

Palliative care models of care

Evidence check

Rapid evidence checks are based on a simplified review method and may not be entirely exhaustive, but aim to provide a balanced assessment of what is already known about a specific problem or issue. This brief has not been peer-reviewed and should not be a substitute for individual clinical judgement, nor is it an endorsed position of NSW Health.

Evidence check

Evidence check question

What organisational models have been shown to improve outcomes for patients in palliative care?

In brief

- Most evaluations focus on specialist palliative care delivered in various settings including: home-based palliative care models; a community-managed model; palliative care integrated with hospitals; or hospices. ^{1,2} Models include primary non-specialist interventions, specialist provider interventions, and hybrid non-specialist/specialist-provider interventions. ³ Models of palliative care generally integrate specialist expertise with primary and community care services, and enable transitions across settings, including residential aged care. ⁴
- **Integrated models of palliative care** aim to improve the coordination between and integration of different specialists and services to support patients with palliative care needs. The models described in the literature include holistic needs assessment and management, and advance care planning. ⁵ There is some evidence that integrated palliative care can reduce hospitalisations and help maintain functional status. ⁶ A randomised trial on fast-track palliative care found that receiving palliative care earlier has a similar effect on reducing symptoms, but greater effects on reducing caregiver burden. ⁷ They have been used for a range of conditions.
 - In burns units, benefits include patients' comfort, decision-making processes and family care. ⁸
 - For people with cancer, integrated palliative care improves short-term quality of life, symptom burden and psychological symptoms. It also increases the likelihood that people will die at home in line with their preferences. ⁹⁻¹² Integrated psychological and palliative care for patients with acute leukaemia reduces traumatic stress symptoms and pain intensity compared with usual care. ¹³
 - In cancer and chronic disease, there is evidence of better symptom control and improved quality of life, enhanced communication between staff, patients and caregivers, a higher proportion of deaths occurring at home, and more cost-effective care. ¹⁴
 - A systematic review of outpatient care models, including interdisciplinary specialist care; physician-only care or nurse-led specialist care in stand-alone clinics; nurse-led

specialist telephone-based interventions; embedded specialist care with variable team makeup; and advanced practice provider based primary care, showed that interdisciplinary specialist-provided ambulatory palliative care had the greatest impact on patient and caregiver outcomes such as quality of life and symptom burden.¹⁵

- For people with long-term neurological conditions, short-term integrated palliative care interventions did not achieve any statistically significant differences in outcomes, when compared to controls.¹⁶
- For respiratory services, early integration with palliative care improved breathlessness mastery and improved survival rates at six months, with significant differences for patients with chronic obstructive pulmonary disease (COPD) and interstitial lung disease; but not those with cancer.¹⁷
- **Multidisciplinary models** use teams of relevant medical groups to organise patient-centred care. Systematic reviews of multidisciplinary specialist palliative care found improved pain and symptom control, increased dying at home, improved patient quality of life, symptom management, and patient satisfaction, but no reduction in hospital admissions or length of stay^{18,19}. In specific conditions, the findings were as follows:
 - A 2019 Cochrane systematic review found low or very low-certainty evidence regarding the difference between palliative care interventions versus usual care for long-term health-related quality of life, adverse events, and hospital admissions for patients with multiple sclerosis. The palliative care interventions included fast-track multidisciplinary standard care and a multidisciplinary palliative approach.²⁰
 - A systematic review of multidisciplinary palliative care for patients with heart failure found statistically significant benefits for patient-reported outcomes.²¹
- **Home-based models** provide appropriate and timely specialist care in the care home. A stepped wedge randomised controlled trial (RCT) and systematic review showed that specialist palliative care can reduce lengths of stay in hospital and the number of hospitalisations, prevent hospital readmissions, and reduce symptom severity compared with usual care or no care^{22,23}. A systematic review of models of palliative care in different settings found positive benefits, including the increased likelihood of dying at home, for home-based models¹⁸. Home-based models have been used for different conditions.
 - Home-based transitional palliative care for patients with end-stage heart failure led to significantly lower readmission rates than the control group, and improved quality of life.^{24,25}
 - In COPD, early integrated palliative home care showed no overall intervention effect for the outcomes, compared with the control group.²⁶
- **General practice models** in a systematic review found that a single specialist palliative care case conference reduced hospitalisations, better maintained functional capacity, and improved quality of life in both patients with cancer and without cancer.²⁷ Another systematic review found most general practitioners believe they have a significant and effective role in delivering palliative care.²⁸
- **Patient-centred models** include 'Respecting Choices', a well-known advance care planning model intended to assist individuals consider, choose, and communicate their preferences to healthcare providers. A systematic review found low-level evidence that this model and its derivatives increase the incidence and prevalence of advance directive and physician orders for life-sustaining treatment completion.²⁹
- **End of life care pathways** include an internationally-recognised model for end of life care known as the 'Liverpool Care Pathway – for the dying patient'. A 2016 Cochrane systematic review found very low-quality evidence of a difference in overall control of breathlessness between the Liverpool Care Pathway and usual care.³⁰ Another systematic review on the

'Liverpool Care Pathway' identified the following key factors to successful implementation: a dedicated facilitator; education and training; audit and feedback; organisational culture; and adequate resources.³¹ A further review found although this pathway is widely recommended, it was only used for around half of the dying patients in the 17 publications included in the review.³²

- **Nurse-led models** involving care led by nurse facilitators and advanced practice nurses are used for different conditions.
 - A multicentre randomised control trial demonstrated that nurse-led advance care planning improves uptake compared to usual care in patients with lung disease.³³
 - A multidisciplinary coordinated intervention with advanced practice nurses found no differences between the two groups on the primary patient-reported outcomes in cancer patients.³⁴
- **Models utilising telehealth**, where technology supports care delivery, are used in cancer patients.
 - Teleconsultations from a hospital-based specialist palliative care consultation team improved patient-experienced symptom burden, compared to usual care, in patients with advanced cancer.³⁵
- **Culturally safe care**
 - An Australian conceptual model for the delivery of culturally safe palliative care services to Aboriginal and Torres Strait Islander people included seven key principles: equity; autonomy/empowerment; trust; humaneness; seamless care; an emphasis on living; and cultural respect.³⁶
 - In a systematic review of service delivery to Aboriginal and Torres Strait Islander people, critical elements were shown to include community engagement, education and training, culturally safe service delivery, flexible organisation and program structure and patient-centred care.³⁶
 - A culturally-tailored patient navigator intervention for Latino patients under advanced care, improved advanced care planning including documentation in the electronic health record, but made no significant difference to pain, hospice use or overall quality of life, compared to the control group.³⁷

Limitations

This review was limited to systematic reviews and randomised controlled trials, so the models evaluated in observational studies have not been captured. This is a synthesis of existing reviews, and an appraisal of the primary publications cited in the reviews was not undertaken. Several definitions of palliative care exist and as such some models describing palliative care in more generic terms may not have been captured by this review. Models of care vary between conditions and contexts, as well as encompassing different interventions and populations. This variability, together with underpowered studies, the heterogeneity of the study methods used, and the potential for bias, poses considerable challenges for evidence synthesis.

