivery of palliative care services in NZ. These include the "Palliative Care Partnership (PCP)" model of integrated palliative care developed by the MidCentral DHB (Stewart *et al.*, 2006 and McKinlay et al., 2007). The key features of this program were:

- Primary and secondary integration
- Patients referred via GP team, secondary care provider, district nurse, private consultation or self referral.
- All referrals are made to Arohanui Hospice and an assessment is made by palliative care coordinator (PCC) and members of PCT.
- Care plan is developed by patient, PCC and PCT.
- Ongoing care provided by hospice PCC and GP team (GPT)

The review methodology was based on a mixed method evaluation approach, including qualitative interviews of stakeholders, analysis according to pre-determined evaluation questions of routinely collected quantitative data and an audit of newly implemented "shared" care-plans used by PCP partners. Sixty three people were interviewed either individually or in focus groups. The evaluation concluded that the PCP was delivering "comprehensive, holistic, and integrated palliative care incorporating both generalist and specialist palliative care skills to people and families/whanau and at a modest cost". The analyses provided in the report suggest that the implementation of the PCP was considered, staged, and supported by standardised mechanisms. Referrers reported a streamlined entry into the PCP with prompt assessment by a PCC. At the time of evaluation the majority of MDHB's GPs (n=56) belonged to the PCP. A sample of 'shared care-plans' used by partners giving in-home care usually at end-of-life, were audited against quality criteria, with all records meeting the criteria for completion.

Another example of a successful NZ palliative care program based on a primary and secondary care partnership comes from the Wairarapa DHB (Thomas, 2009). Like the PCP implemented by the MidCentral DHB, this service has an emphasis on generalist care, with GPs as the lead medical carers. The majority of hands-on patient care is provided by community nursing and the patient's primary health care team, supported by specialist nursing and 24/7 medical advice. Patients are supported by a range of other services coordinated by the key worker and provided access to services supported by a PCC. The palliative care network is overseen by the management group who provide quality control including clinical, financial and organisation oversight. An evaluation of the program compared current service operation with planned outcomes of the Wairarapa Palliative Care Plan and assessed the extent to which the service is meeting each of the strategic directions in the Palliative Care Plan. The results of the review indicate that the service in its current form is meeting the majority of the aims of the planned palliative care service, and has addressed some of the service issues that existed prior to program implementation.

Although the evaluations of the MidCentral and Wairarapa palliative care services suggest that program and implementation goals are being achieved, it is important to note that clinical efficacy and cost effectiveness has not as yet been rigorously assessed. To properly determine the effectiveness of different of systems or programs of palliative care it is necessary use data from the comparative studies and SRs discussed previously in this report.

Part 3: Feasibility of an economic evaluation

As discussed previously, there was little consistent evidence regarding patient quality of life benefits for palliative care compared to usual care in the literature identified. Nor was there sufficient evidence to say that one model of care was superior to another in terms of this outcome. The same conclusion was made in the systematic reviews of home care programs, palliative care teams, specialist palliative care programs, specialist palliative day care and general palliative care models. Further, the results for patient satisfaction were mixed, and depended on the nature of the intervention. However, there was some evidence (Level II) to suggest palliative care programs including a PCT-based intervention may provide patients with symptom control benefits. Additionally, it is known that palliative care patients generally express a preference for dying at home and many of these programs assist in supporting this wish. Finally, caregiver satisfaction was one of the few outcomes for which consistent benefits in favour of the intervention were observed (Level II).

With regard to cost, a number of US based RCTs have shown that the introduction of home care plus interdisciplinary palliative care teams may result in reduced direct costs to the health care system when compared to usual care. These reductions in costs reached statistical significance in two trials, one of which was a good quality RCT (Brumley et al., 2007; Gade et al., 2008), While numerically lower, the differences were not statistically different in the comparison of hospital-based home care versus usual care in the trial by Cummings et al., 1985 and in the comparison of the Advanced Illness Coordinated Care Program and usual care in the trial by Engelhardt et al., 2006. Reductions in hospital based costs appeared to be important components of the cost savings reported in many of these trials.

In summary, while there were inconsistent benefits recorded in the palliative care literature, on balance, these programs appear to show potential benefits for patients and their carers, with few negative effects. From a cost perspective there is some evidence to suggest that these programs may result in reduced total health care costs. If these programs were found to provide benefits for patients and carers at a reduced total cost to the health care system they would dominate usual care and this would provide a strong case for their adoption. However, given the mixed results of the analyses seen in this review, and limited health care resources, the costs of any such program should be carefully assessed to assure that the system provides appropriate use of health care resources to provide value for money for New Zealand citizens.

The cost-effectiveness of these programs may be improved by developing a single New Zealand-wide framework of home based interdisciplinary palliative care. This would assist in the sharing of common specialist and administrative resources to support any such program. Further, a nationwide system is likely to provide clearer career paths for health care providers in this sector and allow movement of healthcare providers from one jurisdiction to another with less disruption to services and loss of expertise. In addition, a single national approach is likely to provide patients and their carers with consistency of care across the country. Further, it would appear that the mix of responsibilities taken by clinicians, nurses and other staff in the interdisciplinary palliative care teams may play an important role in the overall costs associated with these programs.

While the research identified herein were largely US-based, it would not appear to be unreasonable to assume some of the patient and the carer benefits of home based interdisciplinary palliative care programs could also be realised in New Zealand. To determine the cost or cost-effectiveness of such a program it would be important to select the program from the literature that most suited New Zealand paying particular attention to the availability of healthcare staff and resources in this country. Although the current review identified a number of studies reporting NZ pilot palliative care strategies, they were excluded on the basis that they were not comparative and did not report relevant clinical outcomes. In the absence of high-quality evidence specific to the New Zealand setting, the inherent assumption would be that the effectiveness observed in the selected intervention would hold in New Zealand. The costing of these programs would then need to be facilitated by experts in the field describing the appropriate composition of the home based interdisciplinary palliative care team, the intensity of patient follow up and the structure of the program to be implemented.

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Appendix A: Working Party Membership

Name and area of expertise
Barry Keane, Hospice Management
Clare Greensmith, Psycho-social and family support
Deborah Peters, Consumer
Peter Woolford, GP
Ria Earp, Hospice Management
Ross Drake, Paediatric Palliative Care Specialist
Simon Allan, Ministry Palliative Care Senior Clinical Advisor
Sarah Davey, DHB Funding and Planning
Brenda Hall, DHB Funding and Planning
Rod Macleod, Palliative Care Medical Specialist
Bridget Marshall, Liverpool Care Pathway and Aged Residential Care Nursing
Jackie Robinson, Palliative Care Nurse Practitioner
Willie Landman, Palliative Care Medical Specialist
Teresa Read, Quality and Audit

Appendix B: Data Extraction Tables

Systematic review of systematic reviews

Citation	Keirse *et al*., 2009	
Level of evidence	Level I/IV [a]	
Research question/aims	What types of care models do exist for patients who need palliative care and what evidence is available on the diversity and effectiveness of these models?	
Study type/design	Review of SRs and included studies	
Search strategy	Four databases (i.e., Medline, COCHRANE database of Systematic Reviews, the Cumulative Index to Nursing and Allied Health Database-CINAHL and Embase) were searched for papers published in English, Dutch and French between January 1990 and October 2008.	
Type of included studies	Systematic reviews. Systematic reviews were rejected if they did not report on a comprehensive approach to care that evaluated structural and/or organisational aspects and/or outcomes of palliative care. Studies that evaluated (the impact of) only one component of comprehensive palliative care on only 1 aspect of quality of life (e.g. impact of pain medication on pain) were consequently rejected.	
Type of participants	Patients who need palliative care	
Type of intervention	The search terms used referred to palliative care and focused on interventions in palliative care (health facilities, health personnel, health care organisation) and their evaluation.	
Outcomes	Eligible outcomes were not defined *a priori*. During review, outcomes measures were grouped in four categories: 1. Biological outcomes 2. Psycho-social outcomes 3. Economic outcomes 4. Other outcomes	
Data analyses & statistics	SRs were assessed for methodological quality, although individual studies included in the SRs were not. Formal meta-analytic pooling methods were not applicable due to the heterogeneity of interventions and outcomes included in the different reviews. The review is therefore a structured narrative synthesis including a discussion of the studies' characteristics and results.	
Study design of included studies	SRs	Eligible for inclusion in **Part 2**
	Critchley *et al*., 1999 A systematic review of comparative studies (RCTs and non randomised comparative studies) of different palliative care delivery systems (see above).	Y
	Davies *et al*., 2005 A systematic review of quantitative and qualitative studies of specialist palliative day-care for adults with cancer (see above).	Y
	Douglas *et al*., 2003 A literature review of economic studies of clinical nurse specialists.	N
	Hearn *et al*., 1998 A systematic review of RCTs of specialist palliative care teams (see above).	Y
	Harding *et al*., 2005	N

	A systematic review of RCT's, prospective studies with a comparison group, retrospective or observational studies and cross sectional studies in patients with HIV/AIDS.	
	Salisbury *et al*., 1999 A systematic review of descriptive and comparative studies looking at the impact of different models of specialist palliative care on patients' quality of life (see above).	Y
	Sampson *et al*., 2005 A systematic review of controlled trials to assess the efficacy of palliative care in advanced dementia.	N
	Thomas *et al*., 2006 A review of randomised controlled trials of organisation of care at end of life (see above).	Y
	Wadhwa and Lavizzo-Mourey, 1999 A systematic review of studies including a comparison group receiving conventional care (see above).	Y
	Wilkinson *et al*., 1999 A systematic review of RCTs, prospective studies with a comparison group, retrospective or observational studies and cross sectional studies, looking at carer preference for and satisfaction with specialist models of palliative care (see above).	Y
	Zimmermann *et al*., 2008 A systematic review of randomised controlled trials assessing the effectiveness of palliative care (see above).	Y
Authors conclusions	The review concluded that no palliative care model could be identified as giving better outcomes than other models. Care models described in systematic literature reviews were heterogeneous in terms of objectives, caregivers, target populations and interventions. Most care models were organised either in home settings or as transmural care models between settings. Multidisciplinary teams were mostly involved, with different caregivers; however, nurses were most often the leading persons.	
Reviewers notes	Review of SRs, although results from eligible individual studies were also assessed.	

ABBREVIATIONS: CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; RCT, RANDOMISED CONTROLLED TRIAL; SR, SYSTEMATIC REVIEW

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Systematic reviews

Citation	Critchley *et al*., 1999
Level of evidence	Level I/IV [a]
Research question/aims	To conduct a systematic review of comparative studies looking at the effectiveness of different models to provide palliative care services
Study type/design	Systematic review
Search strategy	Searched Medline, HealthStar, CINAHL, CancerLit and Cochrane Library. Appropriate search terms were tailored for individual databases.
Type of included studies	Comparative studies of any methodological design
Type of participants	Patients of any age described as palliative, or as having end-stage or terminal conditions
Type of intervention	"Ways of providing care" in the eligible population

Outcomes	Any outcomes related to the patients, their family members, health care providers or the health care system.	
Data analyses & statistics	Narrative synthesis including tables of study characteristics and results. The results were not meta-analysed due to the heterogeneity of the identified publications.	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	Ward, 1987 4 home care services compared to 4 home care services attached to inpatient hospices. Care included medical, nursing, psychological support and assistance with activities of daily living. Providers included physicians, nurses, social workers and family members. Altogether 957 patients were entered into the study.	N
	Greer *et al.*, 1986 Hospice without beds versus hospice with beds versus conventional oncological care. Altogether 1754 patients with terminal cancer were included.	N
	Aristides and Shiell, 1993 Assessed traditional care versus a home-based palliative care nursing service that provided after-hours care, a day centre and "medical officer positions". The study focused on the added value of limited after-hours care availability. Inpatient hospital days and costs during the last 90 days of life were compared before and after the introduction of the service. Altogether 276 patients were entered into the study.	Y
	Brooks, 1989 Traditional home care compared to hospice home care and conventional oncology care patients who did not receive hospice home care or traditional home care during the terminal phase of their cancer illness. Altogether 1148 patients with terminal cancer were entered into the study.	N
Authors conclusions	In general, the studies included in the SR were poorly reported and difficult to compare. Broad conclusions include: A higher proportion of patients who received services at home died at home. Home care services did not decrease the length of a terminal hospital stay if a patient had to be admitted. Traditional home care services were more expensive in the last 24 weeks of life than hospice home care or conventional care. Hospice groups used fewer interventional therapies and diagnostic tests compared with conventional care. Patients served by hospices without beds spend more time at home, were more likely to die at home and their care was cheaper than other groups. Home care services attached to inpatient hospices could reach more patients than those that provided home care only. Pain relief and symptom control was marginally better in hospices with beds. Provided the direction is competent and the home care nurses are backed up by medical and other services, they can operate for the benefit of patients and carers in the different settings described.	
Reviewers notes	The studies included in this review are all comparative, large and institution-level. Due to the lack of quantitative data and heterogeneity between studies, a narrative synthesis of evidence is provided only.	

ABBREVIATIONS: CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; SR, SYSTEMATIC REVIEW

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Davies *et al.*, 2005
Level of evidence	Level I/IV [a]

Research question/aims	A list of review questions for the role of specialist palliative day-care was devised: Service structure 1. How are units funded, managed and staffed? 2. How many places are available? Care processes 1. What models or standards of best practice exist? 2. How are patients referred and allocated to day care places? 3. What patient groups attend day care? 4. What needs do patients report as they begin attending? 5. What clinical interventions are generally offered? 6. What activities are generally offered? 7. How do staff work together to care? 8. How are patients discharged? Outcomes of care 1. Is symptom control improved? 2. Is health-related quality of life improved? 3. Does day care provide psychological and social support? 4. Does day care affect length of inpatient stay or place of death? 5. How satisfied are patients with care? 6. How satisfied are their relatives? 7. What is the cost of this care?	
Study type/design	Systematic review	
Search strategy	Searched Medline, Embase, British Nursing Index, CINAHL, PsycINFO and CancerLit	
Type of included studies	Studies including the outcome measures of interest published in English (not including historical reviews, personal views, expert consensus and case studies of single patients)	
Type of participants	Patients ≥ 18 years enrolled in specialist palliative day-care services	
Type of intervention	Specialist palliative day-care services.	
Outcomes	Funding, organisation and management of services Staff skill mix and interventions offered to patients and relatives Referral, allocation of places to patients and discharge Uptake of interventions by patients and relatives Patient or relative satisfaction with care Patient outcomes including symptom control, HRQoL and social and psychological support	
Data analyses & statistics	Narrative synthesis including tables of study characteristics and results. The results were not meta-analysed due to the heterogeneity of the identified publications.	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	Wilkes *et al*., 1978 Description of patients attending within the first 2 years of the unit with an evaluation of their views and those of their relatives about the care	N
	Cockburn and Twine 1982 Descriptive report of the practicalities of running the unit	N
	Sharma *et al*., 1993 Questionnaire survey of patients' views and needs and 12-week study of doctors' work in the unit	N
	Edwards *et al*., 1997	N

	Eight-month follow-up study of 39 referred patients. Patients were seen during the first week of attendance, weekly for the first month and then fortnightly afterwards	
	Thompson, 1990 Descriptive report of a unit open 4 days a week, run by an occupational therapist, and care assistants, with student and volunteer support	N
	Kennett, 2000 Semi-structured interviews with patients and staff following a phenomenological approach undertaken by the day-care leader	N
	Copp *et al*., 1998 Telephone survey using semi-structured interviews with the day-care lead	N
	Higginson *et al*., 2000 Postal questionnaire survey of the leaders of each unit; 40 of 43 units replied	N
	Faulkner *et al*., 1993 Qualitative observational study of practice using a visit *pro forma*, following an initial postal questionnaire	N
	Langley-Evans and Payne, 1997 Participant observation over 7 weeks of interaction between patients and between patients and staff. Analysis of field notes, and leaflets and nursing notes using constant comparative method	N
	Douglas *et al*., 2000 Qualitative analysis of interviews with staff and patients and observation in each unit over 5 weeks	N
	Hopkinson and Hallet, 2001 Qualitative analysis of unstructured interviews with patients	N
	Lee, 2000 Case study involving semi-structured interviews with patients and staff, observationof the patients, the unit's work and analysis of documents, notes and meeting minutes produced	N
	Goodwin *et al*., 2002 Prospective multicentre study comparing patients attending day care with matched patients receiving home care (120 consecutive patients attending 5 day care units and 53 receiving other care).	Y
Authors conclusions	The studies of specialist palliative day-care reviewed showed that most services were nurse-led, but varied in funding and the facilities, staff mix, and places that could be offered to patients and their relatives. Approaches to care varied, tending towards a "medical", "social" or a "mixed" model of care. Patients attending represented a select group of patients already receiving palliative care who were mostly aged over 60 years with cancer, white and retired, and whose main needs were for social and emotional support and pain control. There were insufficient studies to provide conclusive evidence that symptom control or HRQoL was improved for these patients, or that any one model of care was associated with better patient outcomes in these areas. However, all studies that had questioned patients or collected in-depth qualitative data reported high levels of satisfaction among patients with the care they received. Patients seemed to value the social element of contact with staff and other patients that the visit provided, being able to take part in a range of activities and having symptoms assessed when required. This suggests that the day care units studied had been successful in achieving a responsive and compassionate service for the patients selected into care.	
Reviewers notes	The studies included in this review are all comparative, large and institution-level. Due to the lack of quantitative data and heterogeneity between studies, a narrative synthesis of evidence is provided only.	

ABBREVIATIONS: CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; HRQOL, HEALTH-RELATED QUALITY OF LIFE; SR, SYSTEMATIC REVIEW

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Francke , 2000	
Level of evidence	Level I/IV [a]	
Research question/aims	1) What evaluative methods and instruments have been used in evaluative studies of palliative support teams? 2) What evaluative outcomes were reported with respect to physical, psychosocial, spiritual problems of patients and relatives as well as consumption and cost of health care?	
Study type/design	Systematic review	
Search strategy	Searched Medline and CINAHL	
Type of included studies	Evaluative studies focusing on the outcomes of a palliative support team on patients, relatives or consumption/cost of care.	
Type of participants	The team evaluated should provide advice or support to terminal patients, relatives or care providers	
Type of intervention	Palliative support teams, defined as teams that give advice about palliative care and often also practical help to patients and/or care providers.	
Outcomes	Any outcomes related to the patients, their family members, health care providers or the health care system.	
Data analyses & statistics	Narrative synthesis including tables of study characteristics and results. The results were not meta-analysed due to the heterogeneity of the identified publications.	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	Abrahm *et al.*, 1996 'Hospice consultation team' of a hospital in Philadelphia including advice, family support, coordination of care and education for care providers. Prospective study design with no control group. In 75 patients with cancer.	N
	Ballinx *et al.*, 1995 'Palliative support team' of a hospital in Belgium including advice, family support and coordination of care. Prospective study design with no control group. In 109 palliative care patients.	N
	Bennett and Corcoran, 1994 'Palliative care team' of a hospital in Leeds providing advice, and referral of patients to other care providers. Retrospective study design with a historical comparison group. In 1716 terminal patients.	N
	Bruera *et al.*, 1990 'Palliative care team' of a hospital in Edmonton providing advice for inpatients and care providers. Retrospective study design with two comparison groups. In 98 terminal patients.	N
	Butters *et al.*, 1992 Two community support teams of a hospital and community care organisations in London, providing advice, counselling, family support and education for care providers. Prospective study design with now control groups. In 140 patients with AIDS/HIV.	N
	Butters and Higginson, 1995 Two community support teams of a hospital and community care organisations in London, providing advice, counselling, family support and education for care providers. Prospective study design with now control groups. In 234 patients with AIDS/HIV.	N

	Campbell *et al*., 1996 'Comprehensive supportive care team' of a hospital in Detroit, providing advice, family support and education for care providers. Retrospective study design with two comparison groups. Includes 35 terminal patients, 35 relatives and 27 care providers.	N
	Carlson *et al*., 1988 Development of a comprehensive supportive care team for the hopelessly ill on a university hospital medical service. Retrospective study design with three comparison groups. Includes 62 terminal patients with global anoxic brain injury.	N
	Ellershaw *et al*., 1995 'Advisory palliative care team' of a hospital in London, providing advice and family support. Prospective study design with no control group. Includes 125 patients with terminal cancer.	N
	Field *et al*., 1989 'Comprehensive supportive care team' in Detroit providing advice, family support and education for care providers. Retrospective study design with two comparison groups. Includes 40 terminal patients with multiple organ failure.	N
	Higginson *et al*., 1992 2 'palliative support teams' of home care organisations and hospitals in London or Kent, providing advice and family support. Prospective study design with no control group. Includes 227 terminal patients.	N
	Higginson & Hearn, 1997 11 'palliative care teams' of hospital and home care organisations in Ireland and England, providing advice, family support and education/training. Prospective study design with no control group. Includes 26 terminal patients.	Y
	Hockley *et al*., 1988 'Symptom control team' of a hospital in London providing advice, family support and education. Prospective study design with now control group. Includes 26 terminal patients.	N
	Jarvis and Burge, 1996 'Palliative care team' (part of a palliative care program) of a hospital in Quebec, providing advice and family support. Prospective study design with no control group. Includes 34 terminal patients.	N
	Lonberger *et al*., 1997 'Palliative care team' of the University of Missouri, providing advice and family support. Retrospective study design with no control group. Includes 10 terminal patients.	N
	McWhinney *et al*., 1994 Metastatic cancer patients (n=146) were randomised to treatment by a palliative care team or were put on a four week waiting list. Prospective study design with control group.	N
Authors conclusions	Sixteen studies on the effectiveness of palliative support teams were analysed. These studies indicated that pain and other physical complaints often decrease, whereas psychosocial and spiritual problems are lesser reduced after referral to a palliative support team.	
Reviewers notes	Includes studies assessing the effectiveness of palliative support teams, rather than models of care. The teams studied all employed a multidisciplinary approach: the core of the teams in all cases consisted of nurses, often closely collaborating with physicians and sometimes also with pastoral and colleagues, social workers and paramedics. All teams were hospital-based or connected to community care carers with the patient) can be summarized.	

