

This is a repository copy of What do we know about different models of providing palliative care? Findings from a systematic review of reviews..

White Rose Research Online URL for this paper: https://eprints.whiterose.ac.uk/115109/

Version: Accepted Version

Article:

Brereton, L., Clark, J., Ingleton, C. orcid.org/0000-0001-5489-1089 et al. (4 more authors) (2017) What do we know about different models of providing palliative care? Findings from a systematic review of reviews. Palliative Medicine, 31 (9). pp. 781-797. ISSN 0269-2163

https://doi.org/10.1177/0269216317701890

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



What is already known about the topic?

- Globally, as demand for palliative care is increasing amongst those with life-limiting illnesses,
 there has been a rapid growth in specialist and generalist palliative care service provision with a
 range of different of models of palliative care service provision being developed and
 implemented internationally.
 - The published evidence has been synthesised in a number of reviews which have attempted to identify the effectiveness and cost effectiveness of different models of palliative care.
 - There is no comprehensive overview of the current evidence base to support decision-making based on the advantages and disadvantages of different models of palliative care or to identify any gaps in the evidence base where more primary research is needed.

What this paper adds?

• The outcomes measured vary considerably, making meta-analysis impossible. None-the-less, the available evidence indicates that irrespective of setting or patient characteristics, models of palliative care appear to show benefits for patients and their carers, with no evidence for negative effects. Some models of palliative care may reduce total healthcare costs.

Heterogeneity, methodological limitations, poor reporting of models and a lack of consensus about outcome measures i.e. what constitutes "benefit to patients" makes it impossible to identify the key components that may enable replication and prediction of which models of provision are most appropriate for specific contexts or for specific patient groups.

• In addition to addressing the problems associated with heterogeneity and poor reporting within studies and reviews themselves, this comprehensive and critical review identifies significant gaps in the evidence base and the urgent need to identify models of palliative care by name, define and describe their components in detail in order to differentiate between them in both practice and research. Consensus is required about important outcome measures in palliative care and appropriate, consistent, outcomes should be selected to demonstrate the model's mechanisms of action (i.e. how it works).

Implications for practice, theory or policy?

- Much has been written and summarised in systematic reviews about models of palliative care in a range of practice settings. However, closer examination of the evidence base highlights a number of areas that warrant further attention for this to be useful to policy makers and clinicians. Much more detailed and systematic reporting of the models in both primary research studies and systematic reviews, ideally using existing checklists such as TIDiER, is essential in order to understand the key components of successful models which could be replicated.
- Further primary studies are required that assess models of palliative care as complex interventions and enable decision makers to determine which models are likely to be most effective in different settings and for different patient groups.

Abstract

Background: A wide range of organisational models of palliative care exist. However, decision makers need more information about which models are likely to be most effective in different settings and for different patient groups.

1 Aims: To identify the existing range of models of palliative care that have been evaluated, what is 2 already known and what further information is essential if the most effective and cost-effective models 3 are to be identified and replicated more widely. 4 Design: A review of systematic and narrative reviews according to the Preferred Reporting Items for 5 Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Study quality was assessed using the 6 AMSTAR tool. 7 Data sources: MEDLINE, EMBASE, PsycINFO, CINAHL, Cochrane Library, Web of Science and ASSIA were 8 searched for reviews about models of service provision from 2000- 2014 and supplemented with Google 9 searches of the grey literature. 10 Results: Much of the evidence relates to home based palliative care, although some models are 11 delivered across care settings. Reviews report several potential advantages and few disadvantages of 12 models of palliative care delivery. However, under-reporting of the components of intervention and 13 comparator models are major barriers to the evaluation and implementation of models of palliative 14 care. 15 Conclusions: Irrespective of setting or patient characteristics, models of palliative care appear to show 16 benefits and some models of palliative care may reduce total healthcare costs. However, much more 17 detailed and systematic reporting of components and agreement about outcome measures is essential 18 in order to understand the key components and successfully replicate effective organisational models. 19