Background

A wide range of organisational models of palliative care exist and cover a range of different settings and conditions. In this review, palliative care has been defined according to the [NSW Health policy directive](#) where palliative care is “An approach that aims to prevent and relieve suffering and improve the quality of life of patients and their families who are facing the problems associated with life-threatening illness through early identification and assessment and treatment of pain and other physical, psychosocial and spiritual issues.”

Methods (Appendix 1)

PubMed was searched on the 21 September 2020. Search terms and inclusion criteria are included in Appendix 1.

Results

Table 1

Source	Summary
Peer reviewed sources	
<p>Palliative care in the Greater China region: A systematic review of needs, models and outcomes</p> <p>Chung et al., 2020 ¹ (Abstract only)</p>	<ul style="list-style-type: none"> • Systematic review of 19 qualitative studies and 47 quantitative studies to examine palliative care needs, models of care, interventions and outcomes. • Nine themes were synthesised: pain control; reduced aggressive end of life care; truth telling; physical, emotional and spiritual support; and achieving preferred place of care/death. • Models of care evaluated were mostly specialist palliative care delivered in various settings (hospitals, residential care and home).
<p>General practice nurses and physicians and end of life: a systematic review of models of care</p> <p>Mitchell et al. 2020 ²⁷ (Abstract only)</p>	<ul style="list-style-type: none"> • Systematic review of 13 studies published between 2000 and 2017 to examine models of end of life care that incorporate or support general practitioners (GPs) and general practice nurses. • A single specialist palliative care case conference reduced hospitalisations, better maintained functional capacity and improved quality of life parameters in patients with and without cancer. • No studies examined models of care aimed at supporting general practice nurses.
<p>Facilitators and barriers to general practitioner and general practice nurse participation in end-of-life care: systematic review</p> <p>Rhee et al., 2019 ³⁸ (Abstract only)</p>	<ul style="list-style-type: none"> • Systematic review of 62 papers published between 2000 and 2017 to provide a description of the barriers to and facilitators of general practitioner and general practice nurse provided palliative or end of life care. • Four specific settings were identified: aged care facilities; out-of-hours care; and resource-constrained settings (rural, and low-income and middle-income countries). • Six themes emerged from the review including patient factors; personal GP factors; general practice factors; relational factors; co-ordination of care; and availability of services. • The organisation of primary care at practice, local and national levels imposes numerous structural barriers that impede more significant involvement.
<p>Comparison of integrated outpatient palliative care with standard care in patients with Parkinson disease and related disorders</p>	<ul style="list-style-type: none"> • Randomised clinical trial between November 2015 and September 2017 to determine if outpatient palliative care is associated with improvements in patient-centred outcomes compared with standard care for patients with Parkinson disease and related disorders, and their caregivers (n = 210).

Source	Summary
Peer reviewed sources	
Kluger et al., 2020 ³⁹	<ul style="list-style-type: none"> • Outpatient integrated palliative care administered by a neurologist, social worker, chaplain and nurse using checklists, with guidance and selective involvement from a palliative medicine specialist. Standard care was provided by a neurologist and a primary care practitioner. • Patients receiving palliative care had better quality of life at six months as well as better symptom burden and rates of advance directive completion compared with standard care alone.
<p>Multisite, randomized trial of early integrated palliative and oncology care in patients with advanced lung and gastrointestinal cancer: Alliance A221303</p> <p>Temel et al., 2020 ⁴⁰</p>	<ul style="list-style-type: none"> • A multicentre, randomised trial of early integrated palliative and oncology care in patients with advanced cancer to confirm the benefits of early palliative care (PC) seen in prior single-centre studies. • Patients were randomly assigned to early integrated palliative and oncology care (n = 195) or usual oncology care (n = 196). • Due to significant morbidity, a high proportion of measures not completed within the protocol window, and for unknown reasons, the rate of missing data was high. Delivery of the intervention was also suboptimal. • Intervention patients reported a mean 3.35 (SD = 14.7) increase in Functional Assessment of Cancer Therapy-General FACT-G scores from baseline to week 12 compared with usual care patients who reported a 0.12 (SD = 12.7) increase from baseline (p = 0.10).
<p>Healthcare providers' views and experiences of non-specialist palliative care in hospitals: A qualitative systematic review and thematic synthesis</p> <p>Nevin et al., 2020 ⁴¹ (Abstract only)</p>	<ul style="list-style-type: none"> • Systematic review and thematic synthesis of 39 papers (of 37 studies) published to March 2018 on healthcare providers' views and experiences of non-specialist palliative care in hospitals. • Non-specialist palliative care in hospitals is operationalised as care in the last weeks and days of life. • The organisation of acute care, inter-disciplinary working practices, clinician attitudes, poor communication structures, and lack of education and training in palliative care principles exacerbates poor and delayed implementation of this care for patients in hospitals.
<p>Reducing time in acute hospitals: A stepped-wedge randomised control trial of a specialist palliative care intervention in residential care homes</p> <p>Forbat et al., 2020 ²²</p>	<ul style="list-style-type: none"> • Stepped-wedge randomised control trial conducted between February 2017 and June 2018 to determine if a model of care providing specialist palliative care in care homes, could reduce length of stay in hospital. • Study included 1,700 residents in 12 Australian care homes for older people. • Specialist Palliative Care Needs Rounds led to reduced length of stay in hospital (unadjusted difference: 0.5 days;