ABBREVIATIONS: CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Garcia-Perez *et al*., 2009	
Level of evidence	Level I/IV [a]	
Research question/aims	To determine the effectiveness and cost-effectiveness of different organisational models of specialised palliative care	
Study type/design	Systematic review	
Search strategy	Searched the Cochrane Library Plus, OVID-Medline, Embase, CINAHL and PsycInfo	
Type of included studies	Types of included studies were clinical trials, cohort studies, case-control studies, comparative studies with historical controls, within group comparison studies, economic evaluations and high quality systematic reviews.	
Type of participants	Adults (18 years and older) with terminal illness included in a palliative care programs.	
Type of intervention	Studies were excluded unless they compared at least two different specialised palliative care programs.	
Outcomes	To be included, the studies had to use the following types of measures: control of pain and other symptoms, psychological symptoms, HRQoL, well-being, functional state, satisfaction, place of death, number of patients cared, number of home visits, number of days at hospital etc.	
Data analyses & statistics	The collected information was synthesised through narrative procedures, and the main characteristics and outcomes of each included study were displayed in a structured table.	
Study design of included studies	Studies In total, six systematic reviews, four original articles on effectiveness (two of which described the same study) and one cost study were included.	Eligible for inclusion in **Part 2**
	Hanks, 2002 (original study) Full PCT (n=175) full service of advice and support to other health care professionals, patients and relatives; compared to telephone-PCT (n=86) limited intervention based on telephone consultation between the PCT and staff directly involved with the patient.	Y
	Greer 1986 and Morris 1986 (original study) - Hospices without beds (home-based hospices) (n=833) - Hospices with beds (hospital-based hospices) (n=624) - Conventional care at oncology units (n=297)	N
	Viney, 1994 (original study) - Small specialist palliative care unit (10 beds) within a general hospital (n=62) - Free standing hospice of 100 beds (n=60) - Conventional care at general hospital (n=61)	N
	Doolittle, 2000 (original study) Cost analysis of traditional hospice compared to telemedicine hospital	Y
	Gysels and Higginson, 2004 (SR) Systematic review included in the National Institute for Clinical Excellence guideline for supportive and palliative care for adults with cancer	N
	Critchley *et al*., 1999 (SR) A systematic review of comparative studies (RCTs and non randomised comparative studies) of different palliative care delivery systems.	N

	Salisbury *et al*., 1999 (SR) A systematic review of descriptive and comparative studies looking at the impact of different models of specialist palliative care on patients' quality of life.	N
	Aldasoro *et al*., 2003 (SR) Systematic review and analysis of health care in hospitals of the Basque Country (Spanish language).	N
	Higginson *et al*., 2003 (SR) Systematic review on the effectiveness of palliative care teams in improving outcomes for patients or caregivers, and reducing costs.	N
	Zimmermann *et al*., 2008 (SR) A systematic review of randomised controlled trials assessing the effectiveness of palliative care.	N
Authors conclusions	None of the studies found that one program was more effective or cost-effective than another.	

ABBREVIATIONS: CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; HRQOL, HEALTH-RELATED QUALITY OF LIFE; PCT, PALLIATIVE CARE TEAM; RCT, RANDOMISED CONTROLLED TRIAL; SR, SYSTEMATIC REVIEW

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Gysels and Higginson., 2004
Level of evidence	Level I/IV [a]
Research question/aims	To determine the effectiveness of different interventions, targeted at health care professionals or the structure in which health care professionals deliver their care, to improve the supportive and palliative care for those affected by cancer. Secondary questions are: 1) Which intervention strategy or parts of intervention strategies are most effective 2) What do the most effective strategies have in common Only the literature review described in Chapter 10 of the guideline (specialist palliative care services) was considered to be relevant to the subject of this report.
Study type/design	Systematic review
Search strategy	Searched Medline, Embase, CINAHL, CancerLit, CDSR, the Cochrane Effective Practice and Organisation of Care Group (EPOC) specialised register and the Cochrane Central Register of Controlled Trials (CENTRAL).
Type of included studies	1. RCTs 2. Controlled clinical trials 3. Controlled before and after studies 4. Interrupted time series and observational studies 5. SRs Qualitative studies were included in the topic areas where higher grade evidence was less feasible and available.
Type of participants	Any person involved in the delivery of supportive and palliative care for those affected by cancer in a hospital, home or community setting.
Type of intervention	Specialist palliative care teams working in home care, hospital based, combined home/hospital care, inpatient units, and integrated inpatient hospices/ home care and hospital advisory.

Outcomes	Objectively measured health professional performance or patient outcomes in a clinical setting and self report measures with known validity and reliability. 1. Any objective measure of health professional performance or patient outcomes to be included. 2. Patient and carer outcome measures: – Pain – Symptom control (nausea/vomiting, constipation, breathlessness, mouth discomfort, insomnia) – Psychological morbidity (anxiety, self-esteem, stress, depression) – Well-being – Perceived death – Quality of life – Functional status – Patient satisfaction – Carer satisfaction – Provider satisfaction – Knowledge – Referral to other services – Place of care – Use of other services – Place of death
Data analyses & statistics	Data were extracted in to tables which defined the study setting, objectives, population, outcome measures, and main results. If available quantitative meta-analyses were extracted from existing systematic literature reviews. Because of the degree of heterogeneity between studies and outcome measures it is not possible to conduct meta-analyses in many of the areas for review.

Studies (from Tables of Evidence: Specialist Palliative Care Services)	Eligible for inclusion in **Part 2**
Addington-Hall *et al.*, 1992 and Raftery *et al.* 1996 RCT (n=203) designed to measure the effects on terminally ill cancer patients and their families of co-ordinating the services available within the National Health Service, from local authorities and from the voluntary sector. 104 patients received routine services plus community based nurse co-ordinators who provided a link between services. In the control arm 99 patients received routinely available services (Grade IB).	Y
Axelsson *et al.*, 1998 Comparison between study group (surgeon half day per week; one full-time specialist nurse; and 6 interested colleagues made occasional home visits) and matched historical group and contemporary reference group (n=97) (Grade IIB).	N
Axelsson & Sjoden 1998 Observational study on palliative support team (Grade IIIC).	N
Bennett & Corcoran 1994 Retrospective examination of records to examine the influence of a hospital palliative care team on the activity of a local hospice home-care team (over a four-year period) (Grade IIIC).	N
Bloom 1980	N

	19 matched pairs to compare the cost of care fore patients who died at home under medical supervision with a control group of patients who died in hospital (Grade IIIB).	
	Bredin *et al*., 1999 RCT (n=119) to evaluate the effectiveness of nursing intervention for breathlessness in patients with lung cancer (Grade IA).	N
	Constantini *et al*., 2003 Quasi-experimental study (n=2503) to determine whether in patients with advanced cancer, a palliative home care team (PHCT) modified hospital utilisation in the last months before death (Grade IB).	Y
	Dessloch *et al*., 1992 Semi-structured interview with patient receiving home care (from specialist palliative care team) (Grade IIIB).	N
	Dunt *et al*., 1989 Quasi experimental study to evaluate the effectiveness and cost-effectiveness of the City mission Hospice Program (Grade IIB).	N
	Edmonds *et al*., 1998 Study to determine symptom prevalence and outcome for inpatients and outpatients referred to a multi-professional hospital palliative care team (n=352) (Grade IIIC).	Y
	Ellershaw *et al*., 1995 Study (n=125) to assess the outcome of interventions made within two weeks of referral with regard to: symptom control, change in patients' and their relatives' insight regarding diagnosis and prognosis, and facilitation of patient placement. Patients were assessed on referral then twice weekly over the subsequent two weeks (unless death or discharge) (Grade IIIC).	N
	Grande *et al*., 2000 RCT evaluation of hospital at home for palliative care (i.e. providing 24-hour nursing care in a patient's home) (Grade IB).	Y
	Hanks *et al*., 2002 RCT (n=261) to assess the effectiveness of a hospital Palliative Care Team comprising two clinical academic consultants, one specialist registrar, and three clinical nurse specialists (Grade IA).	Y
	Higginson *et al*., 1992 Study to demonstrate the use of Support Team Assessment Schedules in a practical setting and to describe the effect of the palliative care teams in achieving their objectives (Grade IIIB).	N
	Higginson and McCarthy, 1987 Prospective assessment of patient symptoms (n=124) to describe and evaluate the work of terminal care support teams (Grade IIIC).	N
	Higginson and Hearn, 1997 Study (n=695) to determine the prevalence of pain, its effect on advanced cancer patients, and the effectiveness of specialist home-care services in controlling pain (two service evaluations) (Grade IIIC).	Y
	Hinton, 1979 To compare patients dying in different circumstances by an assessment of mood and opinions (Grade IIIC).	N
	Hinton, 1994 Non-comparative study to assess whether patients with terminal cancer and their relatives find that competent home care sufficiently	N

	maintains comfort and helps adjustment (Grade IIIC).	
	Hughes *et al*., 1992 Randomised pre-test-multiple post-test study (n=171) to compare the attributes of the Hines model of care (HBHC) with traditional community home care services to which control group patients could be referred (Grade IB).	Y
	Johansson *et al*., 1999 RCT (n=527) to evaluate the effects of intensified primary care on cancer patients' home care nurse contacts, and to study if patients' use of home-care services 6 months after diagnosis can be predicted (Grade IB).	N
	Jones *et al*., 1993 Semi-structured interviews to collect information from principal carers of people who had died at home with cancer; to identify areas of support which need improvement (Grade IIIC).	N
	Jordhøy *et al*., 2000, Jordhøy *et al*., 2001 and Ringdal *et al*., 2002 Cluster RCT (n=434) to assess the effectiveness of an intervention program that aims to enable patients to spend more time at home and die there if they prefer (Grade IA).	Y
	Kane *et al*., 1984 RCT to test the effectiveness of hospices by evaluating comprehensive hospice care and traditional medical care over a two year period (Grade IA).	N
	McCorkle *et al*., 1989 RCT to assess the effects of home nursing care for patients with progressive lung cancer. Interventions include oncology home care program provided by nurses trained to give cancer care & services from other dis, to eciplines as needed; standard home care program provided by registered nurses, physio, home health aides, social worker, OT, speech pathologist; and a control office care program provided by physicians (Grade IB).	N
	McCusker & Stoddard, 1987 Retrospective analysis of cancer deaths from claim forms to evaluate an expanded program of home care for the terminally ill (hospital utilisation and costs of care during last months of life) (Grade IIIB).	N
	McIllmurray & Warren, 1989 Evaluation of three common symptoms in a new palliative care service (n=316) (Grade IIIC).	N
	McMillan *et al*., 1996 Study to evaluate the quality of life of a group of adults, who were serving as primary caregivers for hospice patients, receiving home care (Grade IIIC).	N
	McMillan and Mahon, 1994 Study to evaluate the patient's QoL as perceived by the patient and primary caregiver at admission and after hospice services had been implemented (n=80) (Grade IIIB).	N
	McMillan and Mahon, 1994 To evaluate the effects of hospice services on the QoL of primary caregivers (n=68). Comparison group: apparently healthy non-caregiving adults selected from church group, retirement community, and office setting (n=62) (Grade IIB).	N
	McQuillar *et al*., 1996	N

	Study to evaluate the changes that had been implemented to improve care of cancer and HIV patients. Intervention involved face-to-face discussions about referrals and quarterly lunchtime meetings with doctors, education program for the link nurses, guidelines on pain control for doctors and nurses and information cards for patients (Grade IIIB).	
	McWhinney *et al.*,1994 RCT to evaluate a palliative care home support team based on an inpatient unit. Because of early deaths, problems with recruitment and a low compliance rate for completion of questionnaires, the required sample size was not attained (Grade IC).	N
	National Hospice Study (Morris *et al.*, 1986; Wallston *et al.*, 1988; Goldberg *et al.*, 1986; Greer *et al.*, 1986; Greer and Mor, 1986; Mor *et al.*, 1985; Mor *et al.*, 1988; Mor and Masterton, 1990; Mor *et al.*, 1988; Morris *et al.*, 1986) Quasi-experimental study comparing home hospice, inpatient hospice and conventional care (Grade IIB)	N
	Mulligan, 1989 Comparative study of 3 groups of patients: two groups received service from Foundation for few months to some years and one group had no specialist service available (Grade IIB).	N
	Parkes, 1980 Evaluation of an advisory domiciliary service with the views of spouses of patients who received the care ordinarily provided. Interviews with surviving spouses about 13 months after the patient's death; SCH home care service was compared with matched groups of spouses who had not been visited by the service (Grade IIIB).	N
	Evaluation of inpatient services at St Christopher's Hospice (Parkes, 1979; Parkes, 1985; Parkes and Parkes, 1984) Semi-structured interview - self-assessment of surviving spouses of patients who had died from cancer (Grade IIIC).	N
	Peruselli *et al.*, 1997 Study to describe the patient's quality of life at the outset and during palliative care at home and to define some potential indicators of palliative care outcomes with the aim of assessing the quality of home care as provided by palliative care unit (n=73) (Grade IIIC).	N
	Cartwright and Seale, 1990; Seale, 1991 Evaluative study including inpatient hospice services over more than two sites. Random national sample of deaths of people aged 15 or over who died in 10 randomly sampled areas of England. Interviewers visited the home of the person who died to identify and interview the person who knew most about the last 12 months of life (Grade IIIA).	N
	Serra-Pratt, 2001 A retrospective observational study to provide a comparative assessment of the health care resources consumed during the final month of life of patients undergoing palliative treatment who died from cancer (n=155) (Grade IIIA).	N
	Silver, 1981 Study to identify the life dimensions that hospice addresses and the levels of discomfort or well-being of patients and families achieved in a hospice home care program (n=15). Patients and family were assessed weekly by staff (Grade IIIC).	N
	Tramarin *et al.*, 1992 Prospective study to evaluate the costs and cost-effectiveness of	N

	home-care assistance as an alternative to hospital-based care for patients with AIDS (Grade IIB).	
	Ventafridda *et al*., 1985 Study to determine if home counselling can improve the emotional and behavioural variations of patients and their families. For any type of check up at hospital or at home the patients were asked to complete a self-rating questionnaire; this study examines data at week zero, two and six (Grade IIB).	N
	Ventafridda *et al*., 1990 Study to assess the quality of life and control of physical and emotional symptoms in a group of terminal cancer patients before and during the treatment by a palliative care team (n=115) (Grade IIIB).	Y
	Ventafridda *et al*., 1989 Study to evaluate costs and effectiveness of the program, a comparison between home care and conventional treatment (n=60). Clinical and behavioural data were recorded daily on self-judgement form. Data were collected weekly by nurse responsible for patient care. Data collected for entire period of home care (Grade IIB).	N
	Viney *et al*., 1994 A comparison of the quality of life of terminal cancer patients' in two palliative care units with those in a general hospital. Patients were interviewed by trained interviewers at their bedsides (n=183) (Grade IIB).	N
	Vinciguerra *et al*., 1986 Prospective comparative study, patients were assigned to one or the groups based on geographical location: patients within 10 mile radius received home care program (Grade IIB).	N
	Wakefield and Ashby, 1993 Study to provide evidence concerning caregivers' perceptions and experiences of terminal care service delivery in South Australia. Random sample of case records of patients, letter sent to relative and follow-up phone call 1 week later (Grade IIB).	N
	Wenk *et al*., 1991 Retrospective analysis of patients' notes to assess the effectiveness of a pain and symptom-control model for palliative care (n=118) (Grade IIIC).	N
	Zimmer *et al*., 1985 RCT to evaluate the effectiveness of a Home care team for home bound chronically or terminally ill elderly patients. Patients in the comparative arm were allowed access to existing community services (n=158) (Grade IB).	N
	Zwahlen *et al*., 1991 (translated from French) A retrospective analysis of two years experience of a palliative care team in a regional hospital (Grade IIIC).	N

Authors conclusions	Co-ordination of care The evidence shows that the good co-ordination of services opens up the possibility of home care for patients at the end of life. Enhanced co-ordination and co-operation between organisations enables them to complement each other and provide better quality services. In home care, which is often the patient's wish, the informal caretaker is a crucial part of the health care team. The needs and education of the informal caregiver are important areas to take into account. Lack of emotional support or the inability to adequately alleviate symptoms in certain circumstances can lead eventually to the patient's re-admittance to the hospital in their terminal phase. Zimmer *et al.* (1985) showed that in palliative care teams, patient and caretaker satisfaction are directly related to health care utilisation and cost reduction. Optimal co-ordination, and communication between the various professional caregivers provides better supportive care at home for patients for whom this is the preferred option, and for their immediate caregivers. General palliative care services The recognition of the importance of dying in the place of choice is a realistic proposal as home care increasingly becomes an option. Kane *et al.* (1985) have demonstrated equally effective care in the hospice and the hospital. The beneficial outcomes of psychosocial support may be also considered as deserving attention, especially in areas where pharmacological treatment modalities do not relieve pain completely. Specialist palliative care services The evidence strongly supports specialist palliative care teams working in home, hospitals and inpatient units or hospices as a means to improve outcomes for cancer patients, such as in pain, symptom control and satisfaction, and in improving care more widely. Given the variety of interventions within each team, more work is needed to test the specific components of palliative care team activity (for example to compare different types of hospital team or hospice, or to test specific ways of working within their practice), and to discover if a different skill mix or interventions performed by the team, are more effective than each other.

ABBREVIATIONS: CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; HRQOL, HEALTH-RELATED QUALITY OF LIFE; PCT, PALLIATIVE CARE TEAM; RCT, RANDOMISED CONTROLLED TRIAL; SR, SYSTEMATIC REVIEW

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Hearn and Higginson, 1998	
Level of evidence	Level I/IV [a]	
Research question/aims	To determine whether teams providing specialist palliative care improve the health outcomes of patients with advanced cancer and their families or carers when compared to conventional services.	
Study type/design	Systematic review	
Search strategy	The following databases were searched: Medline (1980–96), psychINFO (1984–96), CINAHL (1982–96), CancerWEB and OncoLink.	
Type of included studies	RCTs and comparative or observational studies	
Type of participants	Patients with advanced cancer and their families were included. Those studies focusing on one cancer site, for example, breast cancer, were not included.	
Type of intervention	Studies which considered the use of specialist teams caring for advanced cancer patients and their families were included.	
Outcomes	Not described	
Data analyses & statistics	The collected information was synthesised through narrative procedures, and the main characteristics and outcomes of each included study were displayed in a structured table.	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	Addington-Hall *et al.*, 1992; Raferty *et al.*, 1996	Y

	RCT (203 patients and 118 carers) to measure the effects on terminally ill cancer patients and their families of co-ordinating the services available within the NHS, from local authorities and from the voluntary sector, and to compare the cost-effectiveness of the service (Grade IB).	
	Hughes *et al*., 1992 RCT (171 patients and their carers) to study the effect of a hospital-based home care program on terminally ill patients and their caregivers (Grade IB).	Y
	Kane *et al.*1984; Kane *et al*., 1985; Kane *et al*., 1986; Wales *et al*., 1983 RCT (247 patients and 152 caregivers) to assess the effect of hospice care on the emotional status of patients and their caregivers and to assess satisfaction (Grade IB).	N
	Zimmer *et al*., 1984; Zimmer *et al*., 1985 RCT (n=158) to study the effectiveness and acceptability of a home health care team (Grade IB).	N
	McWhinney *et al*., 1994 RCT (146 patients and 74 caregivers) to evaluate a home care team based on an inpatient unit (Grade IC).	N
	Higginson *et al*., 1990 Prospective study (n=65) of patients receiving care from two multi professional support teams consisting of doctors, specialist nurses, a social worker, an administrator and volunteers, both liaising with other professionals to assist and advise on patient care (Grade IIB).	N
	Mor *et al*., 1988; Greer and Mor, 1986; Greer *et al.* 1986; Morris *et al*., 1986; Goldberg *et al*., 1986; Mor and Masterson- Allen, 1987 Prospective study (n=1754) of patients and carers attending 40 hospice and 14 conventional care services to evaluate inpatient and home care hospice programs against conventional oncology care (Grade IIB).	N
	Ventafridda *et al*., 1989 Prospective study (n=60) of sequential admissions of patients with terminal cancer with pain, no longer receiving specific oncological treatment to home care or hospital in Milan (Grade IIB).	Y
	Viney *et al*., 1994 Prospective comparison study of three groups: – Group 1 (n = 62) cared for by specialist 10-bed palliative care unit in a general hospital – Group 2 (n = 60) cared for in fully staffed hospice – Control (n = 61) cared for in the small general hospital where Group 1was based.	N
	Wakefield and Ashby, 1993 Retrospective random sample of relatives of adult patients who had died from cancer 12–15 months earlier. – Public hospital (n = 27) – Hospice (n = 22) – Private hospital (n = 19) – Nursing home (n = 14) – Home (n = 18) (Grade IIB).	N

	Cartwright and Seale, 1990; Seale, 1991 Deaths selected from 10 randomly chosen areas of England, stratified by availability of hospice services. – Intervention (n = 45) patient had received hospice care – Control (n = 126) patient had received conventional care (Grade IIIA)	N
	Lunt and Neale, 1987 Quasi-experimental prospective comparative study, intervention groups were from 2 NHS hospices, controls from 3 general medical and 2 general surgical wards in a district general hospital. – Intervention (n = 57 staff, 28 patients) cared for in two purpose built hospices in the South of England – Control (n = 29 staff, 10 patients) cared for in the DGH (Grade IIIA)	N
	McCusker and Stoddard, 1987 Quasi-experimental time series study. Three time periods considered: 1976–77 for pre-home–hospice program; 1978–80 program introduced; 1981–82 fully implemented home–hospice. – Intervention (n = 857) used home care in the six months before death – Control (n = 1017) did not use home care (Grade IIIA)	N
	Parkes, 1979; Parkes, 1979; Parkes and Parkes, 1984 A total of 34 cases and 34 matched controls who died of cancer either in hospital or hospice in 2 London boroughs. The sample was taken from 267 spouses <65 years of age who had been interviewed in an earlier study (Grade IIIA).	N
	Parkes , 1980; Parkes, 1985 A total of 51 cases and 51 matched controls who died from cancer in 2 London boroughs (Grade IIIA)	N
	Higginson *et al*., 1992 Prospective observational study of all referrals to two teams over 17 months and 8 months, respectively. Group 1 (n = 192) cared for by a health service funded team. Group 2 (n = 126) in the care of a voluntary and health authority funded team (Grade IIIC).	N
	Hinton *et al*., 1979 Prospective comparison of care in hospital radiotherapy wards, a Foundation home for cancer patients and a hospice. – Group 1 (n = 20) acute hospital inpatients on 12–20 bed radiotherapy wards, or side wards; – Group 2 (n = 20) Foundation Home inpatients – visited by two GPs; – Group 3 (n = 20) Hospice inpatients on 4–6 bed wards, and a multi-professional approach; and – Group 4 (n = 20) Hospice outpatients attending clinic or visited at home by nurses (Grade IIIC)	N
	Jones, 1993 Observational study with retrospective data collection by interview, carried out in general practices in three health districts in the South of England during 1987 -89 on 207 households receiving professional	N

	support from either: – GP alone (n = 19); – DN and GP (n = 61); – Specialist nurse and GP (n = 14); – Specialist nurse, DN and GP (n = 42) – Nurses, GP and other health professionals (n = 40); – Nurses, GP, other health professionals plus a social worker (n = 25) (Grade IIIC)	
Authors conclusions	It was concluded that all evaluations were of services considered to be leading the field, or were pioneering training and treatments. However, when compared to conventional care, there is evidence that specialist teams in palliative care improve satisfaction and identify and deal with more patient and family needs. Moreover, multi-professional approaches to palliative care reduce the overall cost of care by reducing the amount of time patients spend in acute hospital settings.	