Keywords: palliative care, models organizational, systematic review, meta-review

2

Introduction

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

The potential value of palliative care to improve the management of complex care needs and relieve suffering, is increasingly recognised internationally¹. Demographic changes mean populations are living longer with more chronic and complex health needs. Hence, globally, the demand for palliative care is increasing and there has been a rapid growth in palliative care service provision². Models of palliative care service provision are complex interventions³ developing in various ways internationally⁴ to reflect different cultures, religious beliefs, legal frameworks and resource-settings⁵. Centeno et al's (2013) Atlas of Palliative Care⁴ classifies palliative care in Europe based on the place of provision (acute hospital; care in medium and long term places other than general hospitals and at home) and the level of intervention ('basic', 'specialised' or 'other specialised' care). The Atlas⁴ a**lso provides forty-three detailed, country specific reports⁴. Internationally, generalist or specialist models of palliative care are recognised, categorised by the training and experience of the health care practitioners providing care. A key influence on palliative care provision in each country is the way that palliative and health care is funded in different systems. In 2014, the World Health Assembly (WHA) adopted a Resolution 6 calling upon national governments to improve access to palliative care as a core component of health systems. Given the ongoing rapid expansion of palliative care services world-wide and governmental commitments to the WHA (World Health Assembly) Resolution for further expansion, policy makers and

21 service commissioners urgently require evidence to underpin decision-making.

2

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

*Some work attempting to identify the effectiveness and cost effectiveness of models of palliative care has been completed at review level⁷. However, in addition to evidence about the effectiveness and costeffectiveness of the various organisational models of palliative care, policy makers need review level evidence about the wider advantages (i.e. benefits to patients, carers, professionals and / or the healthcare system) and disadvantages (i.e. drawbacks to patients, carers and the healthcare system) of different models of palliative care. Furthermore, identifying which components of palliative care models are most appropriate for different patient groups and under what circumstances may provide insight into causal pathways and mechanisms of action (i.e. how each model works). This review of review level evidence builds on the existing body of evidence to assist decision making about services and the future the development and evaluation of these models as complex interventions⁸. Complex interventions are characterised by the number of interacting components they have; the number of groups or organisational levels targeted by the intervention; the number and degree of difficulty of behaviours required by those delivering or receiving the intervention; the number and variability of outcomes and the degree of flexibility or tailoring of the intervention to meet individual needs⁸. As the aim of palliative care is to meet patient's individual and holistic needs, models of care will be developed and tailored to the individual or family's needs in a variety of ways. Hence, a clear statement about the underlying theory of the causal mechanisms (i.e. how the model works, for whom and under what circumstances) would assist the evaluation of models of palliative care. Indeed, understanding the key components of models of palliative care is fundamental to their evaluation. Research Aim The overall aim of this systematic review of reviews is to critically evaluate and synthesise the existing evidence base for different types of models of palliative care in different settings and identify the key gaps in the evidence base that still need to be addressed.

Methods

1

10

15

- 2 We conducted a systematic review of systematic and narrative reviews of models of palliative care for
- 3 any adult patient group with life-limiting illnesses. Davidson et al (2006)⁹ describe models of care as an
- 4 overarching design for health care service provision which consists of defined core elements. We define
- 5 the term "model" of palliative care service provision as shown in Box 1, providing explicit details about
- 6 the 'core elements' for clarity. Our definition purposefully excludes process models, such as the
- 7 Liverpool Care Pathway (LCP) or Integrated Care Pathways (ICP), which focus on describing the detailed
- 8 processes of care provision rather than their structural organisation. The focus on structural models is
- 9 entirely appropriate given the desire to inform service commissioning.

11 Box 1: Definition of "model" of palliative care service provision

For this review, the term 'model' of palliative care was defined as any structured 12 care model involving multiple components including 'who delivers (e.g. professionals, paid carers) the intervention (specialist or generalist palliative 13 care), where (setting – e.g. hospital), to whom (care recipients), when (i.e. timing and duration), how (e.g. face to face) and for what purpose (i.e. expected 14

Search strategy

outcomes)?"

- 16 Our search strategy aimed to identify review-level evidence about different structural models of
- 17 palliative care. Excluding process models enabled a focus on the resources required to deliver service
- 18 models rather than processes that assist care delivery.