Source	Summary
Peer reviewed sources	
	<p>adjusted difference: 0.22 days with 95% confidence interval: -0.44, -0.01 and p = 0.038).</p> <ul style="list-style-type: none"> • The intervention also provided a clinically-significant reduction in the number of hospitalisations by 23%, from 5.6 to 4.3 per facility-month. • A conservative estimate of the annual net cost-saving from reduced admissions was A\$1,759,011.
<p>Economic evaluations of palliative care models: A systematic review</p> <p>Mathew et al., 2020 ²³</p>	<ul style="list-style-type: none"> • Systematic review of five papers to describe and critically appraise economic evaluations of palliative care models and to identify cost-effective models in improving patient-centred outcomes. • Two studies compared home-based palliative care models to usual care, and one compared home-based palliative care to no care. • Effectiveness outcomes included hospital readmissions prevented, days at home, and palliative care symptom severity. • All studies concluded that palliative care was cost-effective compared to usual care.
<p>Palliative care interventions for people with multiple sclerosis</p> <p>Latorraca et al., 2019 ²⁰</p>	<ul style="list-style-type: none"> • Cochrane systematic review of three studies to assess the benefits and harms of palliative care interventions compared to usual care for people with any form of multiple sclerosis. • Three studies (146 participants) met the selection criteria. Two studies compared multidisciplinary, fast-track palliative care versus multidisciplinary, standard care while on a waiting-list control. One study compared a multidisciplinary palliative approach versus multidisciplinary standard care at different time points (12, 16 and 24 weeks). • There is low- or very low-certainty evidence regarding the difference between palliative care interventions versus usual care for long-term health-related quality of life, adverse events, and hospital admission in patients with multiple sclerosis.
<p>Early integrated palliative home care and standard care for end-stage COPD (EPIC): a phase II pilot RCT testing feasibility, acceptability, and effectiveness</p> <p>Scheerens et al., 2020 ²⁶</p>	<ul style="list-style-type: none"> • Randomised controlled trial to test feasibility, acceptability and preliminary effectiveness of early integrated palliative home care for end-stage COPD (n=39). • Interventions included: 1) pre-inclusion COPD support training for palliative home care nurses; 2) monthly palliative home care visits; 3) leaflets on coping mechanisms; 4) a protocol on symptom management and support, care plan and action plan; 5) integration of palliative home care and usual care through reporting and communication mechanisms.

Source	Summary
Peer reviewed sources	
	<ul style="list-style-type: none"> Effectiveness analysis showed no overall intervention effect for the outcomes, but between baseline and week 24, fewer hospitalisations in the control group and a trend of higher perceived quality of care in the intervention group were found. A clinically-relevant difference was observed at week 24 for health-related quality of life in favour of the control group. Intervention is feasible and accepted but did not yield the anticipated preliminary effectiveness. Recommendations to enhance the intervention include coordination of care, more general practitioner involvement and more intensive training for palliative home care nurses in COPD support.
<p>General practice physicians' and nurses' self-reported multidisciplinary end-of-life care: a systematic review</p> <p>Senior et al. 2019 ²⁸ (Abstract only)</p>	<ul style="list-style-type: none"> Systematic review of 29 papers on the self-reported role and performance of general practitioners and general practice nurses in (1) specific medical/nursing roles; (2) communication; (3) care co-ordination; (4) access and out-of-hours care; (5) multidisciplinary care. General practitioners report a central role in symptom management, treatment withdrawal, non-malignant disease management and terminal sedation. Information provision included breaking bad news, prognosis and place of death. There was minimal reference to general practice nurses' roles.
<p>Multi-disciplinary palliative care is effective in people with symptomatic heart failure: A systematic review and narrative synthesis</p> <p>Datla et al., 2019 ²¹</p>	<ul style="list-style-type: none"> A systematic review and narrative synthesis of 13 interventional and 10 observational studies to identify evidence in relation to palliative care for people with symptomatic heart failure. The evaluation phase studies, with lower risk of bias, using a multidisciplinary specialist palliative care intervention, showed statistically-significant benefit for patient-reported outcomes (symptom burden, depression, functional status, and quality of life), resource use and costs of care.
<p>Do patients, families, and healthcare teams benefit from the integration of palliative care in burn intensive care units? Results from a systematic review with narrative synthesis</p> <p>Ribeiro et al., 2019 ⁸ (Abstract only)</p>	<ul style="list-style-type: none"> A systematic review with narrative synthesis of five papers to review the evidence about the integration of palliative care in burn intensive care units with respect to (1) the concept, model and design and (2) the benefits and outcomes of this integration. Integrating palliative care into burn units may include benefits such as patients' comfort, aiding decision-making processes, and family care. Multidisciplinary teams may experience lower levels of burden as a result of integrating palliative care in burn units.

Source	Summary
Peer reviewed sources	
<p>Emotion And Symptom-focused Engagement (EASE): a randomized phase II trial of an integrated psychological and palliative care intervention for patients with acute leukemia</p> <p>Rodin et al., 2019 ¹³ (Abstract only)</p>	<ul style="list-style-type: none"> • Randomised controlled trial to test a novel intervention for acute leukaemia care called 'Emotional and Symptom-focused Engagement (EASE) (n=42). • EASE includes (1) EASE-psy, tailored psychotherapy delivered over eight weeks, and (2) EASE-phys, weekly physical symptom screening over eight weeks to trigger early palliative care. • Significant treatment-group differences favouring EASE were observed in traumatic stress symptoms at 4 and 12 weeks, and pain intensity and interference at 12 weeks compared to usual care.
<p>Palliative cancer care in the outpatient setting: which model works best?</p> <p>Hui, 2019 ¹⁵ (abstract only)</p>	<ul style="list-style-type: none"> • Review article of articles evaluating different delivery models of outpatient palliative care. • There are currently many variations for how palliative care is delivered in the outpatient setting, including: <ul style="list-style-type: none"> ○ Interdisciplinary Specialist Palliative Care in Stand-Alone Clinics ○ Physician-Only Specialist Palliative Care in Stand-Alone Clinics ○ Nurse-Led Specialist Palliative Care in Stand-Alone Clinics ○ Nurse-Led Specialist Palliative Care Telephone-Based Interventions ○ Embedded Specialist Palliative Care with Variable Team Makeup ○ Advanced Practice Providers-Based Enhanced Primary Palliative Care. • Interdisciplinary specialist palliative care for ambulatory palliative care has the greatest impact on multiple patient and caregiver outcomes.
<p>Palliative care provision for patients with advanced chronic obstructive pulmonary disease: a systematic integrative literature review</p> <p>Fusi-schmidhauser et al., 2018 ⁵ (abstract only)</p>	<ul style="list-style-type: none"> • A systematic review of 24 papers published from 1960 to 2017 exploring how palliative care is provided in advanced COPD and to identify elements defining integrated palliative care. • A taxonomy for palliative care provision in advanced COPD involves different levels of care provision and integrated care is the last step of this dynamic process. • Palliative care involvement, holistic needs assessment and management, and advanced care planning have been identified as elements of integrated care.
<p>A new model of early, integrated palliative care: palliative rehabilitation for newly diagnosed patients with non-resectable cancer</p>	<ul style="list-style-type: none"> • A description of a palliative care model for newly diagnosed advanced cancer patients; the model was evaluated through a randomised controlled trial investigating the effect of systematic referral to a palliative