ABBREVIATIONS: CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; HBHC, HINES MODEL OF CARE; HRQOL, HEALTH-RELATED QUALITY OF LIFE; OT, OCCUPATIONAL THERAPY; PCT, PALLIATIVE CARE TEAM; PHCT, PALLIATIVE HOME CARE TEAM; QOL, QUALITY OF LIFE; RCT, RANDOMISED CONTROLLED TRIAL; SR, SYSTEMATIC REVIEW

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Higginson *et al*., 2003, Finlay *et al*., 2002	
Level of evidence	Level I/IV [a]	
Research question/aims	Do palliative care teams achieve their aims and improve outcomes for patients or caregivers, or reduce costs? Which model(s) were most effective in delivery? The effects of sub groups of teams operating in hospital, home or inpatient hospice, or with different groups of patients were considered.	
Study type/design	Systematic review	
Search strategy	Searched Medline, CINAHL, CancerLit, PsychInfo, Embase, PallCare Index, EPOC register, System for Information of Grey Literature (SIGEL), Applied Social Science Index (ASSIA), and Sciences Citation Index (SSI) from the data-base inception to end 1999, and updated using Medline, CINAHL, and PsychInfo to end 2000.	
Type of included studies	For inclusion, studies must have compared palliative care or hospice teams with conventional care (present or historical). Anecdotal and case reports or studies without measured outcomes were excluded.	
Type of participants	Study populations were patients with a progressive life threatening illness and their caregivers (defined as family, friends, or significant others).	
Type of intervention	An intervention (team) was defined as two or more health care workers, at least one of whom had specialist training or worked principally in palliative or hospice care. Usual care was routine community and general hospital/oncology services.	
Outcomes	Outcomes were classified as: pain and symptom control, quality of life and death; patient and family satisfaction/morbidity pre- and post-bereavement.	
Data analyses & statistics	Three different approaches to analysis were adopted. This used meta-regression of combined outcomes data (which allowed testing for factors explaining heterogeneity), a traditional meta-analysis (following the methods of Cochrane), and a meta-synthesis (where the focus of the analysis was descriptive and interpretative, rather than hypothetico-deductive).	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	Addington-Hall *et al*., 1992 RCT (203 patients and 118 carers) to measure the effects on terminally ill cancer patients and their families of co-ordinating the services available within the NHS, from local authorities and from the voluntary sector, and to compare the cost-effectiveness of the service	Y

	(Grade IB).	
	Axelsson *et al*., 1998 Comparison between study group (surgeon half day per week; one full-time specialist nurse; and 6 interested colleagues made occasional home visits) and matched historical group and contemporary reference group (n=97) (Grade IIB).	N
	Axelsson & Sjoden 1998 Observational study on palliative support team (Grade IIIC).	N
	Bennett and Corcoran, 1994 Two, then three nurses supported by others in hospital (Grade IIIC)	N
	Bloom 1980 19 matched pairs to compare the cost of care for patients who died at home under medical supervision with a control group of patients who died in hospital (Grade IIIB).	N
	Bruera, 1989 Study of symptom control team including two physicians, one service nurse, one or two research nurses (Grade IIIC)	N
	Dessloch *et al*., 1992 Semi-structured interview with patient receiving home care (from specialist palliative care team) (Grade IIIB).	N
	Edmonds *et al*., 1998 Study to determine symptom prevalence and outcome for inpatients and outpatients referred to a multi-professional hospital palliative care team (n=352) (Grade IIIC).	Y
	Ellershaw *et al*., 1995 Study (n=125) to assess the outcome of interventions made within two weeks of referral with regard to: symptom control, change in patients' and their relatives' insight regarding diagnosis and prognosis, and facilitation of patient placement. Patients were assessed on referral then twice weekly over the subsequent two weeks (unless death or discharge) (Grade IIIC).	N
	Grande *et al*., 2000 RCT evaluation of hospital at home for palliative care (i.e. providing 24-hour nursing care in a patient's home) (Grade IB).	Y
	Higginson *et al*., 1992 Study to demonstrate the use of Support Team Assessment Schedules in a practical setting and to describe the effect of the palliative care teams in achieving their objectives (Grade IIIB).	N
	Higginson and McCarthy, 1987 Prospective assessment of patient symptoms (n=124) to describe and evaluate the work of terminal care support teams (Grade IIIC).	N
	Higginson and Hearn, 1997 Study (n=695) to determine the prevalence of pain, its effect on advanced cancer patients, and the effectiveness of specialist home-care services in controlling pain (two service evaluations) (Grade IIIC).	Y
	Hinton, 1979 To compare patients dying in different circumstances by an assessment of mood and opinions (Grade IIIC).	N
	Hinton, 1994 Non-comparative study to assess whether patients with terminal	N

	cancer and their relatives find that competent home care sufficiently maintains comfort and helps adjustment (Grade IIIC).	
	Hughes *et al*., 1992 Randomised pre-test-multiple post-test study (n=171) to compare the attributes of the Hines model of care (HBHC) with traditional community home care services to which control group patients could be referred (Grade IB).	Y
	Jones *et al*., 1993 Semi-structured interviews to collect information from principal carers of people who had died at home with cancer; to identify areas of support which need improvement (Grade IIIC).	N
	Kane *et al*.1984; Kane *et al*., 1985; Kane *et al*., 1986; Wales *et al*., 1983; Kane *et al*., 1985 RCT (247 patients and 152 caregivers) to assess the effect of hospice care on the emotional status of patients and their caregivers and to assess satisfaction (Grade IB).	N
	McCorkle *et al*., 1989 RCT to assess the effects of home nursing care for patients with progressive lung cancer. Interventions include oncology home care program provided by nurses trained to give cancer care & services from other dis, to eciplines as needed; standard home care program provided by registered nurses, physio, home health aides, social worker, OT, speech pathologist; and a control office care program provided by physicians (Grade IB).	N
	McCusker & Stoddard, 1987 Retrospective analysis of cancer deaths from claim forms to evaluate an expanded program of home care for the terminally ill (hospital utilisation and costs of care during last months of life) (Grade IIIB).	N
	McIllmurray & Warren, 1989 Evaluation of three common symptoms in a new palliative care service (n=316) (Grade IIIC).	N
	McMillan *et al*., 1996 Study to evaluate the quality of life of a group of adults, who were serving as primary caregivers for hospice patients, receiving home care (Grade IIIC).	N
	McMillan and Mahon, 1994 Study to evaluate the patient's QoL as perceived by the patient and primary caregiver at admission and after hospice services had been implemented (n=80) (Grade IIIB).	N
	McMillan and Mahon, 1994 To evaluate the effects of hospice services on the QoL of primary caregivers (n=68). Comparison group: apparently healthy non-caregiving adults selected from church group, retirement community, and office setting (n=62) (Grade IIB).	N
	McQuillar *et al*., 1996 Study to evaluate the changes that had been implemented to improve care of cancer and HIV patients. Intervention involved face-to-face discussions about referrals and quarterly lunchtime meetings with doctors, education program for the link nurses, guidelines on pain control for doctors and nurses and information cards for patients (Grade IIIB).	N
	McWhinney *et al*.,1994 RCT to evaluate a palliative care home support team based on an inpatient unit. Because of early deaths, problems with recruitment and	N

	a low compliance rate for completion of questionnaires, the required sample size was not attained (Grade IC).	
	National Hospice Study (Morris *et al*., 1986; Wallston *et al*., 1988; Goldberg *et al*., 1986; Greer *et al*., 1986; Greer and Mor, 1986; Mor *et al*., 1985; Mor *et al*., 1988; Mor and Masterton, 1990; Mor *et al*., 1988; Morris *et al*., 1986) Quasi-experimental study comparing home hospice, inpatient hospice and conventional care (Grade IIB)	N
	Mulligan, 1989 Comparative study of 3 groups of patients: two groups received service from Foundation for few months to some years and one group had no specialist service available (Grade IIB).	N
	Parkes, 1980 Evaluation of an advisory domiciliary service with the views of spouses of patients who received the care ordinarily provided. Interviews with surviving spouses about 13 months after the patient's death; SCH home care service was compared with matched groups of spouses who had not been visited by the service (Grade IIIB).	N
	Evaluation of inpatient services at St Christopher's Hospice (Parkes, 1979; Parkes, 1985; Parkes and Parkes, 1984) Semi-structured interview - self-assessment of surviving spouses of patients who had died from cancer (Grade IIIC).	N
	Peruselli *et al*., 1997 Study to describe the patient's quality of life at the outset and during palliative care at home and to define some potential indicators of palliative care outcomes with the aim of assessing the quality of home care as provided by palliative care unit (n=73) (Grade IIIC).	N
	Cartwright and Seale, 1990; Seale, 1991 Evaluative study including inpatient hospice services over more than two sites. Random national sample of deaths of people aged 15 or over who died in 10 randomly sampled areas of England. Interviewers visited the home of the person who died to identify and interview the person who knew most about the last 12 months of life (Grade IIIA).	N
	Silver, 1981 Study to identify the life dimensions that hospice addresses and the levels of discomfort or well-being of patients and families achieved in a hospice home care program (n=15). Patients and family were assessed weekly by staff (Grade IIIC).	N
	Tramarin *et al*., 1992 Prospective study to evaluate the costs and cost-effectiveness of home-care assistance as an alternative to hospital-based care for patients with AIDS (Grade IIB).	N
	Ventafridda *et al*., 1985 Study to determine if home counselling can improve the emotional and behavioural variations of patients and their families. For any type of check up at hospital or at home the patients were asked to complete a self-rating questionnaire; this study examines data at week zero, two and six (Grade IIB).	N
	Ventafridda *et al*., 1990 Study to assess the quality of life and control of physical and emotional symptoms in a group of terminal cancer patients before and during the treatment by a palliative care team (n=115) (Grade IIIB).	Y
	Ventafridda *et al*., 1989 Study to evaluate costs and effectiveness of the program, a	N

	comparison between home care and conventional treatment (n=60). Clinical and behavioural data were recorded daily on self-judgement form. Data were collected weekly by nurse responsible for patient care. Data collected for entire period of home care (Grade IIB).	
	Viney *et al*., 1994 A comparison of the quality of life of terminal cancer patients' in two palliative care units with those in a general hospital. Patients were interviewed by trained interviewers at their bedsides (n=183) (Grade IIB).	N
	Vinciguerra *et al*., 1986 Prospective comparative study, patients were assigned to one or the groups based on geographical location: patients within 10 mile radius received home care program (Grade IIB).	N
	Wakefield and Ashby, 1993 Study to provide evidence concerning caregivers' perceptions and experiences of terminal care service delivery in South Australia. Random sample of case records of patients, letter sent to relative and follow-up phone call 1 week later (Grade IIB).	N
	Wenk *et al*., 1991 Retrospective analysis of patients' notes to assess the effectiveness of a pain and symptom-control model for palliative care (n=118) (Grade IIIC).	N
	Zimmer *et al*., 1985 RCT to evaluate the effectiveness of a Home care team for home bound chronically or terminally ill elderly patients. Patients in the comparative arm were allowed access to existing community services (n=158) (Grade IB).	N
	Zwahlen *et al*., 1991 (translated from French) A retrospective analysis of two years experience of a palliative care team in a regional hospital (Grade IIIC).	N
Authors conclusions	Meta-regression (26 studies) found slight positive effect, of approximately 0.1, of palliative and hospice care teams (PCHCTs) on patient outcomes, independent of team make-up, patient diagnosis, country, or study design. Meta-analysis (19 studies) demonstrated small benefit on patients' pain (odds ratio [OR]: 0.38, 95% confidence interval [CI]: 0.23–0.64), other symptoms (OR: 0.51, CI: 0.30–0.88), and a non-significant trend towards benefits for satisfaction, and therapeutic interventions. Data regarding home deaths were equivocal. Meta-synthesis (all studies) found wide variations in the type of service delivered by each team; there was no discernible difference in outcomes between city, urban, and rural areas. Evidence of benefit was strongest for home care. Only one study provided full economic cost-benefit evaluation. This is the first study to quantitatively demonstrate benefit from PCHCTs. Such comparisons were limited by the quality of the research.	

ABBREVIATIONS: CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; DGH, DISTRICT GENERAL HOSPITAL; DN, DISTRICT NURSE; GP, GENERAL PRACTITIONER; NHS, NATIONAL HEALTH SERVICE; RCT, RANDOMISED CONTROLLED TRIAL

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Higginson *et al*., 2002
Level of evidence	Level I/IV [a]
Research question/aims	A systematic literature review of evaluations of hospital based teams to determine whether they affect care in hospital.
Study type/design	Systematic review

Search strategy	Searched Medline, CINAHL, CancerLit, PsychInfo, Embase, PallCare Index, EPOC register, Applied Social Science Index (ASSIA), and Sciences Citation Index (SSI) from the data-base inception to 1998/1999. The database searches were augmented by hand-searching specific journals, contacting authors, and also examining the reference lists of all papers retrieved	
Type of included studies	For inclusion in the review, the evaluation had to comprise a trial design comparing hospital-based palliative care with usual care delivery (present or historical).	
Type of participants	The subjects of the research were defined as those patients with a progressive life-threatening illness, and their family, carers, or close friends.	
Type of intervention	Studies had to describe evaluations of palliative care teams working in hospitals. Such teams were defined as: two or more health care workers, at least one of whom had specialist training or worked principally in palliative care. Usual care included routine community and general hospital/oncology services, and isolated professionals who have undertaken limited training in palliative care.	
Outcomes	The review included papers with a broad range of outcomes and process measures: pain; control of other specific symptoms such as nausea, anorexia, tiredness; improved quality of life and quality of death; patient satisfaction and carer satisfaction pre-bereavement; carer morbidity pre- and post-bereavement.	
Data analyses & statistics	From the outcome data in the included studies, the effect sizes for outcomes was calculated by dividing the estimated mean difference or difference in proportions by the sample standard deviation. Calculating effect sizes allows comparisons between outcomes measured on different scales.	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	Addington-Hall *et al*., 1992 RCT (203 patients and 118 carers) to measure the effects on terminally ill cancer patients and their families of co-ordinating the services available within the NHS, from local authorities and from the voluntary sector, and to compare the cost-effectiveness of the service (Grade IB).	Y
	Axelsson *et al*., 1998 Comparison between study group (surgeon half day per week; one full-time specialist nurse; and 6 interested colleagues made occasional home visits) and matched historical group and contemporary reference group (n=97) (Grade IIB).	N
	Axelsson & Sjoden 1998 Observational study on palliative support team (Grade IIIC).	N
	Bennett and Corcoran, 1994 Two, then three nurses supported by others in hospital (Grade IIIC)	N
	Bruera, 1989 Study of symptom control team including two physicians, one service nurse, one or two research nurses (Grade IIIC)	N
	Edmonds *et al*., 1998 Study to determine symptom prevalence and outcome for inpatients and outpatients referred to a multi-professional hospital palliative care team (n=352) (Grade IIIC).	Y
	Ellershaw *et al*., 1995 Study (n=125) to assess the outcome of interventions made within two weeks of referral with regard to: symptom control, change in patients' and their relatives' insight regarding diagnosis and prognosis, and facilitation of patient placement. Patients were assessed on referral then twice weekly over the subsequent two weeks (unless death or discharge) (Grade IIIC).	N

	Higginson *et al*., 1992 Study to demonstrate the use of Support Team Assessment Schedules in a practical setting and to describe the effect of the palliative care teams in achieving their objectives (Grade IIIB).	N
	Higginson and McCarthy, 1987 Prospective assessment of patient symptoms (n=124) to describe and evaluate the work of terminal care support teams (Grade IIIC).	N
	McQuillar *et al*., 1996 Study to evaluate the changes that had been implemented to improve care of cancer and HIV patients. Intervention involved face-to-face discussions about referrals and quarterly lunchtime meetings with doctors, education program for the link nurses, guidelines on pain control for doctors and nurses and information cards for patients (Grade IIIB).	N
	Ventafridda *et al*., 1990 Study to assess the quality of life and control of physical and emotional symptoms in a group of terminal cancer patients before and during the treatment by a palliative care team (n=115) (Grade IIIB).	Y
	Wenk *et al*., 1991 Retrospective analysis of patients' notes to assess the effectiveness of a pain and symptom-control model for palliative care (n=118) (Grade IIIC).	N
	Zwahlen *et al*., 1991 (translated from French) A retrospective analysis of two years experience of a palliative care team in a regional hospital (Grade IIIC).	N
Authors conclusions	All studies indicated a small positive effect of the hospital team, except for one study in Italy, which documented deterioration in patient symptoms. The Signal scores indicated that the studies were relevant. No study compared different models of hospital team.	

ABBREVIATIONS: CI, CONFIDENCE INTERVAL; CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; HBHC, HINES MODEL OF CARE; OT, OCCUPATIONAL THERAPY; OR, ODDS RATIO; PCHCT, PALLIATIVE AND HOSPICE CARE TEAM; QOL, QUALITY OF LIFE; RCT, RANDOMISED CONTROLLED TRIAL

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Salisbury *et al*., 1999; Wilkinson *et al*., 1999
Level of evidence	Level I/IV [a]
Research question/aims	To evaluate the impact of alternative models on quality of life or symptom control (Salisbury *et al*., 1999). To evaluate the impact of specialist models of palliative care on consumer satisfaction, opinion and preference.
Study type/design	Systematic review
Search strategy	Medline, Embase, Index of Scientific and Technical Proceedings, SIGLE, NHS Project research System, Health Planning and Administration, CancerLit, DHSS data. In addition, various journals were hand-searched and funding bodies contacted.
Type of included studies	Comparative studies which evaluated a model of specialist palliative care, and used quality of life as an outcome measure. Articles were excluded if they consisted of personal opinion, individual case histories or discussion of ethical, legal or educational issues, or studies concerned with the impact of chemotherapy, radiotherapy or surgery on quality of life. A large number of papers were identified which described the development of scales or research instruments to assess quality of life. These papers were excluded unless they included the use of the instrument to assess a model of care.

Type of participants	Studies which measured the impact of palliative care on the quality of life of relatives or carers were excluded. Research which addressed the quality of life of cancer patients who were not necessarily terminally ill was not included unless a specific reference to terminally ill patients was included within the study.	
Type of intervention	Studies were excluded unless they compared at least two different specialised palliative care programs.	
Outcomes	The term 'quality of life' was interpreted broadly, to include not only formal measures which purport to assess quality of life but also measures of pain control, symptom control or general well-being.	
Data analyses & statistics	The collected information was synthesised through narrative procedures, and the main characteristics and outcomes of each included study were displayed in a structured table.	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	Parkes, 1978 Non-randomised retrospective interview study comparing patients who had Received predominantly hospital vs. home based terminal care (n=165).	N
	Parkes, 1979 Comparison of matched pairs by semi-structured interviews with spouses. Patients dying at inpatient hospice with home care program vs. patients dying at other hospitals (n=89).	N
	Hinton, 1979 Observational interview study to compare patients dying in different circumstances by an assessment of mood and opinions (n=80).	N
	Parkes, 1980 Evaluation of an advisory domiciliary service with the views of spouses of patients who received the care ordinarily provided. Interviews with surviving spouses about 13 months after the patient's death; SCH home care service was compared with matched groups of spouses who had not been visited by the service (n=148).	N
	Linn, 1982 RCT of patients receiving death counselling vs. controls (n=120).	N
	Parkes and Parkes, 1984 A total of 34 cases and 34 matched controls who died of cancer either in hospital or hospice in 2 London boroughs. The sample was taken from 267 spouses <65 years of age who had been interviewed in an earlier study.	N
	Zimmer, 1984 and Zimmer, 1985 RCT to evaluate the effectiveness of a Home care team for home bound chronically or terminally ill elderly patients. Patients in the comparative arm were allowed access to existing community services (n=158).	N
	Kane, 1984; Kane 1985; and Kane 1985 RCT (247 patients and 152 caregivers) to assess the effect of hospice care on the emotional status of patients and their caregivers and to assess satisfaction.	N
	Greer, 1986; Greer and Mor, 1986; Morris *et al.*, 1986; and Wallston, 1988 Prospective study (n=1754) of patients and carers attending 40 hospice and 14 conventional care services to evaluate inpatient and home care hospice programs against conventional oncology care.	N

	Ventafridda, 1989 Prospective study (n=60) of sequential admissions of patients with terminal cancer with pain, no longer receiving specific oncological treatment to home care or hospital in Milan	N
	Seale, 1991 Retrospective interview study and analysis of 26 matched pairs to compare hospice care with conventional care.	N
	Addington-Hall, 1992 RCT (203 patients and 118 carers) to measure the effects on terminally ill cancer patients and their families of co-ordinating the services available within the NHS, from local authorities and from the voluntary sector, and to compare the cost-effectiveness of the service.	Y
	Hughes, 1992 Randomised pre-test-multiple post-test study (n=171) to compare the attributes of the Hines model of care (HBHC) with traditional community home care services to which control group patients could be referred.	Y
	Dessloch, 1992 Semi-structured interview with patient receiving home care (from specialist palliative care team) (n=41).	N
	Siegel, 1992 RCT (n=398) to assess an intervention of an automated telephone outreach system coupled with timely social worker assistance in patients with cancer receiving outpatient chemotherapy.	N
	McWhinney, 1994 RCT (n=146 however only 76 completed trial) to evaluate a home care team based on an inpatient unit.	N
	Viney, 1994 - Small specialist palliative care unit (10 beds) within a general hospital (n=62) - Free standing hospice of 100 beds (n=60) - Conventional care at general hospital (n=61)	N
	McQuillar *et al*., 1996 Study to evaluate the changes that had been implemented to improve care of cancer and HIV patients. Intervention involved face-to-face discussions about referrals and quarterly lunchtime meetings with doctors, education program for the link nurses, guidelines on pain control for doctors and nurses and information cards for patients (n=334).	N
	Seale, 1997 Retrospective interview survey of spouses of patients dying in hospice or hospital (n=66).	N
	Higginson, 1997 Study (n=695) to determine the prevalence of pain, its effect on advanced cancer patients, and the effectiveness of specialist home-care services in controlling pain (two service evaluations).	Y
	Field and McGaughey, 1998 Interview study of 55 lay carers of cancer patients, comparing hospital palliative care versus home care during last 6 months of life.	N
	McCarthy *et al*., 1996	N

	Interview survey of randomly selected dementia and cancer patients over the age of 65 at death. Comparison between experiences of people dying from cancer and those with end-stage dementia (n=1683).	
	Seamark, 1996 Retrospective interview survey of lay carer opinions to compare quality of care in community hospitals with care in hospice (n=161)	N
	Butters *et al*., 1993 Interview survey lay carers, patients and community care team to compare views on palliative care given by home care team (n=19).	N
	Field *et al*., 1992 Interview survey to compare lay carers' views on community care and hospice care (n=59).	N
	McCann, 1991 Interview survey of patients with AIDS to compare views on Home Support Team (AST) with GP care and outpatient care (n=261).	N
	Higginson *et al*., 1990 Prospective interview survey of terminally ill cancer patients and their families to evaluate community-based support teams and hospital and community services (n=65).	N
	Wilkes, 1984 Retrospective interview survey of lay carers to compare hospital and home care (n=262).	N
	Foster, 1987 Retrospective interview survey of lay carers to determine their views on hospice care (n=47).	N
	McCusker, 1985 Interview survey of patients and relatives to compare home care and institutional care in the final 6 months of life (n=122 patients and 96 relatives)	N
	Hannan and O'Donnell, 1984 Interview survey of lay carers to evaluate the New York State Hospice Demonstration Program. Community-based hospice versus hospital-based hospice with "scattered beds" versus hospital-based hospice in "autonomous unit" (n=350 carers).	N
Authors conclusions	There was some evidence that inpatient palliative care provided better pain control than home care or conventional hospital care, but this research was dated and open to criticism. Research on palliative home care teams and co-ordinating nurses has demonstrated limited impact on quality of life over conventional care for patients dying at home. Research findings from North America did not reveal any reliable or consistent trends, and this was due primarily to methodological flaws in the research. In the UK, consumers are more satisfied with all types of palliative care, whether provided by inpatient units or in the community, than with palliative care provided by general hospitals. Even though research findings consistently indicate that consumers appreciate the psychosocial climate in hospices, this research was based on small-scale local studies which were mainly focused on a single hospice.	

ABBREVIATIONS: CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; NHS, NATIONAL HEALTH SYSTEM; RCT, RANDOMISED CONTROLLED TRIAL; SIGLE, SYSTEM FOR INFORMATION ON GREY LITERATURE IN EUROPE

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Smeenk *et al*., 1998

Level of evidence	Level I/IV [a]	
Research question/aims	To investigate whether for patients with incurable cancer comprehensive home care programs are more effective than standard care in maintaining the patients' quality of life and reducing their "readmission time" (percentage of days spent in hospital from start of care till death).	
Study type/design	Systematic review	
Search strategy	Medline, Embase, CancerLit and PsychLit	
Type of included studies	Types of included studies were clinical trials, cohort studies, case-control studies, comparative studies with historical controls, within group comparison studies, economic evaluations and high quality systematic reviews.	
Type of participants	Patients with incurable cancer and a control group against which the intervention could be compared	
Type of intervention	The intervention had to be aimed at different aspects of care, and its main goal had to be better support for patients at home; studies of specific home care interventions aimed at just one aspect of care (such as home parenteral nutrition or pain treatment) were to be excluded The control group had to have received standard available (home) care; studies in which the control group received only hospital care were to be excluded	
Outcomes	The dependent variables in the study had to include at least one dimension of quality of life or the readmission rate of patients.	
Data analyses & statistics	The collected information was synthesised through narrative procedures, and the main characteristics and outcomes of each included study were displayed in a structured table.	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	Zimmer *et al*., 1985 RCT to evaluate the effectiveness of a Home care team for home bound chronically or terminally ill elderly patients. Patients in the comparative arm were allowed access to existing community services (n=158)	N
	Greer *et al*., 1986; Mor and Kidder, 1985, Wallston *et al*., 1988 Prospective study (n=1754) of patients and carers attending 40 hospice and 14 conventional care services to evaluate inpatient and home care hospice programs against conventional oncology care.	N
	McCorkle *et al*., 1989 RCT to assess the effects of home nursing care for patients with progressive lung cancer. Interventions include oncology home care program provided by nurses trained to give cancer care & services from other disciplines as needed; standard home care program provided by registered nurses, physiotherapy, home health aides, social worker, OT, speech pathologist; and a control office care program provided by physicians (n=166).	N
	Cummings *et al*., 1990 RCT to determine cost effectiveness of Veterans Administration hospital-based home care (n=419).	Y
	Hughes *et al*., 1992 Randomised pre-test-multiple post-test study (n=171) to compare the attributes of the Hines model of care (HBHC) with traditional community home care services to which control group patients could be referred.	Y
	Addington-Hall *et al*., 1992 RCT (203 patients and 118 carers) to measure the effects on	Y

	terminally ill cancer patients and their families of co-ordinating the services available within the NHS, from local authorities and from the voluntary sector, and to compare the cost-effectiveness of the service	
	McCorkle *et al*., 1994 Study (n=166) on the impact of post-hospital home care on patients with cancer.	N
Authors conclusions	None of the studies showed a negative influence of home care interventions on quality of life. A significantly positive influence on the outcome measures was seen in 2 out of the 5 studies measuring patients' satisfaction with care, in 3/7 studies measuring physical dimensions of quality of life, in 1/6 studies measuring psychosocial dimensions, and in 2/5 studies measuring readmission time. The incorporation of team members' visits to patients at home or regular multidisciplinary team meetings into the intervention program seemed to be related to positive results.	

ABBREVIATIONS: NHS, NATIONAL HEALTH SYSTEM; RCT, RANDOMISED CONTROLLED TRIAL

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Thomas *et al*., 2006	
Level of evidence	Level I (a systematic review of RCTs)	
Research question/aims	To identify and analyse all published RCTs that focus on the organisation of EOL care provided to persons who are terminally ill, near death, or dying.	
Study type/design	Systematic review	
Search strategy	Embase, Medline, CINAHL, AHMED, Psychinfo, ERIC, HealthStar, Sociological Abstracts, and the Cochrane Library (including the Cochrane Controlled Trials Register and Library of Systematic Reviews).	
Type of included studies	RCTs	
Type of participants	Not specifically described	
Type of intervention	Not specifically described	
Outcomes	Not specifically described	
Data analyses & statistics	The collected information was synthesised through narrative procedures, and the main characteristics and outcomes of each included study were displayed in a structured table.	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	Addington-Hall *et al*., 1992; Raferty *et al*., 1996 Randomisation (n=554) to care coordination by district (to community or public health nurses) or to routine care.	Y
	Aronheim *et al*., 2000 Randomisation to either in-hospital palliative care team recommendations or standard care (n=99).	N
	Aikman *et al*., 1999 Randomisation to use either the generic or the HIV-specific forms of the University of Toronto Centre for Bioethics Living Will.	N
	Cornbleet *et al*., 2002 Randomisation of patients to using the Newcastle patient-held record (Lecouturier *et al*., 1999) with notification of physician, or to control (n=241).	N
	Detmar *et al*., 2002 Randomisation of physicians for patients to receive either the European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire—Core 30 (QLQ-C30), or be assigned to a control	N

	group. After 2 months, the physicians were crossed over to the other group (n=273 patients).	
	Ditto *et al*., 2001; Coppola *et al*., 2001 Randomisation of surrogate decision makers to reviewing either scenario-based or value-based directives written by patients and discussing or not discussing the directives, or to control (n=408).	N
	Grande *et al*., 1999 Patients were randomised to hospital-at-home (n=186) or standard hospital, hospice or home care (n=43).	Y
	Grande *et al*., 2000 Randomisation to a hospital-at-home program (24-hour practical nursing care for 2 weeks) or usual EOL care (n=262).	Y
	Hainsworth *et al*., 1996 Nurses on adult medical–surgical units in an urban teaching hospital volunteered to be randomised to receive three 2-hour sessions on personal awareness of death, or no intervention (n=28).	N
	Hanks *et al*., 2002 Randomisation to hospital palliative care team care or to telephone support from team (n=261).	Y
	Hughes *et al*., 1992 Comparison of the costs of home-based palliative care delivered by a home care team based in a Veterans Hospital (HBHC) and usual care (n=175).	Y
	Hughes *et al*., 2000 Randomisation to Veterans Affairs team-managed home-based primary care or to customary Veterans Affairs post-discharge care (n=1966 patients and 1883 caregivers)	Y
	Jordhøy *et al*., 2000; Jordhøy *et al*., 2001; Ringdal *et al*., 2002 Randomisation to team palliative care intervention or to conventional care (n=707)	Y
	Kane *et al*., 1984; Kane *et al*., 1986; Bernstein *et al*., 1985; Kane, Klein, Rothenberg *et al*., 1985; Wales *et al*., 1983 Randomisation to home and inpatient hospice care or to conventional hospital-based care (n=263).	N
	Kissane *et al*., 2003; Chan *et al*., 2004; Kissane *et al*., 2004 Randomisation of patients with their relatives to Family Focused Grief Therapy or to control (n=81 families).	N
	Latimer *et al*., 1998 Randomised either to use a portable health record or to standard care (no portable health record) (n=61).	N
	McCorkle *et al*., 1989 Randomisation to either specialized oncology/palliative home nursing care or to standard home care or to office care (n=243).	N
	McCorkle *et al*., 1998 Randomised to either: (1) Home care intervention (comprehensive clinical assessment; advanced practice nurses; coordination of care with family, primary care physician, community resources and home health agency; three home visits and five telephone calls over 30 day period) or to (2) usual post-surgical care (n=37)	N
	Schwartz *et al*., 2002	N

	Randomisation of patients either to receive two pamphlets and discuss an advance care plan with a health care agent and a nurse facilitator or to receive the Massachusetts Health Care Proxy form (n=61).	
	Van Boxel *et al*., 2003 Nurses were asked to choose six worksheets on physical symptoms and six on psychological issues, then were randomised to receive palliative care workshops by a palliative care consultant either by videoconference or face-to-face; then groups were crossed over.	N
	Zimmer *et al*., 1985 Randomisation either to home health care team (internist, nurse practitioner, medical social worker), available 24/365, or to usual care (n=158).	N
Authors conclusions	It is difficult to synthesize an accurate overview of the state of science of EOL because the RCTs were conducted in different countries and health systems, with varying terminal illnesses and circumstances of dying, and across approximately 20 years of time. Nevertheless, a key finding of this review is that community or home-based EOL care compares favourably with more traditional or conventional hospital-based and episodic medical care in improving symptoms and in the opinions of patients and caregivers.	

ABBREVIATIONS: CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; EOL, END OF LIFE; HBHC, HINES MODEL OF CARE; RCT, RANDOMISED CONTROLLED TRIAL

Citation	Wadhwa and Lavizzo-Mourey, 1999	
Level of evidence	Level I/IV [a]	
Research question/aims	To determine whether multidisciplinary teams, outreach or home care and case management improve the quality of care in two vulnerable populations: the terminally ill and mentally ill.	
Study type/design	Systematic review	
Search strategy	Embase and GENMED databases were search from 1977-1997	
Type of included studies	Prospective studies containing a comparison group receiving conventional care.	
Type of participants	The study population fell into one of the two vulnerable population categories: the terminally ill and mentally ill.	
Type of intervention	The intervention assessed was one or a combination of the three innovative models of care i.e. multidisciplinary teams, outreach or home care and case management.	
Outcomes	The outcomes measured were clinical outcomes or a quality measure.	
Data analyses & statistics	The collected information was synthesised through narrative procedures, and the main characteristics and outcomes of each included study were displayed in a structured table.	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	Mor *et al*., 1988; Wallston *et al*., 1988 Hospice study. Prospective study (n=1754) of cancer patients and carers attending 40 hospice and 14 conventional care services to evaluate inpatient and home care hospice programs against conventional oncology care.	N
	Kane *et al*., 1984 Hospice study. Randomisation to home and inpatient hospice care or to conventional hospital-based care (n=263).	N
	Hughes, 1992	Y

	Home care/multidisciplinary team. Randomised pre-test-multiple post-test study (n=171) to compare the attributes of the Hines model of care (HBHC) with traditional community home care services to which control group patients could be referred	
	Cummings, 1990 Home care/multidisciplinary team. RCT to determine cost-effectiveness of Veterans Administration hospital-based home care (n=419).	Y
	Zimmer *et al*., 1985 Home care/multidisciplinary team. Randomisation either to home health care team (internist, nurse practitioner, medical social worker), available 24/365, or to usual care (n=158).	N
	Addington-Hall *et al*., 1992 Case management/care co-ordination. Randomisation (n=554) to care coordination by district (to community or public health nurses) or to routine care.	Y
Authors conclusions	Patient and caregiver satisfaction was consistently higher with innovative models. In no study was satisfaction lower. Functional, clinical, or psychological improvements were not consistently demonstrated. Costs were inadequately assessed in the studies to draw a summary conclusion.	

ABBREVIATIONS: HBHC, HINES MODEL OF CARE; RCT, RANDOMISED CONTROLLED TRIAL

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Citation	Zimmermann *et al*., 2008	
Level of evidence	Level I/IV [a]	
Research question/aims	To examine systematically the evidence for effectiveness of specialized palliative care in improving quality of life, satisfaction with care, and economic cost.	
Study type/design	Systematic review	
Search strategy	Studies were recovered from the following databases from their inception to January 2008: Medline, Ovid Healthstar, CINAHL, Embase, and the Cochrane Central Register of Controlled Trials.	
Type of included studies	RCTs	
Type of participants	Not specifically described	
Type of intervention	A specialized palliative care service was defined as a service of professionals that provides or coordinates comprehensive care for patients with a terminal illness.	
Outcomes	Studies with at least one of the outcomes of quality of life, satisfaction with care, or economic cost were eligible. Studies evaluating the impact of only one component of comprehensive palliative care on only one aspect of quality of life (e.g., impact of pain medication on pain; impact of medication or psychotherapy on depression) were excluded.	
Data analyses & statistics	Studies were analysed separately for outcomes of quality of life, patient and family satisfaction with care, and economic cost. The studies were too heterogeneous to permit statistical pooling; therefore a qualitative synthesis of the studies was performed, taking into account study power and methodological quality in the analysis.	
Study design of included studies	Studies	Eligible for inclusion in **Part 2**
	McMillan *et al*., 2007; McMillan *et al*., 2006 Using the COPE intervention for family caregivers to improve symptoms of advanced cancer patients receiving hospice homecare – 111 Caregiver coping	Y

	– 109 Nursing visits – 109 Usual hospice homecare	
	Brumley *et al.*, 2007 RCT in patients with CHF, COPD or cancer comparing interdisciplinary home care (n=155) with usual medical care (n=115).	Y
	Rummans *et al.*, 2006 RCT in advanced cancer patients receiving radiation therapy. Patients were randomised to multidisciplinary care (n=49) or usual radiation oncologist care (n=54)	N
	Engelhardt *et al.*, 2006 RCT in patients with advanced CHF, COPD or cancer. Patients were randomised to receive treatment from a home palliative care team (n=110) or usual care (91).	Y
	Aiken *et al.*, 2006 RCT in patients with CHF and COPD to compare a treatment with a home palliative care team (n=110) to usual care (n=91).	N
	Miller *et al.*, 2005 RCT in oncology outpatients, who were randomised to receive Group education/support (n=37) or mailed self-help materials (n=32).	N
	Casarett *et al.*, 2005 RCT in patients from three nursing homes. Patients were randomised to receive treatment from a palliative care team (n=50) or usual care (n=40).	N
	Rabow *et al.*, 2004 Outpatients with cancer, COPD or CHF were randomised to treatment from a palliative care team (n=50) or usual care (n=40).	N
	Hughes *et al.*, 2000 Patients with terminal, severe or homebound CHF or COPD were randomised to receive treatment from a home-based primary care team (n=981) or usual care (n=985).	Y
	Ahronheim *et al.*, 2000 Patients with dementia were randomised to treatment by a palliative care physician/nurse (n=48) or usual care (n=51).	N
	Toseland *et al.*, 1995 Caregivers of cancer patients were randomised to receive counselling (n=38) or usual treatment (n=40).	N
	SUPPORT, 1995 (Connors *et al.*, 1995; Desbiens *et al.*, 1996; Baker *et al.*, 2000) Patients diagnosed with life-threatening disease from five teaching hospitals were randomised to nurse-led treatment (n=2652) or usual hospital care (n=2152)	Y
	Hughes *et al.*, 1992 Palliative care patients were allocated to Veterans' Affairs hospital-based home care (n=86) or usual Medicare home or hospice care (n=85)	Y
	McCorkle *et al.*, 1994 Patients with stage 2 lung cancer (n=166) were randomised to oncology home care, standard home care or office care.	N
	Zimmer *et al.*, 1984	N

	Seriously ill homebound patients were randomised to receive treatment from a home care team (n=82) or usual care (n=76).	
	Kane *et al*., 1984 Veterans' Affairs hospital inpatients were randomised to treatment in an inpatient unit by a hospice home care team (n=137) or usual care (n=110).	N
	Moore *et al*., 2002 Lung cancer outpatients were randomised to a nurse-led follow up intervention (n=100) or usual medical care (n=103).	N
	Hanks *et al*., 2002 Palliative care inpatients from a teaching hospital were randomised to receive treatment by a palliative care physician and nurse (n=175) or a telephone consultation (n=86).	Y
	Grande *et al*., 1999 Patients with cancer, motor neuron disease or AIDS were randomised to hospital-at-home (n=186) or standard hospital, hospice or home care (n=43).	Y
	Addington-Hall *et al*., 1992 Patients with cancer were randomised to an intervention involving nurse coordinators (n=153) or usual care (n=128).	Y
	Jordhøy *et al*., 2001; Ringdal *et al*., 2002; Jordhøy *et al*., 2000 Cancer patients from 8 healthcare districts were randomised to treatment by a multidisciplinary palliative care team (n=235) or usual care by a home care team (n=199).	Y
	McWhinney *et al*., 1994 Metastatic cancer patients (n=146) were randomised to treatment by a palliative care team or were put on a four week waiting list.	N
Authors conclusions	It is difficult to synthesize an accurate overview of the state of science of EOL because the RCTs were conducted in different countries and health systems, with varying terminal illnesses and circumstances of dying, and across approximately 20 years of time. Nevertheless, a key finding of this review is that community or home-based EOL care compares favourably with more traditional or conventional hospital-based and episodic medical care in improving symptoms and in the opinions of patients and caregivers.	

ABBREVIATIONS: CHF, CONGESTIVE HEART FAILURE; CINAHL, CUMULATIVE INDEX TO NURSING AND ALLIED HEALTH LITERATURE; COPD, CHRONIC OBSTRUCTIVE PULMONARY DISEASE; EOL, END OF LIFE; RCT, RANDOMISED CONTROLLED TRIAL;

[A] A SYSTEMATIC REVIEW OF LEVEL II, III AND IV STUDIES

Level II studies

Citation	Addington-Hall *et al*., 1992; Raferty *et al*., 1996
Level of evidence	II
Country	UK (inner London health district)
Research question/aims	To measure the effects on terminally ill cancer patients and their families of coordinating the services available within the NHS and from local authorities and the voluntary sector.
Study type/design	RCT
Patient group	Patients with cancer with a prognosis of less than one year (n=203)

Intervention	All patients received routinely available services. Patients receiving the intervention also received the assistance of two nurse coordinators, whose role was to ensure that patients received appropriate and well coordinated services, tailored to their individual needs and circumstances (n=104). Home care + coordination of care
Comparator	Routinely available services (n=99)
Outcome definitions and measurements	Patients and carers were interviewed at home on entry to the trial and at intervals until death. Interviews after bereavement were also conducted. Outcome measures included presence and severity of physical symptoms, psychiatric morbidity, use of and satisfaction with services, and carers' problems.
Data analyses & statistics	Results from the baseline interview, the interview closest to death and the interview after bereavement were analysed.
Study quality	Fair A: Unknown. To prevent contamination that could occur if patients of the same general practice had been allocated to different groups, general practices were randomly allocated to the coordination or control group, stratified by the number of partners and postal district. B: Unknown. C: Yes D: No E: Yes F: No
Results	Quality of life: The groups did not differ significantly in terms of quality of life, anxiety or depression. Symptoms: Patients in the intervention group were significantly less likely to have experienced vomiting (p=0.05) but there were no other significant differences in the symptoms experienced in the 24 hours before the interview. The coordination group were also less likely to be concerned about itchy skin (p=0.02). Carers of the coordination group were more likely to report that the patient had a cough (p=0.04), less likely to rate the patient's difficulty in swallowing as severe (p=0.03), more likely to report effective treatment for constipation (p=0.01) and less likely to report effective treatment for anxiety (p=0.01). Caregiver satisfaction: There were no significant differences in the experiences of carers. Survival: The median survival after study entry was 385 days in the study group and 340 days in the control group. This was assessed by Cox regression as just significant (p=0.05) Utilisation of resources: There were no differences in the type of analgesics taken, nor in the proportions of patients taking antiemetics, laxatives, antidepressants, sedatives or anxiolytics. The two groups were equally likely to report having had contact with social service agencies, nursing services and general practitioners; however more patients in the intervention group reported contact with a chiropodist (p<0.02). Cost of care: There were no significant differences between groups in terms of finance and benefits.
Authors conclusions	Few differences were found in symptoms and symptom control, service provision and satisfaction, because a high standard of routinely available care left little or no room for further improvements. In conclusion the Wandsworth coordinating service for terminally ill cancer patients failed to produce either better service coordination or improved patient/family outcomes.
Reviewers notes	The authors note that the coordinating service made little difference to outcomes, perhaps because the service did not have a budget with which it could obtain services or because professional skills of the nurse-coordinators may have conflicted with the requirements of the coordinating role.

ABBREVIATIONS: RCT, RANDOMISED CONTROLLED TRIAL; NHS, NATIONAL HEALTH SERVICE

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	Brumley *et al.*, 2007
Level of evidence	II
Country	USA
Research question/aims	To determine whether an in-home palliative care intervention for terminally ill patients can improve patient satisfaction, reduce medical care costs, and increase the proportion of patients dying at home.
Study type/design	RCT in patients with CHF, COPD or cancer comparing interdisciplinary home care (n=155) with usual medical care (n=115).
Patient group	Homebound, terminally ill patients (N=298) with a prognosis of approximately 1 year or less to live plus one or more hospital or emergency department visits in the previous 12 months.
Intervention	In-home palliative care plus usual care delivered by an interdisciplinary team providing pain and symptom relief, patient and family education and training, and an array of medical and social support services. Home care + specialist team
Comparator	Usual care consisted of standard care to meet the needs of the patients and followed Medicare guidelines for home healthcare criteria.
Outcome definitions and measurements	Measured outcomes were satisfaction with care, use of medical services, site of death, and costs of care.
Data analyses & statistics	Differences between study group sample characteristics were analysed using two-tailed t tests for continuous variables where the distribution was normal. Chi-square tests were used to determine significant differences between discrete variables.
Study quality	Good A: Y B: N. Assessors were blinded. C: Y. Mean satisfaction was slightly higher in the intervention group compared to usual care. D: N. 8 intervention group members died before receiving any palliative care, and 5 usual care members withdrew from the study, leaving 297available for analysis E: Y F: N
Results	Patient satisfaction: Patients randomised to in-home palliative care reported greater improvement in satisfaction with care at 30 and 90 days after enrollment ($p<0.05$) Place of death: Patients randomised to in-home palliative care were more likely to die at home than those receiving usual care ($p<0.001$). Survival: Results of the Kaplan-Meier survival analysis did not show significant differences in survival time between study groups (log rank test=2.98; $p=0.08$), although subsequent analysis controlled for survival days due to the strong trend toward higher survival in the usual care group and its potential effect on use of medical services and costs of medical care. Utilisation of resources: 20% of palliative care members went to the emergency department, compared with 33% of usual care members ($p=0.01$; Cramer's V=0.15). Similarly, 36% of those receiving palliative care were hospitalised, compared with 59% of those enrolled in usual care ($p<0.001$; Cramer's V=0.23). Cost of care: Significant differences between palliative and usual care members in cost of care ($t= -3.63$, $p<0.001$) were noted. Linear regression showed that overall costs of care for those enrolled in the IHPC program were 33% less than those

	receiving standard care (p=0.03; 95% CI= -$12,411 to -$780; R^2=0.16).
Authors conclusions	In-home palliative care significantly increased patient satisfaction while reducing use of medical services and costs of medical care at the end of life. This study, although modest in scope, presents strong evidence for reforming end-of-care life.