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Peer reviewed sources	
<p>Nottelmann et al., 2019 ⁴² (Abstract only)</p>	<p>rehabilitation clinic concurrently with standard oncology treatment or standard treatment alone.</p> <ul style="list-style-type: none"> • In the study 132 adults with newly diagnosed advanced cancer were seen in the palliative rehabilitation outpatient clinic. • The basic offer of palliative rehabilitation was two consultations and a 12-week possibility for contacting a palliative rehabilitation team if needed. In addition, patients and family caregivers were offered participation in a 12-week patient/caregiver school combined with individually tailored physical exercise in groups, individual consultations, or both. • The intervention was primarily led by nurses and the main themes of the individual consultations were coping, pain and nutrition. When asked if they would recommend the intervention to others in the same situation, 93% of the respondents agreed, 7% partly agreed, and no one disagreed.
<p>Integrated outpatient palliative care for patients with advanced cancer: A systematic review and meta-analysis</p> <p>Fulton et al., 2018 ⁹</p>	<ul style="list-style-type: none"> • A systematic review and meta-analysis of eight randomised-controlled and two cluster-randomised trials evaluate the effects of integrated outpatient palliative and oncology care for advanced cancer on patient and caregiver outcomes. The review includes 11 companion paper that focus on integrated palliative and oncology care. • Interventions: <ul style="list-style-type: none"> ○ Palliative care was delivered by a multidisciplinary team of two to five clinicians: all included nurses; five included a palliative care physician; three included a mental health professional; and two included chaplains. ○ All studies provided services during outpatient visits; five also included telephone-based care; and three described delivery of written materials. ○ Of the 10 trials, 2 were classified as having basic collaboration on site and 4 as having close collaboration on site with some systems integration. Four studies could not be classified as the authors of the studies did not provide more information as part of the review. • Outcomes: <ul style="list-style-type: none"> ○ Integrated palliative care improved short-term quality of life. ○ At one – three months post randomisation, patients assigned to integrated palliative care showed small but statistically nonsignificant improvements in symptom burden.

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	<ul style="list-style-type: none"> ○ Effects of integrated palliative care on one or more psychological symptoms were reported in all but one study. Six studies reported effects on depression symptoms. ○ In studies following patients from 6 to 35 months, patients receiving palliative care were more likely to die at home. ○ Measures of utilisation were reported inconsistently across studies and none of the studies found intervention effects. ○ Caregiver experience was reported in three trials, with improvement to experience and satisfaction at three and four months, and no differences for quality of life.
<p>Effect of apoyo con cariño (support with caring) trial of a patient navigator intervention to improve palliative care outcomes for Latino adults with advanced cancer</p> <p>Fischer et al., 2018 ³⁷</p>	<ul style="list-style-type: none"> ● A randomised clinical trial to investigate if a culturally tailored patient navigator intervention can improve palliative care outcomes for Latino adults with advanced cancer. ● Intervention: at least five home visits from a patient navigator and an educational packet. ● Outcomes: <ul style="list-style-type: none"> ○ Patients were more likely to have any advance care planning document in the electronic health record. ○ Intervention group patients had a mean (SD) reported change from baseline in the Brief Pain Inventory pain severity subscale score (range, 0-10) of 0.1 (2.6) vs 0.2 (2.7) in control group patients (P = 0.88), and a mean (SD) reported change from baseline in the Brief Pain Inventory pain interference subscale score of 0.1 (3.2) vs -0.2 (3.0) in control group patients (P = 0.66).
<p>What role do Death Doulas play in end-of-life care? A systematic review</p> <p>Rawlings et al., 2018 ⁴³</p>	<ul style="list-style-type: none"> ● A systematic review of five papers describing the role and work of a death doula or death midwife in the context of end of life care, death or dying. ● This review demonstrated a paucity of formal academic literature describing the role and effectiveness of death doulas. ● There is a lack of information on the scope and functions of a death doula. For most papers, no information is provided on the number and demand for death doula services.

Source	Summary
Peer reviewed sources	
<p>Models of non-hospice palliative care: a review</p> <p>Beasley et al., 2018 ³</p>	<ul style="list-style-type: none"> • A secondary analysis of a published systematic review to define the characteristics of non-hospice palliative care. Nine studies from the systematic review were excluded due to not having a hospice/end of life focus, and three additional studies were included as part of the secondary analysis. • Several models of palliative care were identified: primary non-specialist interventions; specialist provider interventions, and hybrid non-specialist/specialist-provider interventions. • Primary non-specialist interventions: <ul style="list-style-type: none"> ○ Interventions provided by healthcare practitioners that had basic palliative care training or providers that were not board-certified palliative care specialists. ○ Subcategories included community home-based and ambulatory clinics. No inpatient interventions were identified using a primary non-specialist intervention. ○ Community/home-based interventions were provided in the home, nursing home, or by telehealth. These interventions were performed by nurses or other healthcare providers, including occupational and mental health therapists. Primary care physicians were consulted, but often were not directly involved with the intervention. ○ The ambulatory clinic interventions used both nurses and a team approach to provide assessment and education for patients. The frequency of visits ranged from one clinic visit up to a combination of 10 clinic visits and phone calls. • Specialist provider interventions: <ul style="list-style-type: none"> ○ Interventions provided by a specialty trained or board-certified palliative care member, or a specialist team. ○ Subcategories include community home-based, inpatient, and ambulatory clinic locations. ○ Interventions include assessment, education and advanced care planning. One study included a 24-hour on call service for symptom management. • Hybrid specialist-primary interventions: <ul style="list-style-type: none"> ○ Community home-based interventions with a focus on team communication among palliative care providers and the primary care team. Patient assessments and education were provided by palliative care providers using home visits and telephone follow-ups.