ABBREVIATIONS: CHF, CONGESTIVE HEART FAILURE; COPD, CHRONIC OBSTRUCTIVE PULMONARY DISEASE; IHPC, INTERDISCIPLINARY HOME PALLIATIVE CARE; RCT, RANDOMISED CONTROLLED TRIAL

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	Cummings *et al*., 1990
Level of evidence	II
Country	USA
Research question/aims	To examine the cost-effectiveness of a Veteran's Administration hospital-based home care program that case managed inpatient and outpatient care.
Study type/design	RCT
Patient group	Severely disabled or terminally ill patients admitted to a Veteran's Administration hospital between 1984 and 1987 (n=419).
Intervention	A hospital-based home care program that provides care to patients using an interdisciplinary team directed by a physician. The comprehensive services provided include medical, nursing, social work, physical therapy and dietetic care (n=208). Home care + specialist team
Comparator	Customary care (n=211)
Outcome definitions and measurements	Functional status, satisfaction with care and morale were measured at baseline and at 1 and 6 months after discharge from the hospital. Healthcare utilisation was tracked for 6 months.
Data analyses & statistics	Multivariate analyses of covariance were used to analyse patient and caregiver outcomes.
Study quality	Poor A: Unknown B: Unknown C: Y D: N. Patient attrition from measurement was largely due to death in both groups E: Y F: N
Results	Quality of life: No group differences in Activities of Daily Living function or cognitive status were observed at either the 1- or 6-month post-test were detected. Patient satisfaction: At one month, HBHC recipients reported significantly higher satisfaction with care (0.1 on a three-point scale, p<0.001) than controls. There were no significant differences in satisfaction at the 6-month post-test. Caregiver satisfaction: HBHC caregivers reported significantly lower satisfaction with care at baseline than control group caregivers. At 1 and 6 months, this finding was reversed. Experimental group caregivers were significantly more satisfied with care at both 1 month (0.1 on a three-point scale, p=0.003) and at 6 months (p=0.04). Survival: Mean survival were similar in both groups at 124.6 (SD=91.44) for the HBHC and 128.2 (SD=70.12) for the control group. Utilisation of resources: The total number of Veteran's Administration hospital days did not differ significantly by group. However, patients receiving HBHC spent a greater proportion of their hospital stay on the intermediate care ward (3 days vs. 1.5 days, respectively; p<0.03) and less time on general care wards (8.5 days vs. 12.2 days,

	respectively; p<0.04) than control patients. A significant difference was observed in the use of outpatient care. Overall, patients in the HBHC group had fewer outpatient clinic visits than their control group counterparts (1.33 visits vs. 3.39 visits, respectively; p<0.0001). Cost of care: Total hospital costs were significantly lower (p=0.03) for the HBHC sample. Total hospital cost was $1200 less per person in the HBHC group than the control group, a cost savings of 29% (mean=$3000 vs. $4246, respectively). As a result, the total institutional costs also differed by group (p=0.052). The HBHC program saved $1154 or 26% in total institution costs compared with customary care. The average total cost of private sector health care services for control group subjects was more than double that of patients in the HBHC group ($1683 vs. $680, p=0.004). The cost of home care was 47% higher in the HBHC group than in the control group ($1206 vs. $640, respectively; p<0.0001). Although the average cost of care (institutional and community-based) for an individual receiving HBHC was not significantly lower than controls, it was 13% lower. Thus, the higher cost of home care for HBHC was offset by the savings achieved in institutional care.
Authors conclusions	The authors conclude that the HBHC model of care is cost-effective and that its expansion to cover the two patient groups throughout the Veteran's Administration system can improve patient care at no cost.
Reviewers notes	Analysis includes severely disabled as well as terminally ill patients.

ABBREVIATIONS: HBHC, HINES MODEL OF CARE; RCT, RANDOMISED CONTROLLED TRIAL; SD, STANDARD DEVIATION;

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	Engelhardt *et al.*, 2006
Level of evidence	II
Country	USA
Research question/aims	To evaluate the Advanced Illness Coordinated Care Program (AICCP), delivered by allied health personnel to improve care for patients coping with advanced illness and in need of preparation for end-of-life care.
Study type/design	RCT
Patient group	Patients had chronic obstructive pulmonary disease, chronic heart failure, or cancer diagnoses. Participants were recruited from 3 Department of Veterans Affairs medical centres, a home care organisation, and 2 managed care organisations (n=275).
Intervention	The AICCP delivers care coordination and support through 6 functions: physician support, health literacy, care coordination, prevention of psychosocial concerns, and advance planning (n=133). Home care + team coordination
Comparator	Usual care (n=142)
Outcome definitions and measurements	The AICCP was evaluated for effects on satisfaction with care, advance planning, consistency of care with patient preferences, and healthcare costs.
Data analyses & statistics	To assess the effect of AICCP on satisfaction with healthcare and communication with providers, a random effects regression model was used. Patient satisfaction scores were examined for significant effects of group, time, and group-by-time interaction.

Study quality	Fair A: Yes B: Unknown C: Yes D: N E: Y F: N
Results	Patient satisfaction: The AICCP patients reported significantly greater increases in satisfaction from pretest (mean=3.70, SD=0.74) to posttest (mean=4.07, SD=0.68) than usual care patients, whose pretest mean was 3.83 (SD=0.76) and whose posttest mean was 3.98 (SD=0.67; p=0.03). Effect size of AICCP on patient satisfaction was 0.18. Cost of care: On average, AICCP costs per patient were $12123 vs. $16 295 for usual care a $4172 (25%) difference, with an effect size of 0.18. This represents a statistically nonsignificant trend toward total lower cost from 6 months pre-enrollment to 6 months post-enrollment.
Authors conclusions	The AICCP improved satisfaction with care and helped patients develop and revise more advance directives, sooner, without affecting mortality. This program may be delivered in a range of managed care, fee-for-service, and group-model settings.

ABBREVIATIONS: AICCP, ADVANCED ILLNESS COORDINATED CARE PROGRAM; RCT, RANDOMISED CONTROLLED TRIAL; SD, STANDARD DEVIATION

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	Grande *et al.*, 1999, Grande *et al.*, 2000
Level of evidence	II
Country	UK
Research question/aims	To evaluate the impact of a Cambridge hospital at home service (CHAH) on patients' quality of care, likelihood of remaining at home in their final 2 weeks of life, place of death and general practitioner (GP) visits.
Study type/design	RCT
Patient group	Patients with any diagnosis whose prognosis was two weeks or less, as estimated by clinicians and for respite care for patients with cancer, motor neurone disease, and AIDS. Patients were aged 16 years or above and residents of the former Cambridge health district. (n=299).
Intervention	Hospital at home provides practical home nursing care for up to 24 hours a day for up to two weeks. The service was used mainly for terminal care during the last two weeks of life. The hospital at home team consisted of 6 qualified nurses, two nursing auxiliaries, and a nurse coordinator. Agency nurses were also used as required (n=186). Hospital at home
Comparator	Standard care comprised care in hospital or hospice or care with input from general practice, district nursing, Marie Curie nursing, Macmillan nursing, evening district nursing, social services, a flexible care nursing service or private care (n=43).
Outcome definitions and measurements	Demographic data were collected on referral. Death certification, including place of death, was obtained from the Office for National Statistics (Grande *et al.*, 1999). Perceived symptom control, adequacy of care and patients' ability to remain at home during their final 2 weeks. The impact on general practitioner (GP) workload was also investigated (Grande *et al.*, 2000).

Data analyses & statistics	An intention to treat analysis was undertaken using Pearson χ^2 tests for nominal data, while interval data were analysed by Student's *t* test when normally distributed and Mann-Whitey U tests when skewed. Tests were two tailed with α=0.05.
Study quality	Good A: Y B: N. It was not possible to blind recipients to the fact that the hospital at home service was provided. C: Y D: Y E: Y F: N
Results	Symptoms: Carers were more likely to give patients in the control group high ratings of pain compared with those in the CHAH group (mean 3.00 versus 2.52, Z=1.971, p=0.049). All other comparisons were nonsignificant (P > 0.05) Place of death: While patients who were actually admitted to hospital at home were more likely to die at home than controls (78% vs. 58%), these results do not allow us to conclude that hospital at home enabled more patients to die at home. Intention to treat analysis did not show that the patients allocated to hospital at home were more likely to die at home (67%) than patients allocated to standard care, and it may be that patients who were most suitable for remaining at home were also most likely to receive hospital at home care. The results are therefore inconclusive in terms of causation, but suggestive of an effect associated with receipt of hospital at home. The study attained less statistical power than initially planned. Utilisation of resources: The CHAH group had fewer GP evening home visits (mean 0.17 vs. 0.61) and night visits (mean 0.04 versus 0.26) in the penultimate week of life compared to the control group (Z=2.295, p=0.022 and Z=3.610, p=0.0003, respectively). There was no difference in daytime visits or in night and evening visits in the last week of life (p>0.05)
Authors conclusions	Whilst CHAH was not found to increase the likelihood of remaining at home, it appeared to be associated with better quality home care.
Reviewers notes	Problems with recruitment, attrition, and the vulnerability of the patient group made the conduct of an RCT difficult.

ABBREVIATIONS: CHAH, CAMBRIDGE HOSPITAL AT HOME SERVICE; GP, GENERAL PRACTITIONER; RCT, RANDOMISED CONTROLLED TRIAL

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	Hanks *et al*., 2002
Level of evidence	II
Country	UK
Research question/aims	To assess the effectiveness of a hospital Palliative Care Team (PCT) on physical symptoms and health-related quality of life (HRQoL); patient, family carer and primary care professional reported satisfaction with care; and health service resource use.
Study type/design	RCT
Patient group	Patients were inpatient referrals palliative care needs. Initially only patients with cancer were included, but following a pilot study, all diagnostic groups were admitted, since non-cancer patients represent a significant proportion of the total (10%) (n=261).

Intervention	The full PCT service ('full-PCT') This was the usual service delivered by the PCT, which during the study comprised two clinical academic consultants, one specialist registrar and three clinical nurse specialists (2.5 full-time equivalents). The PCT has close links with a clinical psychologist, a local hospice and community based palliative care services and access to social workers, rehabilitation staff and the chaplaincy in the hospital (n=175). Hospital and home care + PCT
Comparator	A more limited form of intervention was devised as a control. This involved no direct contact between the PCT and the patient or their family. Instead, within one working day of referral, a telephone consultation took place between a senior medical member of the PCT and the referring doctor and also between a PCT nurse specialist and a member of the ward nursing staff directly involved with the patient. A second telephone consultation could be made if necessary but thereafter no further follow-up or advice was given (n=86).
Outcome definitions and measurements	Symptom control and HRQoL were measured by EORTC QLQ-C30 (items 29 and 30); visual analogue scales and the Memorial Pain Assessment Card (MPAC). Hospital stay was measured as the length of index admission and readmissions. Patient satisfaction with hospital care was assessed by four items derived from the MacAdam's Assessment of Suffering Questionnaire. Carers were sent a questionnaire within 3 days of the patient's recruitment which included the FAMCARE scale, the Hospital Anxiety and Depression scale (HADS) and some additional questions about the way in which information and communication issues were handled in hospital. Data on resource use in the hospital setting, by the PCT and in primary care were collected from patient records and questionnaires.
Data analyses & statistics	The randomised groups were compared on an intention to treat basis, including the use of confidence intervals. All analyses therefore included individuals in the group to which they were randomised, regardless of whether they subsequently switched groups. The primary analyses involved regression models comparing the allocated groups in respect of outcomes at follow-up, adjusting for baseline scores as covariates.
Study quality	Good A: Y B: N. The researchers who undertook the assessments were blind to the group allocation. C: Y D: Y E: Y F: N
Results	Patient satisfaction: Patients in both treatment groups expressed high levels of satisfaction with their hospital care and there were no apparent differences between the groups Symptoms: For symptom scores, there was a highly significant improvement in scores for all times in the both groups after one week. However, comparison of the mean scores at 1 week adjusted for baseline scores showed no statistically significant differences between the groups. Carer satisfaction: Carers of patients in both treatment groups expressed high levels of satisfaction with their hospital care and there were no apparent differences between the groups Utilisation of resources: There was very little difference in the length of hospital stay or rates of readmission between the two groups. Hospital resource use (number of diagnostic images, diagnostic tests or visits from other hospital therapists) was very similar in the two groups.
Authors conclusions	These data reflect a high standard of care of patients dying of cancer and other chronic diseases in an acute hospital environment, but do not demonstrate a difference between the two models of service delivery of specialist palliative care.

ABBREVIATIONS: EORTC, EUROPEAN ORGANISATION FOR THE RESEARCH AND TREATMENT OF CANCER; FAMCARE, FAMILY SATISFACTION WITH ADVANCED CANCER CARE; HADS, HOSPITAL ANXIETY AND DEPRESSION SCALE; HRQOL, HEALTH RELATED QUALITY OF LIFE; PCT, PALLIATIVE CARE TEAM; QLQ-C30, QUALITY OF LIFE QUESTIONNAIRE C-30; RCT, RANDOMISED CONTROLLED TRIAL

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	Hughes *et al.*, 2000
Level of evidence	II
Country	USA
Research question/aims	To assess the impact of Team-Managed Home-Based Primary Care (HBPC) on functional status, health-related quality of life (HR-QoL), satisfaction with care, and cost of care.
Study type/design	RCT
Patient group	Hospitalised patients were eligible if they lived within the 25- to 35-mile catchment area served by their hospital's HBPC program and had 2 or more activities of daily living (ADL) impairments or a prognosis of terminal illness. Patients who did not meet the latter 2 criteria, but were homebound with a primary diagnosis of congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD), also were included. Patients referred from outpatient clinics or nursing homes with the same diagnoses were eligible if they had been hospitalised within the past 3 months (n=1966). Note that 79.3% of patients enrolled in this study were not terminally ill. Subgroup analyses by terminal/non-terminal patient subgroup were provided.
Intervention	A Veterans Affairs (VA) Team-Managed Home-Based Primary Care (TM/HBPC) program. Home-based primary care (n=981), including a primary care manager, 24-hour contact for patients, prior approval of hospital readmissions, and HBPC team participation in discharge planning. Physicians were salaried staff who are designated a specific percentage of time to the HBPC program. Other disciplines encompassed by the home care team can include social workers, dieticians, therapists, pharmacists, and health technicians (paraprofessional aides) (n=981). Home care + PCT
Comparator	Patients in the control group could access any Veteran's Administration (VA) sponsored services for which they were eligible with the exception of HBPC, and non-VA post-acute services for which they were eligible, such as Medicare home health or hospice care, and were encouraged to speak with their physicians about aftercare needs (n=985).
Outcome definitions and measurements	Patient functional status, patient and caregiver HRQoL and satisfaction, caregiver burden, hospital readmissions, and costs over 12 months. Patient functional status was assessed using the Barthel Index. Patient and caregiver HRQoLs were assessed using the Medical Outcomes Study, short form, 36-item (MOS SF-36) subscales. Subscale items also were aggregated into a Mental Component Scale (MCS) and a Physical Component Scale (PCS), to compare physical and mental health HRQoL outcomes. Patient and caregiver satisfaction with the patient's care was assessed using selected Ware Satisfaction with Care scales.
Data analyses & statistics	Patients continued in the study for 1 year unless they died, withdrew, or were lost to follow-up. Patient- and caregiver-centred outcome measures were analysed using repeated measures analysis of covariance. Patient and caregivers were included in the analyses if they responded to at least 1 of 3 post-tests.

Study quality	Good A: Y B: Unknown C: Y D: N E: Y F: Y
Results	Quality of life: No difference was observed in functional status (Barthel Index) among terminal or non-terminal patients by treatment group. However, patients in the treatment group improved significantly vs. those in the control group in 6 of 8 HRQoL scales, including emotional role function, social function, bodily pain, mental health, vitality, and general health. Patient satisfaction: There was no difference in patient satisfaction with care among terminal patients during 12 months. However, nonterminal patients in the treatment group reported significant increases of 5 to10 points in 5 of 6 dimensions of satisfaction with care while scores for the control group remained the same or declined slightly. Caregiver satisfaction: Caregivers of terminal patients in the HBPC group showed significant HRQoL improvements ($p<0.05$ overall) compared with the control patients in all but 2 dimensions of the SF-36, the exceptions being vitality and general health. Utilisation of resources: The impact on VA hospital readmissions for all patients by treatment group and by disease stratum shows a 7.9% ($p=0.07$) relative reduction in proportion of TM/HBPC group patients admitted in the first 6 months, with most of the reduction occurring among those with severe disability; however, this reduction was not sustained at 12 months. Similarly, an 11% ($p=0.06$) relative reduction in mean number of TM/HBPC group readmissions was seen at 6 months but was not sustained at 12 months. This relative reduction was 22% ($p=0.03$) in the subset with severe disability. Finally, no significant group differences were seen in number of rehospitalisation days at 6 or 12 months. Cost of care: At 6 months, VA hospital readmission costs for the TM/HBPC group were lower, but home-based care and nursing home care costs were significantly higher than the control group costs (data not shown). Despite significantly lower private sector costs, total TM/HBPC costs were 6.8% higher than the total control group costs. At 12 months HBPC ($p<0.001$) and nursing home ($p=0.02$) costs were significantly higher for the TM/HBPC group than the control group, and only outpatient costs were significantly lower in the TM/HBPC group compared with the control group ($P=.02$). As a result, total VA costs were 18.1% higher in the TM/HBPC group ($P<.001$). This increase was partially offset by a 9% reduction in the TM/HBPC group for private sector or non-VA costs ($p<0.001$). However, total costs of VA and private sector care combined were 12.1% higher for the TM/HBPC group ($P=.005$). This $3000 difference was approximately equal to the cost of the TM/HBPC intervention and amounted to a mean add-on of $282 per client per month.
Authors conclusions	The HBPC intervention improved most HRQoL measures among terminally ill patients. It improved caregiver HRQoL, satisfaction with care, and caregiver burden and reduced hospital readmissions at 6 months, but it did not substitute for other forms of care. The higher costs of HBPC should be weighed against these benefits.

ABBREVIATIONS: ADL, ACTIVITIES OF DAILY LIVING; CHF, CONGESTIVE HEART FAILURE; COPD, CHRONIC OBSTRUCTIVE PULMONARY DISEASE; HBPC, HOME-BASED PALLIATIVE CARE; HRQOL, HEALTH RELATED QUALITY OF LIFE; MCS, MENTAL COMPONENT SCALE; MOS SF-36, MEDICAL OUTCOMES STUDY SHORT FORM-36; PCS, PHYSICAL COMPONENT SCALE; TM/HBPC, TEAM-MANAGED HOME-BASED PRIMARY CARE; VA, VETERANS ADMINISTRATION

[A] THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	Jordhøy *et al.*, 2000, Jordhøy *et al.*, 2001 and Ringdal *et al.*, 2002
Level of evidence	II

Country	Norway
Research question/aims	To examine similarities and differences in satisfaction with care, quality of life and place of death between patients who had participated in an intervention with a comprehensive palliative care program and those in a conventional care program (controls).
Study type/design	RCT
Patient group	Patients with advanced cancer (n=434)
Intervention	The Palliative Medicine Unit has 12 inpatient beds, an outpatient clinic, and a consultant team that works in and out of the hospital, including two palliative-care nurses, a social worker, a priest, a nutritionist, and a part time physiotherapist. During the study, the unit employed three fulltime physicians, of whom one was in charge of the consultant service. The team worked only daytime hours. (n=235). Transmural care + coordination of care, supervision and advice
Comparator	Conventional care (n=199)
Outcome definitions and measurements	Place of death and time spent in institutions in the last month of life (Jordhøy *et al.*, 2000) Quality of life assessed using EORTC QLQ-C30 and Impact of Event scale (IES) (Jordhøy *et al.*, 2001) Family satisfaction as measured by the FAMCARE Scale (Ringdal *et al.*, 2002)
Data analyses & statistics	Since the unit of randomisation was the cluster, and because of possible correlation within clusters, the analysis of outcomes had to reflect the design. The significance of differences between treatment groups was tested by bootstrap estimation to fit regression models, allowing for clustering. All randomised patients were included in the analysis of hospital admissions. As 1 month was considered consistent with an intervention period that was likely to show a clinically significant effect, it was decided to use the HRQoL scores for the first 4 months (assessments) to test our hypotheses. For this period, the area under the curve (AUC) score for each HRQoL scale/item was used as a summary measure to avoid multiple comparisons and to evaluate both early and continuous effects. The AUC is equivalent to the total HRQL experienced by the patient on a given scale/item and also allows for unequal time periods between assessments. To adjust for possible baseline differences, the AUC calculation for each patient was based on changes from baseline. For the patients who withdrew or dropped out before death during the first 4 months, the last value carried forward was used to impute the missing subsequent values. The latter approach might, however, introduce a bias if the main reason for drop-out was deterioration. Hence, the analyses were repeated imputing worse possible scale/item score for the missing ones.
Study quality	Good A: N. Cluster randomised trial. B: Unknown C: At baseline, patients differed for housing, access to informal help, home-care nursing, and, slightly, for living situation. D: All randomised patients were included in the analysis of hospital admissions. For HRQoL scores, patients who withdrew or dropped out were treated using the last observation carried forward (LOCF) method. E: Y F: N
Results	Quality of life: For the AUC estimates, no statistically significant differences between the intervention and control groups were found, neither for psychologic distress, pain, physical and emotional functioning (p=0.1), or for any of the other EORTC QLQ-C30 scores. At later assessments and for scores that were made within 3 months before death, there was also no consistent tendency in favour of any treatment group on the main outcomes or other EORTC QLQ-C30 scales/items.

	Caregiver satisfaction: Respondents related to the patients who had participated in the intervention group reported lowest scores, that is, highest satisfaction with care, on all items except item 6, "availability of a hospital bed," and item 14, "Time required to make a diagnosis." In total, 11 of the 18 negative differences in mean scores were statistically significant at the 0.05 level. Place of death: The time spent at home was not significantly increased, although intervention patients spent a smaller proportion of time in nursing homes in the last month of life than did controls (7·2% vs. 14·6%, p<0·05). Survival: Median survival was 99 days (95% CI 79–119) in the intervention group and 127 days (88–166) in the control group (p=0·1, adjusted for diagnostic groups). 34 (14%) intervention patients and 35 (18%) controls died within 1 month of enrolment. Utilisation of resources: The proportion of time spent in nursing homes was higher for the control group for the entire observation period and in the last month before death. Overall, the proportion of hospital readmission time did not differ for the entire follow-up or for the last month. For the entire follow-up, the intervention and control patients spent a mean of 35% and 37% of time, respectively, in institutions (p=0·6). In the last month of life, the mean percentages were 52% and 59% (p=0·06).
Authors conclusions	The palliative-care intervention enabled more patients to die at home. More resources for care in the home (palliative care training and staff) and an increased focus on use of nursing homes would be necessary, however, to increase time at home and reduce hospital admissions (Jordhøy *et al.*, 2000). A general program of palliative care may be important to ensure flexibility and to meet the needs of terminally ill patients. However, to achieve improvements on a group level of the various dimensions of quality of life, specific interventions directed toward specific symptoms or problems may have to be defined, evaluated, and included in the program (Jordhøy *et al.*, 2001). The respondents related to the patients in the intervention group reported significantly higher satisfaction with care than the respondents related to the patients in the control group (Ringdal *et al.*, 2002).
Reviewers notes	Compared with most RCTs within the area, the study was large, had good compliance and any serious contamination between treatment groups was avoided by cluster randomisation.

ABBREVIATIONS: AUC, AREA UNDER CURVE; EORTC, EUROPEAN ORGANISATION FOR RESEARCH AND TREATMENT OF CANCER; FAMCARE, FAMILY SATISFACTION WITH ADVANCED CANCER CARE; IES, IMPACT OF EVENT SCALE; QUALITY OF LIFE QUESTIONNAIRE-C30; LOCF, LAST OBSERVATION CARRIED FORWARD; QLQ-C30, QUALITY OF LIFE QUESTIONNAIRE-C30; RCT, RANDOMISED CONTROLLED TRIAL

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	SUPPORT (Connors *et al.*, 1995; Desbiens *et al.*, 1996; Baker *et al.*, 2000)
Level of evidence	II
Country	USA
Research question/aims	To examine factors associated with family satisfaction with end-of-life care, and to evaluate the pain experience of seriously ill hospitalised patients and their satisfaction with control of pain in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)
Study type/design	RCT
Patient group	2652 patients were randomised to the intervention group and 2152 patients were randomised to the control group. The paper by Baker *et al.* (2000) presents results for family members and other surrogate respondents for 767 seriously ill hospitalised adults who died.

Intervention	Physicians in the intervention group received estimates of the likelihood of 6-month survival for every day up to 6 months, outcomes of cardiopulmonary resuscitation (CPR) and functional disability at 2 months. A specially trained nurse had multiple contacts with the patient, family, physician and hospital staff to elicit preferences, improve understanding of outcomes, encourage attention to pain control and facilitate advance care planning and patient-physician communication. Hospital care + clinical nurse specialist
Comparator	Usual care
Outcome definitions and measurements	Caregiver satisfaction, timing of do-not-resuscitate order, patient-physician CPR choice, days in aggressive treatment, pain and hospital resource use.
Data analyses & statistics	To limit contamination, patients were assigned to intervention or control status based on the specialty of their attending physician. Observed imbalances in baseline patient characteristics were also adjusted using a propensity score that corrected for selection bias associated with being assigned intervention status.
Study quality	Poor A: N B: N C: Demographics for randomised population were reported; however demographics for subgroup reported by Baker *et al.* (2000) were not. D: Unknown E: Y F: Y
Results	Symptoms: Reported pain increased for the 1677 intervention patients and surrogates interviewed in the second week, compared with the control group (adjusted ratio, 1.14; 95% CI, 1.00 to 1.33) Caregiver satisfaction: Sixteen percent of respondents reported dissatisfaction with patient comfort and 30% reported dissatisfaction with communication and decision-making. Factors found to be significantly associated with satisfaction with communication and decision-making were hospital site, whether death occurred during the index hospitalisation (adjusted odds ratio (AOR) 2.2, 95% CI, 1.3-3.9), and for patients who died following discharge, whether the patient received the SUPPORT intervention (AOR 2.0, 1.2-3.2). Utilisation of resources: There was no difference in hospital resource use between the intervention and control arm (adjusted ratio, 1.05; 95% CI, 0.99 to 1.12).
Authors conclusions	The intervention failed to improve care or patient outcomes. Enhancing opportunities for more patient-physician communication, although advocated as the major method for improving patient outcomes, may be inadequate to change established practices. To improve the experience of seriously ill and dying patients, greater individual and societal commitment and more proactive and forceful measures may be needed. The SUPPORT intervention may have had a positive impact on family satisfaction with end-of-life care. In particular, when deaths occurred after hospital discharge, family members of SUPPORT intervention patients were significantly more satisfied with communication and decision-making than families of control patients.

ABBREVIATIONS: AOR, ADJUSTED ODDS RATIO; CI, CONFIDENCE INTERVAL; CPR, CARDIOPULMONARY RESUSCITATION; SUPPORT, STUDY TO UNDERSTAND PROGNOSES AND PREFERENCES FOR OUTCOMES AND RISKS OF TREATMENTS

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	Gade *et al.*, 2008
Level of evidence	II
Country	USA

Research question/aims	Measure the impact of an interdisciplinary palliative care service (IPCS) on patient satisfaction, clinical outcomes, and cost of care for 6 months post-hospital discharge.
Study type/design	RCT
Patient group	Eligible patients were 18 or more years of age, hospitalised with at least one life-limiting diagnosis, and whose attending physician indicated they "would not be surprised if the patient died within 1 year." (n=517)
Intervention	The IPCS teams included a palliative care physician and nurse, hospital social worker and chaplain. The team met prior to each consultation to share what was known about the patient from the medical record, baseline questionnaire, and hospital providers. The entire team then met with the patient/family to address symptoms, diagnosis, prognosis, and goals of care. Psychosocial and spiritual concerns were identified and advance directive forms were discussed. After the patient/family meeting, the team convened briefly to synthesise a palliative care plan and organise follow-up by team members. IPCS provided consultation on intervention patients to the attending, involved subspecialists and staff on all aspects of palliative care, including treatment recommendations. The team was available Monday through Friday. A palliative care physician was on call after hours (n=280). Home care + specialist team
Comparator	Usual hospital care (UC) (n=237)
Outcome definitions and measurements	The primary study outcomes were symptom control, levels of emotional and spiritual support, patient satisfaction, and total health services costs at 6 months post-index hospitalisation. Secondary measures included survival, number of advance directives (ADs) at discharge, and hospice utilisation within the 6 months post-index hospitalisation (hospitalisation during which study enrollment occurred).
Data analyses & statistics	A p value of 0.05 was significant. Categorical variables were summarised as percentages; continuous variables as means or medians (for skewed data). Continuous measures for IPCS and UC patients were compared using t tests for normally distributed measures and Wilcoxon two-sample tests for measures with skewed distributions. Categorical measures were tested using χ^2 tests or Fisher's exact test. All time to event measures (e.g., survival, days to hospice admission) were analysed using Cox proportional hazard models. Patients with life-limiting illnesses often have physical and cognitive limitations that necessitate the use of proxies, which was the case in this study.
Study quality	Fair A: Y B: Unknown C: There were no differences in any baseline measures between the IPCS and UC groups except for the life-limiting diagnoses of stroke and end-stage renal disease (ESRD) D: Five patients withdrew their consent and were dropped from the study. E: Y F: N
Results	Quality of life: There were no differences between IPCS and UC for mean enrollment and discharge scores for the Physical, Emotional/Relationship, Spiritual Area composite scales or the Quality of Life scale. Patient satisfaction: The IPCS group reported higher mean satisfaction for both the Place of Care Environment scale (IPCS: 6.8; UC: 6.4, p< 001.) and the Doctors, Nurses/Other Health Care Providers Communication scale (IPCS: 8.3; UC: 7.2, p<0.001). Survival: There was no difference in survival between IPCS and UC. Utilisation of resources: Number of days from index hospital admission to study enrollment, days from enrollment to hospital discharge, and hospital length of stay did not differ between the IPCS and UC patients. There was no difference in mean total costs between groups for their index hospitalisation (IPCS: $20,783; UC: $15,841, p=0.08).

	IPCS patients had significantly longer median hospice stays than UC participants (IPCS: 24 days; UC: 12 days, p=0.04). The median days from study enrollment to hospice admission was 1 day shorter for IPCS patients compared to UC patients but the difference was not significant (p=0.14). The percentage of patients admitted to hospice did not differ (p=0.50). Cost of care: Total mean health costs for the IPCS group were lower by $6,766 per patient compared to UC patients (IPCS: $14,486; UC: $21,252, p=0.001). After subtracting the cost of staffing the IPCS ($1,911 per patient), the net savings was $4,855 per patient. Cost savings were largely driven by a significant difference in hospital readmission costs (IPCS: $6,421 per patient versus UC: $13,275 per patient, p= 0.009). There was no difference in the number of hospital readmissions but IPCS patients had significantly fewer ICU stays on readmission (IPCS: 12; UC: 21, p=0.04).
Authors conclusions	IPCS patients reported greater satisfaction with their care experience and providers' communication, had fewer ICU admissions on readmission, and lower total health care costs following hospital discharge.

ABBREVIATIONS:AD, ADVANCE DIRECTIVE; ICU, INTENSIVE CARE UNIT; IPCS, INTERDISCIPLINARY PALLIATIVE CARE SERVICE; RCT, RANDOMISED CONTROLLED TRIAL; UC, USUAL CARE

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	McMillan *et al*., 2007; McMillan *et al*., 2006
Level of evidence	Level II
Country	USA
Research question/aims	To determine whether hospice plus a coping skill training intervention improved family caregivers' QoL, burden, coping, and mastery, compared with hospice plus emotional support, and usual hospice care.
Study type/design	A three group randomised controlled trial was conducted including baseline, 16 day, and 30 day assessments conducted from March 1999 to May 2003.
Patient group	The sample consisted of 354 family caregivers of community dwelling hospice patients with advanced cancer. The population was drawn from consecutive admissions to a large non-profit community-based hospice in the southeastern United States. Caregivers had to be providing care for adult patients with cancer, and both had to consent to participate, have at least a sixth grade education, be able to read and understand English, and achieve a minimum score of seven on the Short Portable Mental Status Questionnaire.
Intervention	Patient/caregiver pairs were randomly divided into three groups, including a control group (n=109) who received standard hospice care, a group (n=109) who received standard hospice care plus three supportive visits from an intervention nurse, and a group (n=111) who received standard care plus three visits to teach a coping skills intervention. Caregivers in the COPE experimental group were taught a problem solving method by the intervention nurse to assist them with assessing and managing patient symptoms. This coping intervention derives from the conceptual and research literature on problem solving training and therapy. Hospice care + nurse or coping skills intervention
Comparator	Caregivers in the control group received hospice standard care and participated in data collection (n=109).

Outcome definitions and measurements	Caregiver QoL was assessed with the Caregiver Quality of Life Index-Cancer (CQoL-C), which is 35 items scored by using a five point Likert-type scale that yields a single QoL score. Burden associated with patient cancer symptoms was assessed with the Memorial Symptom Assessment Scale (MSAS). The instrument includes 24 patient symptoms such as pain, lack of energy, diarrhoea, and shortness of breath. The MSAS was adapted by asking caregivers to rate how distressing patient symptoms were to them (caregivers). General caregiver mastery was assessed by a six-item scale including caregivers' reports of their feelings of control and confidence in caregiving. Caregivers completed the Caregiver Demands Scale (CDS), which has 46 items that assess burden and mastery specific to caregiving tasks including assistance with meals, intimate care, treatments, and supervision of the patient. The impact of the interventions on coping responses was assessed using the Brief COPE, a psycho-educational intervention that has been widely used in stress research. The Brief COPE Scale has 28 items scored by a 5-point Likert-type format.
Data analyses & statistics	ANOVA and chi-squared tests were used to examine differences as a function of treatment group to ensure that the randomisation procedure produced comparable groups. ANOVA and chi-squared tests were also used to determine whether attrition had an impact on sample composition. To examine longitudinal changes in outcomes for the caregivers across three times of measurement (baseline, Day 16, Day 30), random effects regression models were applied to the study data.
Study quality	Good A: Although the sample could not be randomly selected, the dyads were randomly assigned to the three treatment conditions at baseline by using a computerised randomisation procedure by telephone. B: Data collectors were blind to treatment conditions and had contact with intervention staff only at regularly scheduled staff meetings where individual cases were not discussed. C: Y D: Y E: Y F: N
Results	Symptoms: The results of this analysis indicated that the treatment group by time interactions were not statistically significant for the comparison between usual care and support condition for symptom burden. By contrast, for the comparison between the usual care group and the COPE intervention group, the group by time interactions for symptom burden were statistically significant ($p<0.001$). For symptom burden, significant improvements being seen in the COPE intervention group ($p<0.001$) but not for the usual care group. Caregiver satisfaction: The results of this analysis indicated that the treatment group by time interactions were not statistically significant for the comparison between usual care and support condition for caregiver QoL, symptom burden or caregiving task burden. By contrast, for the comparison between the usual care group and the COPE intervention group, the group by time interactions for caregiver QoL ($p= 0.042$), symptom burden ($p<0.001$), and caregiving task burden ($p= 0.04$) were all statistically significant. For caregiver QoL, only the COPE intervention group showed statistically significant improvements in QoL ratings over time ($p=0.033$), whereas the usual care group experienced no significant change over time. Finally, none of the time effects for the usual care or COPE intervention group were statistically significant for the caregiving task burden measure; however, the source of interaction was likely due to the finding that the COPE group improved over time, whereas the usual care group exhibited increased burden scores.
Authors conclusions	The COPE intervention was uniquely effective in improving caregivers' overall QOL and in decreasing burden related to patients' symptoms and caregiving tasks, which are essential goals of hospice and palliative care.

Reviewers notes	The study was only in cancer patients. There was a high rate attrition, however all patients with baseline measurements were included in the final analysis.

ABBREVIATIONS: ANOVA, ANALYSIS OF VARIANCE; CQOL-C, CAREGIVER QUALITY OF LIFE INDEX-CANCER; MSAS, MEMORIAL SYMPTOM ASSESSMENT SCALE; QOL, QUALITY OF LIFE;

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Citation	Bakitas *et al.*, 2009a; Bakitas *et al.*, 2009b
Level of evidence	Level II
Country	USA
Research question/aims	To determine the effect of a nursing-led intervention on quality of life, symptom intensity, mood, and resource use in patients with advanced cancer.
Study type/design	Randomised controlled trial conducted from November 2003 through May 2008 of 322 patients with advanced cancer in a rural, comprehensive cancer centre in New Hampshire and affiliated outreach clinics and a VA medical centre in Vermont.
Patient group	The sample consisted of 354 family caregivers of community dwelling hospice patients with advanced cancer. The population was drawn from consecutive admissions to a large non-profit community-based hospice in the southeastern United States. Caregivers had to be providing care for adult patients with cancer, and both had to consent to participate, have at least a sixth grade education, be able to read and understand English, and achieve a minimum score of seven on the Short Portable Mental Status Questionnaire.
Intervention	Project ENABLE was a phone-based, nurse-led educational, care coordination palliative care intervention model. Intervention services were provided weekly for the first month and then monthly until death, including bereavement follow-up call to the caregiver (n=161). Home care + nurse-led phone intervention
Comparator	Participants assigned to usual care were allowed to use all oncology and supportive services without restrictions including referral to the institutions' interdisciplinary palliative care service (n=161).
Outcome definitions and measurements	Quality of life was measured by the Functional Assessment of Chronic Illness Therapy for Palliative Care. Symptom intensity was measured by the Edmonton Symptom Assessment Scale. Mood was measured by the Centre for Epidemiological Studies Depression Scale. These measures were assessed at baseline, 1 month, and every 3 months until death or study completion. Intensity of service was measured as the number of days in the hospital and in the intensive care unit (ICU) and the number of emergency department visits recorded in the electronic medical record.
Data analyses & statistics	For quality of life, symptom intensity, and mood, 2 sets of longitudinal, intention to treat (ITT) analyses were undertaken for all participants with baseline and 1 or more follow-up assessments using repeated measures analysis of covariance to examine the effect of the intervention on (i) the total sample in the year after enrollment and (ii) the sample of participants who died. Mean, median, and maximum values were calculated for chart review data on number of days in the hospital, number of days in the ICU, and number of emergency department visits at baseline and the sums of the total days and visits over the length of enrollment. Groups were compared using the Wilcoxon rank sum test.

Study quality	Good A: Patients and their caregiver were randomly assigned to the intervention or usual care using a stratified randomisation scheme developed for each of the 2 primary sites. B: Referring clinicians were neither informed nor formally blinded to participant assignment. C: In a baseline covariate analysis, it was found that treatment and the baseline outcomes were statistically significant predictors. These were included as adjusting variables in the analyses to meet the conditions for missing at random. D: The ITT population was used in the longitudinal and survival analysis E: Y F: Longitudinal analyses were undertaken for the subset of participants who died during the study.
Results	Quality of life: Longitudinal ITT analyses for the total sample revealed higher quality of life (mean p=0.02) (Functional Assessment of Chronic Illness Therapy for Palliative Care scores) in the intervention group compared with the usual care group. Symptoms: There was a trend toward lower symptom intensity (p=0.06) (ESAS scores) in the intervention group compared with the usual care group. Survival: Post hoc, exploratory analyses demonstrated no statistically significant differences in survival between the 2 groups. Utilisation of resources: There were no statistically significant differences between groups in the number of days in the hospital (6.6 vs. 6.5, respectively; p=0.14), number of days in the ICU (0.06 vs. 0.06; p=0.99), or in the number of emergency department visits (0.86 vs. 0.63; p=0.53).
Authors conclusions	Compared with participants receiving usual oncology care, those receiving a nurse-led, palliative care–focused intervention addressing physical, psychosocial, and care coordination provided concurrently with oncology care had higher scores for quality of life and mood, but did not have improvements in symptom intensity scores or reduced days in the hospital or ICU or emergency department visits.
Reviewers notes	The intervention was primarily conducted by telephone. It is possible that a more robust effect, particularly in reducing symptom intensity, may have been seen with in-person interactions

ABBREVIATIONS: ESAS, EDMONTON SYMPTOM ASSESSMENT SYSTEM; ICU, INTENSIVE CARE UNIT; ITT, INTENTION TO TREAT; VA, VETERANS ADMINISTRATION

THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Level III-1 studies

Citation	Costantini *et al*., 2003
Level of evidence	Level III-1 (Intervention)
Country	Italy
Research question/aims	To determine if, in patients with advanced cancer, a palliative home care team (PHCT) modified hospital utilisation in the last six months before death.
Study type/design	Quasi-randomised experimental study
Patient group	Referral criteria to the PHCT included a diagnosis of advanced terminal cancer requiring palliative care, age at least 18 years, and family and patient consent to be followed at home by the PHCT (n=2503).
Intervention	The PHCT is a free service comprising 12 physicians, seven registered nurses, three psychologists and 25 volunteers (n=189). Home care + palliative care team
Comparator	Patients not followed by the PHCT received usual care from hospitals, their general practitioners and other health services (n=378 matched for primary tumour).
Outcome definitions and measurements	The outcome measure was the number of days spent in hospital in the last 180 days before death, both before and after PHCT admission.
Data analyses & statistics	Characteristics of cases and controls were compared using the chi-squared test for heterogeneity for categorical variables (gender, education, marital status and place of birth), and nonparametric statistics for linear variables (age, time from first diagnosis and time from diagnosis of advanced metastatic disease). The outcome (days in hospital) was calculated separately for before and after PHCT referral, and for cases and controls.
Study quality	Fair A: N B: N C: There were no significant differences between PHCT users (cases) and controls for age, gender, marital status and diagnosis. However, PHCT users had a lower level of education compared with controls. Median time between first diagnosis and death was significantly longer for PHCT users (381 days) compared with controls (273 days). The interval between the date of first diagnosis of advanced or metastatic disease and death was also significantly longer for PHCT users (231 days) as compared with non-users (142 days). D: Y E: Y F: N
Results	Utilisation of resources: After admission to the PHCT, the percentage of days in hospital increased for both cases and controls. The percentage was significantly higher in the control group (30.3%; 95% CI: 26-34) than in cases (19.0%; 95% CI: 15-23). This corresponds to a relative reduction of 37%, and an absolute reduction of 11%, of days spent in hospital.
Authors conclusions	A PHCT appears to reduce days in hospital and allows patients to spend more time at home. The differences in time in care between groups require further investigations.
Reviewers notes	For the purpose of this study, type and quality of care provided by both the hospitals and the PHCT were not addressed, and it was assumed to be at least comparable between the two settings of care.

ABBREVIATIONS: CI, CONFIDENCE INTERVAL; PHCT, PALLIATIVE HOME CARE TEAM;

[A] THE QUALITY OF RCTS WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) WAS ALLOCATION TO TREATMENT GROUPS CONCEALED FROM THOSE RESPONSIBLE FOR RECRUITING SUBJECTS?; (B) WAS THE STUDY DOUBLE-BLINDED; (C) WERE PATIENT CHARACTERISTICS AND DEMOGRAPHICS SIMILAR BETWEEN TREATMENT ARMS AT BASELINE; (D) WERE ALL RANDOMISED PATIENTS INCLUDED IN THE ANALYSIS?; (E) WERE THE STATISTICAL METHODS APPROPRIATE?; (F) WERE ANY SUBGROUP ANALYSES CARRIED OUT?

Level III-2 studies

Citation	Goodwin *et al*., 2002
Level of evidence	Level III-2 (Intervention)
Country	UK
Research question/aims	To evaluate the effectiveness of palliative day care in improving pain, symptom control, and quality of life (QOL)
Study type/design	Prospective comparative study in a group of new referrals attending five centres.
Patient group	The day care patients were consecutive new referrals to five palliative day care centres. Comparison patients were identified from the home care nursing teams within each of the five palliative care services. Eligibility criteria for both groups of patients were: over 18 years of age, well enough to be interviewed (for approximately 35–45 minutes), and no obvious confusion/not severely cognitively impaired.
Intervention	Five palliative day care centres in the UK provided facilities for medical and nursing assessment of all patients. At each centre, there was a variety of social, recreational, and therapeutic activities. The centres often employed specialists, such as art therapists and aromatherapists. All patients received the usual palliative care services (home care, inpatient services, and outpatient services), but the comparison group did not attend day care (n=120). Palliative day care
Comparator	All patients received the usual palliative care services (home care, inpatient services, and outpatient services), but the comparison group did not attend day care (n=53).
Outcome definitions and measurements	Patients were assessed at 3 interviews (baseline, 6–8 weeks, and 12–15 weeks) using measures of health-related quality of life: McGill Quality of Life Questionnaire (MQOL) and Palliative Care Outcome Scale (POS).
Data analyses & statistics	There were two main analyses: 1) patient demographic data were analysed using chi-square and 2) QOL data were compared, based on distribution of scores, using the Mann-Whitney test (MQOL and POS), and Wilcoxon Signed Rank for within group differences (POS data only); $p<0.05$ was taken as significant.
Study quality	Fair A: The baseline characteristics of the day care group and the comparison group were similar, except that the day care group was on average slightly younger, and patients in the comparison group were more likely to be retired or unable to work. B: Unknown C: Y D: An issue that was raised in the design of the study was the inability to interview the day care patients before they attended day care, which would have provided baseline data before the intervention.
Results	Quality of life: For the MQOL, there were no statistically significant differences between the groups, except for a non-significant difference at baseline in the support domain (p=0.065). There was a marginally significant baseline difference for the POS item 'pain control' (p=0.053), where the comparison group had more severe/overwhelming scores. The comparison group were also significantly worse at the second interview for the POS item 'symptom control' (p=0.025). At final interview, there was a statistically significant difference in the POS item 'practical matters addressed' (p=0.026), where the day care group had more severe/overwhelming scores. However, this was based on five outliers in the comparison group and when the outliers were removed the results were non-significant.
Authors conclusions	Palliative day care was not found to improve overall health-related quality of life. The limitations of the QOL measures in identifying the effects (patient outcomes) of palliative day care and the differences between the two patient groups (age, employment, unequal sample sizes) were limitations of the study and indicate the need for further research in this area.