Source	Summary
Peer reviewed sources	
	<ul style="list-style-type: none"> ○ Specialist-primary models were inpatient. The palliative care team consulted with the primary healthcare teams after the initial visit to make recommendations and create a plan of care.
<p>Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: a comprehensive review</p> <p>Shahid et al., 2018 ³⁶</p>	<ul style="list-style-type: none"> ● A systematic review of 39 studies on the provision of culturally safe palliative care service delivery to Indigenous people in Australia, New Zealand, Canada and the United States, and to compare people's preferences, needs, opportunities and barriers to palliative care. <ul style="list-style-type: none"> ○ Needs: to collaborate and to engage meaningfully with communities and families when designing and evaluating a program; and the need for more education and training for both the Indigenous communities and healthcare staff in palliative care. ○ Preferences: living with family and within community (including community and/or extended family member gathers); dying at home; open, honest communication; and respect for patient choice. ○ Barriers: distance and affordability of services; staffing; lack of funding and resources; and poor availability of culturally appropriate services. ● Innovations and models of care: <ul style="list-style-type: none"> ○ An Australian conceptual model included seven key principles: equity (equal access); autonomy/empowerment (respecting patients' choices); trust (acknowledgement and consideration of the historical context of colonisation and its impact on the lives of Indigenous people and empathy while providing care); humane (non-judgemental care with a focus on quality of life and choice for patients and their families); seamless care (collaboration of a multidisciplinary team of health professionals and community-based organisations, working together across the continuum of care); emphasis on living (rather than on dying), and cultural respect (respect towards cultural practices and beliefs, culturally-based lifestyle. ○ Other service delivery models showing short-term outcomes: include patient navigators, outreach care, palliative shared care, outreach model, home-based service, hospice-based care; and integrated health service delivery models. ● Critical elements: <ul style="list-style-type: none"> ○ Community engagement

Source	Summary
Peer reviewed sources	
	<ul style="list-style-type: none"> ○ Education and training to upskill health staff, community stakeholders and family members ○ Culturally safe service delivery ○ Flexible organisation and program structure ○ Patient-centred care ○ Quality improvement in service delivery
<p>Effect of early and systematic integration of palliative care in patients with advanced cancer: a randomised controlled trial</p> <p>Vanbutsele et al., 2018 ¹⁰</p>	<ul style="list-style-type: none"> ● A randomised control trial to examine whether early and systematic integration of palliative care alongside standard psychosocial oncological care provides added benefit compared with usual care (n = 186). ● Results show early and systematic integration of palliative care in oncological care improves quality of life for patients with cancer. ● The positive effect is based on several core components: training of the palliative care team; the provision of semi-structured consultations by palliative care nurses; frequent symptom assessment and participation in multidisciplinary oncology meetings; and reporting in the electronic patient file.
<p>A systematic review of palliative care intervention outcomes and outcome measures in low-resource countries</p> <p>Potts et al., 2018 ²</p>	<ul style="list-style-type: none"> ● A systematic review of 18 papers to evaluate palliative care outcomes measures, outcomes and interventions in low-resource countries. ● Interventions evaluated include home-based palliative care models; a community-managed model; palliative care integrated with hospitals, hospices or HIV clinics; and models focused on patients' self-management. ● Across outcomes evaluated, results were reported in the direction of benefit associated with palliative care interventions.
<p>Respecting choices and related models of advance care planning: a systematic review of published evidence</p> <p>Mackenzie et al., 2018 ²⁹</p>	<ul style="list-style-type: none"> ● A systematic review of 16 studies on Respecting Choices®; a copyrighted program for advance care planning to assist individuals to consider, choose and communicate preferences to healthcare providers. ● Respecting Choices is a well-known model of advance care planning intended to assist individuals consider, choose, and communicate their preferences to healthcare providers. ● There is low-level evidence that Respecting Choices® and derivative models increase the incidence and prevalence of advance directive and physician orders for life-sustaining treatment completion.
<p>Effects of early integrated palliative care on caregivers of patients with lung and</p>	<ul style="list-style-type: none"> ● A randomised control trial of early integrated palliative care with oncology care versus oncology care alone for

Source	Summary
Peer reviewed sources	
<p>gastrointestinal cancer: a randomized clinical trial</p> <p>Jawahri et al., 2019 ¹¹</p>	<p>patients with incurable lung and non-colorectal gastrointestinal cancers (n = 275).</p> <ul style="list-style-type: none"> At week 12, caregivers in the intervention group reported significantly lower total psychological distress, including lower depression but not anxiety symptoms, compared with caregivers in the control groups. No significant intervention effects on caregivers' total psychological distress, depression or anxiety at week 24.
<p>The effect of weekly specialist palliative care teleconsultations in patients with advanced cancer -a randomized clinical trial</p> <p>Hoek et al., 2017 ³⁵</p>	<ul style="list-style-type: none"> A randomised control trial to determine if weekly teleconsultations from a hospital-based, specialist palliative care consultation team improved patient-experienced symptom burden compared to care as usual (n = 74). Results show weekly teleconsultations compared to usual palliative care leads to worse reported symptom scores among home-dwelling patients with advanced cancer.
<p>What do we know about different models of providing palliative care? Findings from a systematic review of reviews</p> <p>Brereton et al., 2017 ¹⁸</p>	<ul style="list-style-type: none"> A systematic review and narrative synthesis of 18 papers to evaluate and synthesise the existing evidence base for different types of models of palliative care in different settings. Three reviews report on home-based models of palliative care with positive benefits identified for patients with advanced illness, including an increased likelihood of dying at home. One study found multidisciplinary teams to be more effective than single disciplinary teams in one review. A team approach is found to improve pain and symptom control, as well as reduce anxiety in some cases. Five reviews all identify some advantages of team-based models of palliative care in terms of effectiveness. One review based on four studies reports little evidence to support the effectiveness of interdisciplinary teams. The impact of palliative care teams on home deaths was equivocal; but hospice at home teams lead to more home deaths and fewer deaths in nursing homes.
<p>Advance care planning uptake among patients with severe lung disease: a randomised patient preference trial of a nurse-led, facilitated advance care planning intervention</p> <p>Sinclair et al., 2016 ³³</p>	<ul style="list-style-type: none"> A randomised controlled trial to assess whether a systematic nurse-led intervention increases advanced care planning in patients with advanced respiratory disease (n = 149). Nurse facilitators offered facilitated advanced care planning discussions, prompted further discussions with doctors and loved ones, and assisted participants to appoint a substitute medical decision-maker and complete an advance directive.