Reviewers notes	Recruitment has also been highlighted as a problem in evaluation of palliative care services. In this study, the comparison group was a difficult group to identify and recruit. An ideal control patient was identified as one who wanted to attend day care but was unable (e.g., poor mobility, infected with resistant organism).

ABBREVIATIONS: MQOL, MCGILL QUALITY OF LIFE QUESTIONNAIRE; POS, PALLIATIVE CARE OUTCOME SCALE; QOL, QUALITY OF LIFE

THE QUALITY OF OTHER STUDIES WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) HAS SELECTION BIAS BEEN MINIMISED?; (B) HAVE ADEQUATE ADJUSTMENTS BEEN MADE FOR RESIDUAL CONFOUNDING?; (C) WAS FOLLOW-UP FOR FINAL OUTCOMES ADEQUATE?; (D) HAS MEASUREMENT OR MISCLASSIFICATION BIAS BEEN MINIMISED?

Citation	Hanson *et al*., 2008
Level of evidence	Level III-2 (Intervention)
Country	USA
Research question/aims	To describe the impact of palliative care consultation on symptoms, treatment, and hospital costs.
Study type/design	A prospective observational study of an interdisciplinary palliative care consultation service in one tertiary academic medical centre.
Patient group	The study sample consisted of seriously ill hospitalised patients referred to the palliative care team between July 1, 2002 and June 30, 2005 who provided direct or surrogate consent for enrollment in the research database. The study sample for financial analysis was a one year subset of palliative care cases with hospital LOS greater than four days who could be matched to controls.
Intervention	Enrolled palliative care patients received inpatient consultation from an interdisciplinary team consisting of an advance practice nurse and a physician, each with added training and certification in palliative care. Both lead consultants saw the patient daily until death or discharge; unit-based social workers and chaplains were included in consultation at the discretion of the advance practice nurse (n=104). Inpatient consultation with interdisciplinary team
Comparator	To test impact on costs, a one-year subset of cases with lengths of stay >4 days (n = 104) was compared to all available controls (n = 1,813) matched on the 3M All Patients Refined Diagnosis Related Group, Version 20, and mortality risk scores.
Outcome definitions and measurements	Only cost outcomes are eligible (due to presence of a control group).
Data analyses & statistics	To determine if palliative care is associated with reduced costs, palliative care cases in 2004 who had a hospital LOS greater than four days were matched to controls with the same APR-DRG and mortality risk score rating. Direct costs per hospital day for cases were compared to the average direct costs for all matched controls for each case. To test whether a higher ‘‘dose’’ of palliative care consultation had a greater effect in terms of cost-savings, the cost comparisons were repeated for subsets of cases with increasing duration of palliative care consultation. Cost differences for cases who received palliative care consultation for 25% or 50% or more of their hospital stay were examined.
Study quality	Good A: The generalisability of the findings is strengthened by the inclusion of all consecutive palliative care patients, rather than restricting analysis to ICU transfers or patients who die in hospital. B: Matched controls were used to adjust for other patient characteristics, such as age, diagnosis, and mortality risk. C: Y D: Y

Results	Cost of care: Compared to controls, palliative care cases had no significant difference in variable costs across their entire hospitalisation ($16,748 vs. $15,926, P ¼ 0.78). Palliative cases and controls also did not differ significantly in total LOS (16.6 vs. 13.8 days, p=0.11), or ICU days (2.4 vs. 3.4 days, p=0.35). When daily costs were examined across the entire hospitalisation, as a measure of intensity of medical resource use, palliative care cases had significantly lower variable cost per day ($897 vs. $1004, p=0.03). There was a greater relative cost savings effect when palliative care intervention affected a higher proportion of total hospital days, as the cost reduction was 10.7% for all palliative care cases and 20.5% for those with >50% hospital days with palliative care consultation.
Authors conclusions	Palliative care consultation is followed by decisions to forego costly treatment and improved symptom scores, and earlier palliative care intervention results in greater cost-savings.
Reviewers notes	In the controlled analysis of cost data, palliative care patients and controls may still differ in ways that are not adjusted for by matching on APR-DRG and mortality risk subclass score. Matching is an effective analytic method to balance potential measured confounders between two comparison groups. Unmeasured differences, such as the willingness to accept fewer life-sustaining treatments, may still account for differences between patients receiving palliative care consultation and those who do not.

ABBREVIATIONS: APR-DRG, ALL PATIENT REFINED DIAGNOSIS GROUPS; ICU, INTENSIVE CARE UNIT; LOS, LENGTH OF STAY;

THE QUALITY OF OTHER STUDIES WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) HAS SELECTION BIAS BEEN MINIMISED?; (B) HAVE ADEQUATE ADJUSTMENTS BEEN MADE FOR RESIDUAL CONFOUNDING?; (C) WAS FOLLOW-UP FOR FINAL OUTCOMES ADEQUATE?; (D) HAS MEASUREMENT OR MISCLASSIFICATION BIAS BEEN MINIMISED?

Citation	Brumley *et al.*, 2003
Level of evidence	Level III-2 (Intervention)
Country	USA
Research question/aims	To evaluate the effectiveness of the Kaiser Permanente (KP) TriCentral Palliative Care (TCPC) Program.
Study type/design	Non-randomised experimental trial (n=588)
Patient group	Patients with a diagnosis of COPD, CHF, or cancer; two or more emergency department visits or hospital admissions in the past year; and limited life expectancy.
Intervention	The TCPC Program is an interdisciplinary, home-based program for patients at the end of life. The program offers these patients enhanced pain control, symptom management, and psychosocial support to improve quality of life and care while reducing the overall cost of care. The TCPC Program provides gradual transition for patients with a 12-month survival prognosis and thus allows them to retain their primary care physician while receiving home visits from the palliative care team and physician (n=210). Home care + palliative care team
Comparator	Usual care (KP home health patient) (n=348)
Outcome definitions and measurements	Data collected from the interviews included demographic data as well as patients' rating of their illness severity, quality of life, and satisfaction with services. The Reid-Gundlach Satisfaction with Services instrument was used to measure patient satisfaction with services. The patient satisfaction survey yielded overall ratings for three categories: satisfaction with services, perception of service providers, and likelihood of recommending services to others in the future. Service utilisation data were collected from KP administrative databases. The cost effectiveness of the TCPC model was evaluated using staff costs only.

Data analyses & statistics	Statistically significant between group differences in number of days of service and illness severity were controlled as covariates when service use data were analysed. Multivariate analysis of covariance (MANCOVA) also controlled for Type I error associated with multiple tests. Post hoc Student t-tests were conducted on each dependent variable to determine group differences for each variable. Multiple regression was conducted to determine the portion of costs explained by study group, controlling for days of service, severity of illness, and diagnosis of CHF.
Study quality	Fair A: N B: Y C: Unknown D: Y
Results	Patient satisfaction: No statistically significant difference in mean satisfaction scores was seen between intervention and comparison groups at baseline, although satisfaction at baseline was high for both groups. However, at 60 days after enrollment, the satisfaction score for the intervention group increased significantly from baseline ($p = .01$), whereas scores for the comparison group remained unchanged. Resource use: The intervention group had fewer emergency department visits, inpatient days, skilled nursing days, and physician office visits than did the comparison group, although the intervention group had more home care visits than did the comparison group. Cost of care: For the TCPC group, per-patient cost reduction was seen across diagnoses (range $3514 to $8293) but was significant for patients who had cancer ($p = .001$) or COPD ($p = .02$). Per-patient costs for the intervention group averaged $6580 less than for the comparison group, a significant reduction of 45% ($p <0. 001$).
Authors conclusions	The results of this study indicate that enrollment in the TCPC palliative care model produced lower costs of care as well as higher patient satisfaction than did enrollment in usual health care services. These findings remained highly significant even after the data were controlled for days of service, severity of illness, and having a CHF diagnosis.
Reviewers notes	Because the cost-effectiveness calculation did not include fixed costs (such as building maintenance), which are higher for acute care services compared with home-based services, the cost reduction results are conservative.

ABBREVIATIONS: CHF, CONGESTIVE HEART FAILURE; COPD, CHRONIC OBSTRUCTIVE PULMONARY DISEASE; KP, KAISER PERMANENTE; MANCOVA, MULTIVARIATE ANALYSIS OF COVARIANCE; TCPC, TRICENTRAL PALLIATIVE CARE

THE QUALITY OF OTHER STUDIES WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) HAS SELECTION BIAS BEEN MINIMISED?; (B) HAVE ADEQUATE ADJUSTMENTS BEEN MADE FOR RESIDUAL CONFOUNDING?; (C) WAS FOLLOW-UP FOR FINAL OUTCOMES ADEQUATE?; (D) HAS MEASUREMENT OR MISCLASSIFICATION BIAS BEEN MINIMISED?

Citation	Casarett *et al*., 2008
Level of evidence	Level III-2 (Intervention)
Country	USA
Research question/aims	To determine whether inpatient palliative consultation services improve outcomes of care.
Study type/design	Retrospective telephone surveys conducted with family members of veterans who received inpatient or outpatient care from a Department of Veterans Affairs (VA) medical facility in the last month of life.
Patient group	Veterans had received inpatient or outpatient care from a participating VA in the last month of life. One family member completed each survey.

Intervention	This project was conducted in five VA Medical Centers and their affiliated nursing homes and clinics. The sites range in size from 114 to 980 beds and have between 2,850 and 7,050 admissions (acute care plus long-term care) per year. These teams rely primarily on physicians, nurse practitioners, or both, who contribute between 1.0 and 2.5 full time equivalents to the consultation service. They also include nurses, social workers, chaplains, volunteers, and other disciplines on an as-needed basis (e.g., physical therapists, occupational therapists, and psychologists) (n=296). Inpatient palliative consultations
Comparator	Usual care (no inpatient palliative consultation) (n=228)
Outcome definitions and measurements	Interviews used the Family Assessment of Treatment at End-of-life (FATE) survey. The telephone survey assessed nine aspects of the care the patient received in his or her last month of life: the patient's well-being and dignity (4 items), adequacy of communication (5 items), respect for treatment preferences (2 items), emotional and spiritual support (3 items), management of symptoms (4 items), access to the inpatient facility of choice (1 item), care around the time of death (6 items), access to home care services (4 items), and access to benefits and services after the patient's death (3 items).
Data analyses & statistics	A propensity score was created to account for non-random assignment between the two groups. Predictors with a p value <0.25 were considered for inclusion in a multivariate model. The final model was applied to each patient in the sample, calculating his or her propensity score. A linear regression model was then developed to examine the effect of palliative consultations on the FATE score (all 32 items), after adjusting for the propensity score and additional patient characteristics that were associated with the FATE score.
Study quality	Fair A: No. There were some differences between patients at baseline, including the proportion of patients with a previous hospitalisation (higher in those receiving the intervention), the proportion of patients with cancer (higher in the intervention group) and the proportion of patients experiencing pain and/or confusion (higher in the intervention group) B: Y C: Y D: N
Results	Symptoms: In ordinal logistic regression models, adjusting for propensity score, age, and ethnicity, patients who received a consultation had better scores for pain (adjusted mean 2.15 vs. 1.88; p=0.04) and symptoms related to posttraumatic stress disorder (adjusted mean 1.92 vs. 0.77; p=0.02). There was no difference for confusion (adjusted mean 0.56 vs 0.16; P5.17) or dyspnea (adjusted mean 1.03 vs. 0.87; p=0.40)
Authors conclusions	Palliative consultations improve outcomes of care, and earlier consultations may confer additional benefit.
Reviewers notes	This study has two main limitations that should be noted. First, it was conducted in a VA population, whose demographic characteristics are atypical of the larger U.S. population. Second, this study relied on families' perceptions of care rather than on direct assessments of patients' perceptions. However, retrospective surveys of family members have several important advantages over patient assessments. For instance, retrospective surveys can assess the care of patients whose prognosis is uncertain and who therefore might not be prospectively identified as ''terminally ill.'' They also make it possible to examine the care of patients who are unable to respond to surveys or questionnaires.

ABBREVIATIONS: FATE, FAMILY ASSESSMENT OF TREATMENT AT END-OF-LIFE; VA, VETERANS AFFAIRS

THE QUALITY OF OTHER STUDIES WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) HAS SELECTION BIAS BEEN MINIMISED?; (B) HAVE ADEQUATE ADJUSTMENTS BEEN MADE FOR RESIDUAL CONFOUNDING?; (C) WAS FOLLOW-UP FOR FINAL OUTCOMES ADEQUATE?; (D) HAS MEASUREMENT OR MISCLASSIFICATION BIAS BEEN MINIMISED

Citation	Dudgeon *et al.*, 2008, Dudgeon *et al.*, 2009
Level of evidence	Level III-2 (Intervention)

Country	Canada
Research question/aims	To evaluate the effectiveness of implementation of the Palliative Care Integration Project (PCIP), which uses common assessment tools, collaborative care plans, and symptom management guidelines for cancer patients as a strategy to improve the quality, coordination, and integration of palliative care across organisations and health care sectors.
Study type/design	A pre-post design to measure the impact on symptom management, caregiver burden and satisfaction with care delivery, and service utilisation was used.
Patient group	Cancer patients in the palliative phase of their illness, and their carers
Intervention	The PCIP includes the development of evidence-based collaborative care plans (CCPs), the development of evidence-based Symptom Management/Medical guidelines, the use of common, validated assessment tools, and application of the CCPs, medical guidelines and assessment tools in the different care settings in the region. Study includes 513 patients in 2001 increasing to 579 patients in 2003. Integration project
Comparator	Pre-post design
Outcome definitions and measurements	Two cohorts of eligible patients and caregivers completed Edmonton Symptom Assessment Scales (ESAS), Caregiver Reaction Assessment (CRA) and FAMCARE Scales. Chart audits were also conducted.
Data analyses & statistics	The analyses for the entire patient caregiver-related data began by examining the sources for data quality and accuracy. Distributions of the continuous variables from patient and caregiver interviews were also examined for normality using visual examination of data (e.g., scatter plots). Outliers, extreme, and influential values were noted. Univariate analysis of all the data provided description demographic statistics, for example, frequency distribution, percentages, mean, median. The results from the ESAS, FAMCARE, and CRA were analysed for mean, standard deviation, and median statistics.
Study quality	Poor A: N B: N C: Unknown D: N
Results	Symptoms: Audits of 53 charts pre-implementation and 63 post-implementation showed an increase in documentation of pain from 24.5% to 74.6% ($p<0.001$) of charts. There was minimal change in the intensity of symptoms ($p=0.591$) Caregiver satisfaction: There was no change in the burden on the caregiver ($p=0.086$) or caregiver satisfaction with care ($p=0.942$) Place of death: Administrative data showed a decrease in the percentage of deaths in acute care from 43.1% to 35.7% ($p=0.133$). Utilisation of resources: Administrative data showed a decrease in the percentage of patients with at least one emergency room visit from 94.3% to 84.8% ($p<0.001$) and in the percentage of patients with at least one admission to the acute care hospital ($p<0.001$).
Authors conclusions	This study showed that implementation of common assessment tools, collaborative care plans, and symptom management guidelines across health sectors can result in some increased documentation of symptoms and efficiencies in care. Future projects should consider imbedding a continuous quality improvement

Reviewers notes	One of the limitations of this study is its pre-post implementation design. It is impossible to control for the many factors that change over a one-year period in the health care system. In 2002, one of the nursing agencies that provided home palliative care was closed. In 2003, SARS greatly affected the health care system and no doubt had some influence on ED visits and admissions to the hospital. It is interesting, however, to note that hospital length of stay for all cancer patients in this whole region increased during the same time period.

ABBREVIATIONS: CCP, COLLABORATIVE CARE PLAN; CRA, CAREGIVER REACTION ASSESSMENT; ED, EMERGENCY DEPARTMENT; ESAS, EDMONTON SYMPTOM ASSESSMENT SCALES; FAMCARE, FAMILY SATISFACTION WITH ADVANCED CANCER CARE; PCIP, PALLIATIVE CARE INTEGRATION PROJECT; SARS, SEVERE ACUTE RESPIRATORY SYNDROME

THE QUALITY OF OTHER STUDIES WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) HAS SELECTION BIAS BEEN MINIMISED?; (B) HAVE ADEQUATE ADJUSTMENTS BEEN MADE FOR RESIDUAL CONFOUNDING?; (C) WAS FOLLOW-UP FOR FINAL OUTCOMES ADEQUATE?; (D) HAS MEASUREMENT OR MISCLASSIFICATION BIAS BEEN MINIMISED?

Citation	Aristides and Shiell, 1993
Level of evidence	Level III-2 (Intervention)
Country	Australia
Research question/aims	To perform an economic evaluation of a domiciliary palliative care nursing service operating in NSW.
Study type/design	A pre-post study design was used to determine hospital use (inpatient days) and cost during the patients' last 90 days of life, before and after the introduction of the program.
Patient group	Terminally ill patients (n=123)
Intervention	The continuing community cancer care (4C) program provided after-hours and weekend nursing care in Western Sydney and Wentworth Area Health Services of NSW. The program also funded a day centre, additional home care services and two new medical officer positions. The main objective of the program was to maintain terminally ill patients at home, increasing the quality of life for both patient and carer. Home care + palliative care nursing service
Comparator	Pre-post design
Outcome definitions and measurements	The use of hospital bed-days and hospital costs incurred by patients during the last 90 days of their life was compared before and after the introduction of 4C.
Data analyses & statistics	Various statistical tests were performed to assess the likelihood that any changes observed after the introduction of 4C were the result of the program and were not likely to have arisen by chance. Analysis was by intention to treat, so that patients in the 4C group who did not receive 4C services were included in the statistical analysis. A chi-squared test was used to test for differences in the proportion of patients who were admitted to hospital before and after 4C. The distribution of the length of stay data for patients who were admitted was highly skewed so a non-parametric test was used to test for differences in inpatient days and costs. A one-tailed test was used in the comparison of inpatient days because the introduction of 4C was not expected to increase lengths of stay.
Study quality	Fair A: N B: Various statistical tests were performed to assess the likelihood that any changes observed after the introduction of 4C were the result of the program and were not likely to have arisen by chance. C: Unknown D: Y. Most outcomes were objective measures of resource use.

Results	Utilisation of resources: A higher proportion of patients were admitted at least once before the introduction of 4C than afterwards but the difference is not statistically significant at conventional levels. There was a shift in admissions away from the tertiary centre to non-tertiary hospitals. The average number of days spent in hospital by a patient once he or she had been admitted fell slightly following the introduction of 4C from 23.8 days to 22.9 days. The difference is not statistically significant, indicating that 4C was not successful in reducing length-of-stay once a patient had been admitted to hospital. Cost of care: The 4C program reduced average hospital costs per patient by $300, but the difference in cost before and after the introduction of 4C is not statistically significant. Over 550 patients registered with 4C during the 1991-1992 financial year and so the annual expenditure of the program translates into an approximate average cost per patient referred to the after-hours nursing service of $1000. The net average cost of the 4C program is therefore approximately $700 per patient.
Authors conclusions	There was no statistically significant difference in hospital use and cost during patients' last 90 days of life, before and after introduction of the program. There were therefore no savings to offset the operating costs of the program. However, future savings might be achieved if after-hours access to painkilling drugs is improved.
Reviewers notes	Unavoidable limitations in study design have introduced bias into the analysis. The main factors to consider are selection bias, long-term trends in length of stay, and the use of resources provided by hospitals other than those studied in this paper.

THE QUALITY OF OTHER STUDIES WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) HAS SELECTION BIAS BEEN MINIMISED?; (B) HAVE ADEQUATE ADJUSTMENTS BEEN MADE FOR RESIDUAL CONFOUNDING?; (C) WAS FOLLOW-UP FOR FINAL OUTCOMES ADEQUATE?; (D) HAS MEASUREMENT OR MISCLASSIFICATION BIAS BEEN MINIMISED?

Citation	Edmonds *et al*., 1998
Level of evidence	Level III-2 (Intervention)
Country	UK
Research question/aims	This study reports on use of an expanded STAS (E-STAS) to determine symptom prevalence and outcome for inpatients and outpatients referred to a multi-professional hospital palliative care team (PCT).
Study type/design	Pre-post prospective assessment of E-STAS scores before and after the introduction of a Palliative Care Team intervention.
Patient group	All new patients referred to the PCT between August 1996 and May 1997 (n=352).
Intervention	The PCT was established in 1992, and consists of two full time clinical nurse specialists and two part-time doctors (a consultant for two sessions and a senior registrar for five sessions), who work in an advisory capacity.
Comparator	Pre-post design
Outcome definitions and measurements	The E-STAS is an extended version of the STAS, designed to evaluate interventions for the control of physical and psychological symptoms.
Data analyses & statistics	Data from the first and last clinical assessment were analysed. Comparative data were only used for those patients who completed more than three clinical assessments. Mean E-STAS scores were compiled for each symptom in those patients with an E-STAS score of greater than or equal to one (≥1) on the first clinical assessment, and compared with the mean score for each symptom in the same patients on the last assessment. The two-tailed paired t-test was employed for comparison of the two sets of data. A p value of less than 0.05 was taken as significant.
Study quality	Poor A: All new patients to the PCT were included in the study population B: N C: Only patients who completed three or more assessments were included in the comparative analysis D: Unknown

Results	Symptoms: The change in mean E-STAS scores for each symptom in the 122 patients with a score ≥1 on first assessment and who completed three or more E-STAS forms showed that the PCT intervention resulted in statistically significant improvements in the mean E-STAS score for all symptoms except depression. These symptoms include pain, mouth discomfort, anorexia, nausea, vomiting, constipation, breathlessness and psychological distress.
Authors conclusions	This study suggests that use of the reduced E-STAS may help to document the prevalence of symptoms in patients referred to a hospital PCT, and that input from the team may improve symptom control in hospital inpatients.
Reviewers notes	Before and after assessments were carried out in a single population. In addition, results were not compared with other settings. It is unclear if variables (other than PCT intervention) would have affected results over time. The exclusion of patients with less than three assessments could bias the results.