Source	Summary
Peer reviewed sources	
	<ul style="list-style-type: none"> At six months, formal advanced care planning uptake was significantly higher in the intervention sample compared with usual care.
<p>Systematic review of the effectiveness, barriers and facilitators to general practitioner engagement with specialist secondary services in integrated palliative care</p> <p>Carmont et al., 2017 ⁶</p> <p>(Abstract only)</p>	<ul style="list-style-type: none"> A systematic review of 17 studies to evaluate the effectiveness of interventions designed to engage general practitioners and specialist secondary services in integrated palliative care. There is some evidence that integrated palliative care can reduce hospitalisations and maintain functional status. There are substantial barriers to providing integrated care.
<p>Effects of early integrated palliative care in patients with lung and GI cancer: a randomized clinical trial</p> <p>Temel et al., 2016 ¹²</p>	<ul style="list-style-type: none"> A randomised controlled trial to evaluate the impact of early integrated palliative care in patients with newly diagnosed incurable lung or non-colorectal GI cancer compared to usual oncology care (n = 350). Results show integrated care improves quality of life and mood in patients with incurable cancers. Intervention patients were also more likely than usual care patients to report that knowing about their prognosis was “very helpful” or “extremely helpful” in making decisions about treatment and coping with the disease.
<p>Integrated palliative care in Europe: a qualitative systematic literature review of empirically-tested models in cancer and chronic disease</p> <p>Siouta et al., 2016 ⁴⁴</p>	<ul style="list-style-type: none"> A systematic review of 14 studies to identify empirically evaluated models of palliative care (PC) in cancer and chronic disease in Europe. Includes seven models for chronic disease, four for integrated care in oncology, two for both cancer and chronic disease, and two for end of life pathways. All the included studies placed their focus on symptom treatment. All but one study showed positive outcomes in terms of better symptom control and better quality of life; better communication between personnel, patients and caregivers; more deaths at the patients’ homes; and more cost-effective care. Proposed framework of integrated palliative care: <ul style="list-style-type: none"> Focus of intervention: the focus of intervention will be placed on symptom treatment, consulting of patients/family and training of the personnel. Setting: the design of the framework is such that it can be applied to every care setting.

Source	Summary
Peer reviewed sources	
	<ul style="list-style-type: none"> ○ Timing of intervention: the intervention can be initiated throughout the disease trajectory either concurrently or in the end of life. ○ Composition of team: the framework requires a multidisciplinary team with members that are trained in the delivery of PC. This team can consist of general practitioners, physician specialists, nurses and specialist nurses, psychologists, social workers, and administrative assistants. ○ Collaboration strategy: the collaboration strategy refers to the ways that the represented disciplines cooperate and assess emerging issues and should be based on the involvement of the multidisciplinary team, its meetings, and the utilisation of protocols.
<p>Integrated palliative care in the Spanish context: a systematic review of the literature</p> <p>Garralda et al., 2016 ⁴⁵</p>	<ul style="list-style-type: none"> ● A systematic review of 49 papers to identify literature on integrated palliative care in the Spanish context, either in cancer or other advanced chronic diseases. ● The results show that explications of integrated palliative care in the Spanish literature exist, but that there is insufficient evidence of its impact in clinical practice.
<p>Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial</p> <p>Wong et al., 2016 ²⁴</p>	<ul style="list-style-type: none"> ● A randomised control trial to examine the effects of home-based transitional palliative care for patients with end-stage heart failure after hospital discharge (n = 84). ● The design of the Transitional Care Palliative-ESHF (TCP-ESHF) program was based on two main conceptual guides: the recommended principles of palliative for patients with heart failure; and the 4Cs for transitional care model (comprehensiveness, continuity, coordination and collaboration). ● The intervention group (n = 43) had a significantly lower readmission rate than the control group (n = 41) at 12 weeks.
<p>Effect of short-term integrated palliative care on patient-reported outcomes among patients severely affected with long-term neurological conditions</p> <p>Gao et al., 2020 ¹⁶</p>	<ul style="list-style-type: none"> ● A randomised control trial to determine the effectiveness of a short-term integrated palliative care intervention for people with long-term neurological conditions (n = 350 patients and 229 informal caregivers). ● The intervention lasts from six to eight weeks from referral and includes: comprehensive assessment; personalised care planning; case management and care coordination; and advising existing care providers. ● There were no statistically-significant differences between trial arms for the primary outcome (eight symptoms – pain, shortness of breath, nausea, vomiting, constipation,

Source	Summary
Peer reviewed sources	
	<p>spasms, difficulty sleeping, and mouth problems) or any of the secondary outcomes (changes in other palliative care symptoms, palliative care needs, psychological stress, health-related quality of life and satisfaction).</p>
<p>To what degree is palliative care integrated in guidelines and pathways for adult cancer patients in Europe: a systematic literature review</p> <p>Van Beek et al., 2016 ⁴⁶</p>	<ul style="list-style-type: none"> • A systematic review of 74 papers (60 guidelines and 14 pathways) to assess the integration of palliative care in the content of guidelines/pathways of adult cancer patients in Europe published from January 1995 to December 2013. • Nearly 80% of the studies placed emphasis on the holistic approach, namely the assessment of the patient's physical, psychological, social and spiritual issues, although only half of these recommendations (37%) specified the exact timing of when these holistic assessments should take place.
<p>End-of-life care pathways for improving outcomes in caring for the dying</p> <p>Chan et al., 2016 ³⁰</p>	<ul style="list-style-type: none"> • Updated version of a Cochrane review published in Issue 11, 2013 in the Cochrane Library. Includes one new study. • A review to assess the effects of end of life care pathways, compared with usual care (no pathway) or with care guided by another end of life care pathway across all healthcare settings. • The primary outcomes of this review were physical symptom severity, psychological symptom severity, quality of life, and any adverse effects. • There was very low-quality evidence of a difference in overall control of breathlessness that favoured the Liverpool Care Pathway group compared to usual care. The study reported an odds ratio (OR) of 2.0 with 95% confidence intervals (CIs) 1.1 to 3.8. Very low-quality evidence of no difference was found for pain, nausea and vomiting.
<p>The needs, models of care, interventions and outcomes of palliative care in the Caribbean: a systematic review of the evidence</p> <p>Maharaj et al., 2016 ⁴⁷</p>	<ul style="list-style-type: none"> • A systematic review of nine papers to assess palliative care needs in the Caribbean published between 1987 and 2014. • Results highlights the need for healthcare policy, training of staff, education, access to analgesia, and palliative care support services in this region.
<p>Elements of optimal paediatric palliative care for children and young people: An integrative</p>	<ul style="list-style-type: none"> • A systematic review of seven papers to identify the key elements of optimal paediatric palliative care from the perspectives of children and young people with palliative care needs and their parents published between 2000 and 2013.

Source	Summary
Peer reviewed sources	
<p>review using a systematic approach</p> <p>Virdun et al., 2015 ⁴⁸ (Abstract only)</p>	<ul style="list-style-type: none"> Paediatric palliative care should be flexible, responsive and tailored to the needs of children and their families.
<p>An advanced practice nurse coordinated multidisciplinary intervention for patients with late-stage cancer: a cluster randomized trial</p> <p>Mccorkle et al., 2015 ³⁴</p>	<ul style="list-style-type: none"> A randomised control trial to evaluate the effects of a multidisciplinary coordinated intervention by advanced practice nurses at the clinic level on outcomes with patients newly diagnosed with late-stage cancer (n = 146). The essential components of the 10-week standardised intervention delivered by different members of each team included monitoring patients' status, providing symptom management, executing complex care procedures, teaching patients and family caregivers, clarifying the illness experience, coordinating care, responding to the family, quality of life, and collaborating with other providers. No differences between the two groups on the primary patient-reported outcomes (symptoms, health distress, depression, functional status, self-reported health) at one- and three-months post baseline; however, physical and emotional symptoms remained stable or significantly improved from baseline for both groups. Overall, secondary outcomes remained stable within the groups.
<p>Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: A systematic review</p> <p>Pringle et al., 2015 ⁴⁹</p>	<ul style="list-style-type: none"> A systematic review of 33 papers to examine international evidence relating to dignity and person-centred care for people with palliative care needs in the acute hospital setting published between 1 January 2000 and 1 April 2014. Acute hospital staff require adequate training, including symptom control, and the correct environment in which to deliver dignified and person-centred end of life care.
<p>Patients' preferences in palliative care: A systematic mixed studies review</p> <p>Sandsdalen et al., 2015 ⁵⁰</p>	<ul style="list-style-type: none"> A systematic review of 23 studies to identify preferences for palliative care among patients in the palliative phase of their illness published from 1946 and 2014. Four themes emerged representing patient preferences for care. The theme 'Living a meaningful life' illustrated what patients strived for. The opportunity to focus on living required the presence of 'Responsive healthcare personnel', a 'Responsive care environment' and 'Responsiveness in the organisation of palliative care'.

Source	Summary
Peer reviewed sources	
<p>An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial</p> <p>Higginson et al., 2014 ¹⁷</p>	<ul style="list-style-type: none"> • A randomised control trial to assess the effectiveness of early palliative care integrated with respiratory services for patients with advanced disease and refractory breathlessness (n = 105). • Breathlessness support services improved breathlessness mastery. The improvement in survival requires further investigation.
<p>Systematic realist review of key factors affecting the successful implementation and sustainability of the Liverpool care pathway for the dying patient</p> <p>McConnell et al., 2013 ³¹</p>	<ul style="list-style-type: none"> • A systematic review of 58 papers to investigate factors that help or hinder successful implementation and sustainability of the 'Liverpool Care Pathway', which is recommended internationally as a best practice model for care at end of life. • The key components of the intervention (a dedicated facilitator, education and training, audit and feedback) must be configured to influence the beliefs of staff in relation to end-of-life care and increase their motivation and self-efficacy in relation to using the Liverpool Care Pathway.
<p>Evaluation of a new model of short-term palliative care for people severely affected with multiple sclerosis: a randomised fast-track trial to test timing of referral and how long the effect is maintained</p> <p>Higginson et al., 2011 ⁷</p>	<ul style="list-style-type: none"> • A randomised control trial to examine (1) whether the timing of referral to short-term palliative care affected selected outcomes, and (2) the potential staff-modifying effect of the short-term palliative care intervention (whether the effects were sustained over time after care was withdrawn) (n = 52). • A higher rate of improvement in Zarit (Caregiver) Burden Interview score was seen in the fast-track group. After withdrawal of palliative care, effects were maintained at 12 weeks, but not at 24 weeks. • Overall, receiving palliative care earlier has a similar effect on reducing symptoms but greater effect on reducing caregiver burden, compared to later referral.
<p>Effects of person-centred and integrated chronic heart failure and palliative home care. PREFER: a randomized controlled study</p> <p>Brännström et al., 2014 ²⁵</p>	<ul style="list-style-type: none"> • A randomised control trial to evaluate the outcome of person-centred and integrated palliative advanced home care and heart failure care for patient symptoms, health-related quality of life, and hospitalisations compared with usual care at one, three and six months (n = 36). • Patients in the intervention group were offered a multidisciplinary approach involving collaboration between specialists in palliative and heart failure care, i.e. specialised nurses, palliative care nurses, cardiologists, palliative care physicians, physiotherapists, and occupational therapists. The patients were also offered structured, person-centred care (PCC) at home.