ABBREVIATIONS: E-STAS, EXPANDED SUPPORT TEAM ASSESSMENT SCHEDULE; PCT, PALLIATIVE CARE TEAM; STAS, SUPPORT TEAM ASSESSMENT SCHEDULE

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Citation	Higginson and Hearn, 1997
Level of evidence	Level III-2 (Intervention)
Country	UK
Research question/aims	To report the prevalence of cancer pain, its effect on advanced cancer patients and the effectiveness of specialist home-care services in controlling pain.
Study type/design	Pre-post prospective study with repeated measurements and no control group.
Patient group	Terminal cancer patients (n=695)
Intervention	Multidisciplinary palliative care teams (PCTs) of hospital and home care organisations in Ireland and England. Two projects were involved: palliative care evaluation project (PEP) included five teams in the southeast of England, and the Irish Cancer Society (ICS) project included six teams in Ireland. Community and hospital based teams could be included; teams were representative of the type of service available. All teams worked with existing services and followed the philosophy of the hospice movement and palliative care. Team members visited and advised on inpatients. The original hospital consultant remained in charge of inpatient care. Hospital and home care + multidisciplinary palliative care teams
Comparator	Pre-post design
Outcome definitions and measurements	The Karnofsky Performance Index (KPI) was used as an indicator of functional status and was recorded for each patient at referral and weekly thereafter by the key team worker. Pain was recorded using body charts; its severity was rated at referral and then weekly using one item of a standardised validated measure: the Support Team Assessment Schedule (STAS). Severity is rated according to the effect of pain on the patient. Data were recorded by all teams for a minimum 6-month period.
Data analyses & statistics	The severity of pain was calculated for patients at referral and after 2 weeks of care, and Wilcoxon's signed rank test was used to test for significant changes in score. A probability of less than 0.05 was taken as significant, using two-tailed tests. The presence of pain was compared with physical functioning at referral, place of care at referral and the time spent in care before death using the chi-squared test for association.
Study quality	Fair A: Includes all patients referred to PCTs. B: The presence of pain was compared with physical functioning at referral, place of care at referral and the time spent in care before death using the chi-squared test for association. C: Unknown D: Unknown

Results	Symptoms: After two weeks of care by the services, there was a significant reduction in the levels of pain (Wilcoxon signed-rank test, Z = -7.19; p<0.0001), and no patients experienced overwhelming pain. Presence of pain and severity were not associated with the Karnofsky score, or with the time in care before death or with place of care at referral.
Authors conclusions	These data emphasise that pain prevalence in advanced cancer patients cared for in the community is as high as that observed in other settings. Multidisciplinary palliative care teams are shown here to be effective in alleviating pain.
Reviewers notes	Before and after assessments were carried out in a single population. In addition, results were not compared with other settings. It is unclear if variables (other than PCT intervention) would have affected results over time.

ABBREVIATIONS: ICS, IRISH CANCER SOCIETY; KPI, KARNOFSKY PERFORMANCE INDEX; PCT, PALLIATIVE CARE TEAM; PEP, PALLIATIVE CARE EVALUATION PROJECT; STAS, SUPPORT TEAM ASSESSMENT SCHEDULE;

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Citation	Ventafridda *et al.*, 1990
Level of evidence	Level III-2 (Intervention)
Country	Italy
Research question/aims	To assess the quality of life and control of physical and emotional symptoms in a group of terminal cancer patients before and during the treatment by a palliative care team (PCT), and to assess possible relationships among physical, emotional and functional symptoms.
Study type/design	Pre-post prospective study. The study involved weekly self-descriptive record (32 items at 4 levels of intensity). Patient contact in out-patient clinic (49%), hospital ward (3%), patients' home (48%).
Patient group	All patients reviewed during a sample week by the Pain Therapy and Palliative Care Division (National Cancer Institute), were examined in a cross-sectional study. They had originally been referred to the Division because of pain or other symptoms resulting from the progression of cancer that was no longer responsive to anti-cancer treatments (n=115).
Intervention	Hospital team part of whole service, four hospital nurses (seven doctors and 100 volunteers worked across hospital and home care).
Comparator	Pre-post design
Outcome definitions and measurements	Pain, other symptoms (vomiting), QoL (felt sad or depressed).
Data analyses & statistics	The data reported on the questionnaires during the sample week were compared to those collected at time zero. The baseline recordings of five patients could not be assessed because they were incomplete; thus, the records of 115 patients during therapy and those of 110 of the same patients at time zero were analysed. The answers given by the home-care patients were also analysed and compared to those of outpatients to assess possible differences in symptom control and subjective perception of the disease. Associations among symptoms were also assessed by means of Spearman's Test for nonparametric data.
Study quality	Poor A: Eligible population includes all patients reviewed during a sample week. B: Unknown C: Unknown D: Unknown

Results	Quality of life: Statistical improvements seen in difficulties at work, difficulties in visual free time activities, feeling sad or depressed, feeling anxious or scared and feeling nervous or insecure. There were many areas where no improvements were seen. Symptoms: Statistical improvements seen in pain, feeling weak, drowsiness and not feeling well. There were many areas where no improvements were seen.
Authors conclusions	Although the disease progressively develops, palliative care teams can enhance the quality of the lives of patients during the terminal stages of illness.
Reviewers notes	Before and after assessments were carried out in a single population. In addition, results were not compared with other settings. It is unclear if variables (other than PCT intervention) would have affected results over time.

ABBREVIATIONS: PCT, PALLIATIVE CARE TEAM; QOL, QUALITY OF LIFE

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Citation	Follwell *et al.*, 2009 (also described by Zimmermann *et al.*, 2006).
Level of evidence	Level III-2 (Intervention)
Country	Canada
Research question/aims	To assess the efficacy of an Oncology Palliative Care Clinic (OPCC) in improving patient symptom distress and satisfaction.
Study type/design	Pre-post prospective study
Patient group	Eligible patients had metastatic cancer, were at least 18 years old, and were well enough and had sufficient English proficiency to provide informed consent and complete questionnaires. All newly referred patients were considered for participation (n=150).
Intervention	Outpatients are referred to the OPCC by oncologists for management of pain or other symptoms and end-of-life planning. Patients are seen first by a palliative care registered nurse case manager, who assesses the patient and collects the names of the patient's medications. The palliative care physician then conducts a full medical, physical, and psychosocial assessment, after which recommendations are made for symptom and palliative care treatment, education, counselling, and home support. The palliative care team includes a social worker and psychiatrists, who are involved depending on patient need and preference; other specialists are consulted as necessary. Referrals to home care and community hospice and palliative care agencies are made as appropriate. A complete note is dictated for the patient's electronic medical record and is also sent to the patient's oncologist and family physician. Follow-up appointments at the OPCC are tailored to the needs of each patient. Patients with uncontrolled symptoms are called by their palliative care physician or nurse within 1 week. All patients are given contact information for the nurse and physician and the number for the 24-hour on-call service staffed by palliative care physicians; patients are encouraged to call if their symptoms are poorly controlled. The average time to follow-up is approximately 1 month, but medications are titrated over the telephone in the interim. Follow-up time can range from a few days (e.g., patients with poorly controlled symptoms) to months (e.g., symptom-free patients referred for planning). Patients who are too ill to return are referred to home palliative care physicians in the community.
Comparator	Pre-post design
Outcome definitions and measurements	The primary end points of symptom control and patient satisfaction were assessed using the Edmonton Symptom Assessment Scale (ESAS) and patient-adapted Family Satisfaction with Advanced Cancer Care (FAMCARE) scale at baseline, 1 week, and 1 month. The individual symptom scores and Total Distress Scores (TDS) were secondary outcomes.
Data analyses & statistics	Determination of efficacy was based on statistically significant change in the primary end points (EDS and overall FAMCARE score) at 1 week or 1 month. Clinical efficacy was evaluated for individual symptoms and defined as an improvement in ESAS score by at least one unit in at least 40% of patients for that symptom.

Study quality	Fair A: Baseline characteristics of participants and nonparticipants are listed, with nonparticipants were older than participants (median age, 67 v 60 years, respectively; p=0.07) B: Unknown C: Y D: Unknown
Results	Symptoms: In the 123 patients with 1-week follow-up data, there was a mean improvement of 8.8 in EDS (9.8%; p< .0001) and of 10.8 in TDS (9.8%; p< .0001). Statistically significant improvements occurred for all symptoms except well-being, including pain, fatigue, nausea, anxiety, dyspnea, and insomnia (all p<0.0001), as well as depression, drowsiness, and constipation (all p<0.002). More than 40% of the 150 patients enrolled had a reduction of symptom score by at least 1 point at 1 week for pain, fatigue, anxiety, and insomnia and more than 60% of those scoring 8 to 10 out of 10 had an improvement of at least 1 point for all symptoms except fatigue, appetite, and constipation. In the 88 patients who were assessable at 1 month, there was a significant improvement in TDS (p<0.0001) and EDS (p<0.0001) and statistically significant improvement in symptom control for anxiety, insomnia, dyspnea, depression, and pain. Patient satisfaction: The mean baseline total FAMCARE score was 34.7, with a mean improvement score of 6.1 (p<0.0001) at 1 week and 5.0 at 1 month (p<0.0002). FAMCARE domains that showed the greatest improvement were “Information given about how to manage pain”, “Doctor’s attention to symptoms,” “Pain relief,”“How thoroughly the doctor assesses symptoms,” and “Speed with which symptoms are treated” (all p<0.0001).
Authors conclusions	This phase II study demonstrates efficacy of an OPCC for improvement of symptom control and patient satisfaction with care. Randomised controlled trials are indicated to further evaluate the effectiveness of specialised outpatient palliative care.
Reviewers notes	The study had a high rate of patient attrition. This may result in bias because patients who are retained are likely to be those with better outcomes.

ABBREVIATIONS: EDS, ESAS DISTRESS SCORE; ESAS, EDMONTON SYMPTOM ASSESSMENT SCALE; FAMCARE, FAMILY SATISFACTION WITH ADVANCED CANCER CARE; OPCC, ONCOLOGY PALLIATIVE CARE CLINIC; TDS, TOTAL DISTRESS SCORE

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Citation	Kusajima *et al*., 2009
Level of evidence	Level III-2 (Intervention)
Country	Japan
Research question/aims	To clarify patients' characteristics and the level of symptom management in the transition to specialised home palliative care and to examine prospectively real-time evaluation of both terminal cancer patients and their families.
Study type/design	Pre-post prospective program evaluation conducted via a questionnaire survey. Assessment occurred at baseline and after 2 weeks of intervention.
Patient group	The participants were terminal cancer patients and their families who had been referred to the specialised home palliative care service (n=100).
Intervention	Specialised home palliative care (SHPC) service comprising palliative care physicians, nurses, caseworkers, and other care specialists. Each patient was visited at least once per week by a physician and at least 3 times per week by a nurse. If required, a visit was also carried out every day.
Comparator	Pre-post design

Outcome definitions and measurements	Quality of life: Self-reported health status by patients (EQ-5D). Families' health status and families' perception of patients' health status. Data was collected by conducting face to face interviews. Patient symptoms were assessed by medical professionals.
Data analyses & statistics	Descriptive statistics were calculated for the study sample, and patient and family characteristics and patients' symptoms were compared at the initial assessment according to the care setting before the start of the intervention. To compare each group the Wilcoxon rank sum test, Student t test, the Chi-square test and Fisher exact test were used where appropriate. Patients' and families' evaluations between the initial assessment and an assessment 2 weeks later were also compared. The Wilcoxon signed-ranks test was performed for comparisons between these 2 occasions. The significance level was set at $p<0.05$ (2-tailed).
Study quality	Fair A: Unknown B: N C: Y D: Unknown
Results	Quality of life: There were significant deteriorations in self-reported health status scores for mobility ($p<0.001$) and self-care ($p=0.01$). There were no significant deteriorations regarding the scores for pain/discomfort and anxiety/depression. Symptoms: There were significant improvements in symptom scores of pain (P ¼ .02), appetite loss ($p<0.001$), and constipation ($p<0.001$). Similarly, the number of moderate to extreme symptoms decreased significantly ($p=0.01$). However, no significant improvement was observed in symptom score for dry mouth ($p=0.003$). Caregiver satisfaction: There was a significant improvement in anxiety regarding care at home ($p=0.002$). However, there were significant deteriorations in the frequency of night-time awakening for patient care ($p<0.001$) and in the physical status ($p=0.01$). The families' perception of patients' physical and psychological status did not change significantly.
Authors conclusions	The SHPC service could contribute to patients' symptoms and families' psychosocial status. On the whole, the evaluation of the SHPC service was positive during the 2-week period after starting home care.
Reviewers notes	Data was not obtained from all patients. The results may not generalise to all terminal cancer patients and their family at home. The largest cause of missing data in the study resulted from a patient's functional deterioration or death. In addition, results were not compared with other settings.

ABBREVIATIONS: EQ-5D, EUROQUOL 5D; SHPC, SPECIALISED HOME PALLIATIVE CARE

THE QUALITY OF OTHER STUDIES WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) HAS SELECTION BIAS BEEN MINIMISED?; (B) HAVE ADEQUATE ADJUSTMENTS BEEN MADE FOR RESIDUAL CONFOUNDING?; (C) WAS FOLLOW-UP FOR FINAL OUTCOMES ADEQUATE?; (D) HAS MEASUREMENT OR MISCLASSIFICATION BIAS BEEN MINIMISED?

Citation	Veerbeek *et al.*, 2008
Level of evidence	Level III-2 (Intervention)
Country	Netherlands
Research question/aims	To investigate the effect of using the Liverpool Care Pathway (LCP) on communication during the last 3 days of life and on the level of bereavement in relatives after the patient's death.
Study type/design	Pre-post study comparing the relatives' evaluation of communication and level of bereavement between relatives of patients who died before the introduction of the LCP (baseline period) and relatives of patients who died after the introduction of the LCP (intervention period).

Patient group	A university hospital, a general hospital, a complete nursing home, another nursing home, a residential care organisation, and a home care organisation in the southwest of the Netherlands participated in the study. All patients receiving care from any of these institutions between November 2003 and February 2006 were informed of the study. Patients 18 years or older who died during this period were eligible to participate in the study. Includes 140 patients in the intervention period and 131 patients in the baseline period.
Intervention	In the United Kingdom, the LCP was developed to improve care for dying patients. It promotes clear communication around the dying and death of the patient, and it supports psychosocial and spiritual care to patients and their relatives, for example, by promoting adequate communication and support and giving relatives a brochure for bereavement after the death of the patient.
Comparator	Pre-post design
Outcome definitions and measurements	Levels of communication and bereavement. The questions about whether and how the relative was told about the imminent death of the patient, about medical decision making, and about psychosocial support were based on items from the Views of Informal Carers - Evaluation of Services (VOICES) questionnaire. Relatives were also asked to fill in the Leiden Detachment Scale (LDS), which includes 7 items about bereavement.
Data analyses & statistics	Differences between the baseline period and the intervention period were statistically tested, using χ^2 and Student's t tests where appropriate. The investigators assessed associations between the comprehensiveness of information and LCP use and between the level of bereavement and LCP use, while correcting for differences (using multivariate regression analysis) in the gender of the patients, age of relatives, place of death, and relationship between the patient and the relative. The significance level was set at $p<0.05$.
Study quality	Fair A: N B: Y C: Data were analysed using the intention to treat principle D: Unknown
Results	Caregiver satisfaction: Communication was evaluated similarly in both periods, except that in the intervention period more relatives (93%) found the information about the patient's situation and care comprehensible when compared with the baseline period (85%; p=0.05). However, Place of death and the type of relationship between the patient and the relative largely explained the difference in comprehensibility of information between both periods. The sum score of the LDS was significantly lower in the intervention period when compared with the baseline period (p=0.01), indicating a significantly lower bereavement level in relatives of patients in the intervention period.
Authors conclusions	LCP use during the dying phase seems to moderately contribute to lower levels of bereavement in relatives.
Reviewers notes	Relatives filled in questionnaires for 59% of the eligible patients in this study. The group of relatives who did not participate might have had higher bereavement levels.

ABBREVIATIONS: LCP, LIVERPOOL CARE PATHWAY; LDS, LEIDEN DETACHMENT SCALE; VOICES, VIEWS OF INFORMAL CARERS - EVALUATION OF SERVICES

THE QUALITY OF OTHER STUDIES WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) HAS SELECTION BIAS BEEN MINIMISED?; (B) HAVE ADEQUATE ADJUSTMENTS BEEN MADE FOR RESIDUAL CONFOUNDING?; (C) WAS FOLLOW-UP FOR FINAL OUTCOMES ADEQUATE?; (D) HAS MEASUREMENT OR MISCLASSIFICATION BIAS BEEN MINIMISED?

Level III-3 studies

Citation	Spettell *et al*., 2009
Level of evidence	Level III-3 (Intervention)
Country	USA
Research question/aims	To evaluate the impact of comprehensive case management (CM) and expanded insurance benefits on use of hospice and acute health care services among enrollees in a national health plan.
Study type/design	Retrospective cohort design with three intervention groups, each matched to a historical control group.
Patient group	Patients with advanced illness and their families. Intervention groups were health plan enrollees who died after 2004: 3491 commercial enrollees with CM; 387 commercial enrollees with CM and expanded hospice benefits; and 447 Medicare enrollees with CM.
Intervention	The ‘‘Compassionate Care Program’’ included comprehensive case management services provided by health plan nurse case managers who received extensive training in palliative care. The 3 included interventions were: commercial enrollees with CM; commercial enrollees with CM and expanded hospice benefits; and Medicare enrollees with CM. Case management
Comparator	Control groups consisted of enrollees who died in 2004 prior to the start of the palliative care CM program.
Outcome definitions and measurements	Primary outcomes were rates of hospice use and mean number of days in hospice; however, emergency visits, ICU stays, and acute inpatient stays were also reported.
Data analyses & statistics	Generalised linear models were used to compare outcome variables between groups with a subject effect variable to adjust for the paired nature of the data. McNemar’s test was used for comparing proportions. Kaplan-Meier methods were used to estimate the number of days between hospice enrollment and death, and group differences were tested using a two-sided log rank test.
Study quality	Fair A: Patients in the study were compared to matched historical control groups of patients from 2004 B: All models included a variable for the geographical region where the member resided to adjust for regional differences in hospice use. C: Unknown D: Y. Most outcomes were objective measures of resource use.
Results	Utilisation of resources: For each group receiving CM, the percentage of members using hospice more than doubled compared to its control group (Enhanced Benefits CM 69.8% versus 27.9%, p<0.0001; CM 71.7% versus 30.8%, p<0.0001). The mean number of days with hospice increased from 21.4 days to 36.7 days (p<0.0001) for the Enhanced Benefits CM group, and from 15.9 days to 28.6 days (p<0.0001) for the CM group. The rate of use of hospice in the Medicare CM Group was 62.9%. The percentages of members with an acute inpatient stay after program enrollment were reduced for the Enhanced Benefits CM Group (16.8% versus 40.3%, p<0.0001), CM group (22.7% versus 42.9%, p<0.0001), and Medicare CM group (30.0% versus 88.4%, p<0.0001) compared to their respective control groups. The number of acute inpatient days was reduced for the Enhanced Benefits CM group (1549 versus 3986 days per thousand members, p<0.0001), CM Group (2311 versus 3858 days per thousand members, p<0.0001), and Medicare CM Group (2309 versus 15,217 per thousand members, p<0.0001) compared to their respective control groups. The proportion of members with ICU stays during an acute inpatient admission was significantly lower for all of the groups receiving CM compared to their respective control groups, as was ICU days per thousand member (Enhanced Benefits CM Group 899 versus 2542, p<0.0001, CM Group 1356 versus 2162, p<0.0001, Medicare CM Group; 1189 versus 9840, p<0.0001) compared to the control groups.

Authors conclusions	Comprehensive health plan CM and more liberal hospice benefit design may help to break down barriers to hospice use; benefits might be liberalised within the context of such case management programs without adverse impact on total costs.
Reviewers notes	The patients studied did not represent all patients with advanced illness who died during the time period studied; rather they represented a cohort of individuals whose illness became known to the health plan's case management program through secondary identification mechanisms. Identification mechanisms based on concurrent review of inpatient cases, referrals, and claims-based predictive modelling algorithms are imperfect. Furthermore, the patients in the study were compared to matched historical control groups of patients from 2004. It is possible that some portion of the increases in hospice use reflect national trends in greater hospice use. It is also possible that there were differences in unmeasured characteristics such as preferences and attitudes between the groups influenced hospice election.

ABBREVIATIONS: CM, CASE MANAGEMENT; ICU, INTENSIVE CARE UNIT

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Citation	Doolittle, 2000
Level of evidence	Level III-3 (Intervention)
Country	USA
Research question/aims	To examine the expenses of providing telehospice care and to compare them with the costs associated with the delivery of traditional hospice services.
Study type/design	A retrospective cost analysis comparing a traditional hospice with a telehospice.
Patient group	Number and characteristics of patients not reported.
Intervention	The telehospice was a service utilising ordinary telephone-based videoconferencing equipment to link hospice providers with patients and families in their homes. During the time when the cost data were accrued, the telehospice service included telemedicine visits provided by nurses and social workers. Home care + telehospice
Comparator	Traditional hospice care including home visits.
Outcome definitions and measurements	Cost data for personnel costs and operational expenses on the project were obtained from the director of the Kendallwood hospice. Equipment costs were obtained from the director of the Kansas University TeleMedicine Services Department. The cost per patient visit (whether conventional or via telemedicine) was extrapolated from several sources. The individual hospice providers and the Kendallwood hospice office manager made estimates of time spent on the project. Time sheets were analysed for the time spent on in-person evaluations, including travelling time and the time spent with the patient. For telehospice visits, the time spent on the telemedicine system was recorded by the hospice nurse.
Data analyses & statistics	Descriptive statistics
Study quality	Poor A: Unknown B: Unknown C: Unknown D: Unknown
Results	Cost of care: For the first study period, costs were measured for traditional hospice home visits. During the second, expenses were monitored for traditional (in-person) and telehospice visits. For traditional care, the cost per visit was $126 and $141, for the first and second time periods, respectively. The average telehospice visit was $29.
Authors conclusions	The authors state that the "evaluation suggests that the program had an impact on the substance use of study participants, birth outcomes, and the growth and development of children".

Reviewers notes	Poor quality study with insufficient description of patients, study design and analyses

THE QUALITY OF OTHER STUDIES WAS ASSESSED USING THE FOLLOWING QUESTIONS: (A) HAS SELECTION BIAS BEEN MINIMISED?; (B) HAVE ADEQUATE ADJUSTMENTS BEEN MADE FOR RESIDUAL CONFOUNDING?; (C) WAS FOLLOW-UP FOR FINAL OUTCOMES ADEQUATE?; (D) HAS MEASUREMENT OR MISCLASSIFICATION BIAS BEEN MINIMISED?

Appendix C: Excluded Studies Annotated by Reason for Exclusion

[Add here, annotated by reason for exclusion]

Treating tobacco use and dependence: a systems approach. A guide for health care administrators, insurers, managed care organisations, and purchasers. (2000). Retrieved from http://www.ahrq.gov/clinic/tobacco/systems.htm Title/abstract excluded: Inappropriate study design.

Agency for Healthcare Research and Quality (2008). New evidence provides clinicians with better tools to help smokers quit. *Rockville, MD. : Press Release Date: May 7, 2008* Retrieved from http://www.ahrq.gov/news/press/pr2008/tobupdatepr.htm Title/abstract excluded: Inappropriate study design.