Source	Summary
Peer reviewed sources	
	<ul style="list-style-type: none"> • Results show patients receiving the intervention had improved health related quality of life compared with controls, improvement with nausea and total symptom burden, and self-efficacy. • Fifteen re-hospitalisations (103 days) occurred in the intervention group, compared with 53 (305 days) in the control group.
<p>Assessing the uptake of the Liverpool Care Pathway for dying patients: a systematic review</p> <p>Stocker et al., 2013 ³² (Abstract only)</p>	<ul style="list-style-type: none"> • A systematic review of 17 papers on Liverpool Care Pathway uptake published between January 1990 and July 2012. • A total of 18,052 patients with cancer and non-cancer diagnoses were placed on the pathway, in a variety of inpatient and primary care settings. Although the Liverpool Care Pathway is widely recommended, it is only used for around half of dying patients. Reasons may include lack of knowledge, high staff turnover and concerns about applicability, particularly for unpredictable dying trajectories.
<p>Elements of effective palliative care models: a rapid review</p> <p>Luckett et al., 2014 ⁴</p>	<ul style="list-style-type: none"> • A rapid review of electronic databases and the grey literature from 1,959 peer-reviewed articles, 23 reported systematic reviews, 9 additional randomised control trails, and 34 non-randomised comparative studies to identify evidence-based models of palliative care to inform policy reform in Australia. • Variation in the content of models, contexts in which these were implemented, and lack of detailed reporting meant that elements of models constituted a more meaningful unit of analysis than the models themselves. • Case management was the element most consistently reported in models for which comparative studies provided evidence for effectiveness. • Essential attributes of population-based palliative care models identified by policy and addressed by more than one element were communication and coordination between providers (including primary care), skill enhancement, and capacity to respond rapidly to individuals' changing needs and preferences over time. • Models of palliative care should integrate specialist expertise with primary and community care services and enable transitions across settings, including residential aged care.
<p>Team-based models for end-of-life care: an evidence-based analysis</p>	<ul style="list-style-type: none"> • Literature search located 10 randomised controlled trials to determine whether an optimal team-based model of care exists for service delivery at end of life: hospital, direct contact; home, direct contact; home, indirect

Source	Summary
Peer reviewed sources	
Health Quality Ontario, 2014 ¹⁹	<p>contact; comprehensive, indirect contact; comprehensive, direct contact; comprehensive, direct and early contact. Direct contact is when team members see the patient; indirect contact is when they advise another health care practitioner (e.g. a family doctor) who sees the patient.</p> <ul style="list-style-type: none"> • A comprehensive model was described as one that provides continuity of service across inpatient and outpatient settings, e.g. in hospital and then at home. • All teams consisted of a nurse and physician at the minimum, at least one of whom had a specialty in end of life health care. • More than 50% of the teams offered services that included symptom management, psychosocial care, development of patient care plans, end of life care planning, and coordination of care. • Moderate-quality evidence that the use of a comprehensive direct contact model initiated up to nine months before death improved informal caregiver satisfaction and the odds of having a home death and decreased the odds of dying in a nursing home. • Moderate-quality evidence that the use of a comprehensive, direct and early (up to 24 months before death) contact model improved patient quality of life, symptom management and patient satisfaction. • Review did not find that using a comprehensive team-based model had an impact on hospital admissions or length of stay. • Study found low-quality evidence that the use of a home team-based model increased the odds of having a home death.
<p>End-of-life care pathways for improving outcomes in caring for the dying</p> <p>Chan et al., 2013 ⁵¹</p>	<ul style="list-style-type: none"> • This is an updated version of a Cochrane review first published in Issue 1,2010 of The Cochrane Library. The original review identified 920 titles; no additional studies met criteria for inclusion in the review update. • Since the last version of this review, no new studies have met criteria for inclusion in the review update. With recently documented concerns related to the potential adverse effects associated with Liverpool Care Pathway (the most commonly-used end of life care pathway), the study does not recommend decision making based on indirect or low-quality evidence. All health services using end of life care pathways are encouraged to have their use of the pathway to date, independently audited. Any subsequent use should be based on carefully documented evaluations.

Source	Summary
Peer reviewed sources	
<p>Paediatric palliative care in sub-Saharan Africa: a systematic review of the evidence for care models, interventions, and outcomes</p> <p>Harding et al., 2014 ⁵²</p>	<ul style="list-style-type: none"> • A systematic review of five articles to assess the evidence for paediatric palliative care models, interventions, and outcomes to appraise the state of the science and inform best practice. • Of the five articles identified in the peer-reviewed literature, four reported services with evaluation data and the fifth reported only service description. • One study offers a model of integration that may enhance sustainability through effective referral networks, achieving a model of care aimed at delivering palliative care across diverse health care settings and at the geographical point of need.

Appendix

PubMed search terms

((“palliative care”[mh] OR palliat*[tiab] OR hospices[mh] OR “terminally ill”[tw] OR “Terminal Care”[mh] OR “terminal care”[tw] OR “end of life”[tiab])

AND (Models, Organizational[MeSH] OR organizational innovation[MeSH] OR "Patient-Centered Care/organization and administration"[Mesh] OR Delivery of Health Care, Integrated[MeSH] OR "model of care"[tiab] OR "models of care"[tiab] OR "care model*" [tiab] OR "care delivery model*" [tiab] OR "organisation of"[tiab] OR "organisational model*" [tiab] OR "organisation model*" [tiab] OR "organization of"[tiab] OR "organizational model*" [tiab] OR "organization model*" [tiab] OR "healthcare delivery model*" [tiab] OR "integrated care"[tiab] OR "integrated model*" [tiab] OR multidisciplinary[ti] OR "integrated"[ti] OR model[ti] OR “shared care”[ti]))

AND (((systematic[Title] AND review[Title]) OR (Systematic Review[Filter]) OR (“meta-analysis”[Title/Abstract]) OR (“meta analyses”[Title/Abstract]) OR (Meta-Analysis[Filter])) OR (“randomized controlled trial”[pt] OR "controlled clinical trial"[pt] OR "randomized"[tiab] OR "placebo"[tiab] OR "clinical trials as topic"[mesh:noexp] OR "randomly"[tiab] OR "trial"[ti]) AND (english[Filter])) NOT (animals[mh] NOT humans[mh] AND (english[Filter]))))

Inclusion and exclusion criteria

Inclusion	Exclusion
<ul style="list-style-type: none"> Published 2010 to present Organisational models of care (the way in which care is delivered) Palliative care as per the definition described in the background section of this review Systematic reviews/meta-analysis or randomised controlled trials English language 	<ul style="list-style-type: none"> All other study designs

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