Assessment of quality of included studies

1 We searched seven databases (MEDLINE via OVID SP, EMBASE via OVID SP, PsycINFO via OVID SP, 2 CINAHL via EBSCO, Cochrane Library via Wiley Interscience (Cochrane Databases of Systematic Reviews 3 and Database of Abstracts of Reviews of Effects) for reviews published in English between 2000 and 4 2014 (Box 2). The search included palliative care terms with a validated systematic review filter 10 5 tomaximise sensitivity whilst reducing the number of records retrieved. Searches were conducted in 6 April/May 2014 and updated in October 2014. 7 Reference lists of included reviews were scrutinised to identify additional reviews that potentially met 8 the inclusion criteria. We also undertook Google searches using key search terms ('systematic review',' 9 'palliative care,' 'specialist palliative care' and 'adults') to examine ten relevant websites (Marie Curie, 10 Sue Ryder, St Christopher's Hospice, King's Fund, Help the Hospice, The National Institute for Health and 11 Care Excellence (NICE), The World Health Organisation (WHO), The European Association for Palliative 12 Care (EAPC), The National Council for Palliative Care (NCPC) and Hospice UK) for review level evidence 13 on palliative care models. 14 15 Study selection 16 Identified citations were uploaded to a Reference Manager database and duplicate references were 17 removed. Two reviewers independently screened all titles and abstracts (where available) to identify 18 reviews that met the inclusion criteria (Table 1). The full text of potentially relevant titles was 19 independently assessed by two reviewers and, where there was disagreement, a third reviewer was 20 consulted to determine inclusion. 21

Following study selection, two reviewers independently assessed the methodological quality of included

studies using the AMSTAR (A MeaSurement Tool to Assess Reviews) tool 11 which was specifically

4 designed to assess the quality of systematic reviews. Scores were totalled, allowing the review to be

classified as low quality (3 or lower), medium quality (4 to 7) or high quality (8 to 11). Reviews were

included regardless of their quality. (Table 3).

Data extraction

Two reviewers independently extracted data from each included review using predefined and piloted data extraction forms specifically designed for the review. Data were extracted about the key characteristics of the reviews including information about the advantages and disadvantages of models and used to inform Table 2, which was subsequently circulated to all reviewers for confirmation. No

additional quality checks were made.

Synthesis

As the evidence base mainly consists of narrative reviews of studies with diverse methodologies, we undertook a narrative data synthesis following methods outlined by Popay et al (2006)¹². The aim was to undertake a preliminary synthesis, with the intention of explaining which models were effective for which patient groups in which particular settings. We envisaged being able to identify causal pathways and mechanisms of action (i.e. how each model works). We also wanted to explore relationships within and between studies before determining the robustness of the synthesis. The evidence reported in each review was tabulated to provide a descriptive summary of the main characteristics and outcomes of

1 each included review (Table 2). Where reported, we also extracted the definition and a description of 2 the interventions reported as well as their components as described within each review. The lack of 3 detail included in the reviews limited synthesis as it was not possible to identify theory underpinning 4 how and why the intervention works or for whom, although reviews did report on the advantages and 5 disadvantages associated with models. 6 Results 7 Search results All results are presented in compliance with PRISMA guidelines¹³ (Figure 1). A total of thirteen reviews 8 9 were identified from the electronic searches. A further four reviews were identified from searching the 10 reference lists of included publications. One further publication⁷, was identified by a scoping exercise which informed the funding bid. This review is a Health Services Assessment Collaboration publication 11 from New Zealand and was therefore not found within the search strategy. Eighteen reviews ^{7,14-30} met 12 13 the inclusion criteria. AMSTAR quality scores ranged from 2-11 (Table3). 14 15 Characteristics of included reviews 16 17 Table 2 summarises the characteristics of included reviews which were published between 2002 and 18 2014, most (n=11) being published in, or after, 2008. Included reviews consisted of studies that involved meta-analyses 14,15,16,26,28,29 ; meta synthesis 26 and narrative reviews 7,17,18,19,20,21,22,23,24,25,27,30 . One of the 19 narrative reviews present the results by grade of evidence 137 and another focuses on costs and cost 20 effectiveness data of models across all care settings¹⁸. 21

2

7

Population, intervention, comparator and outcomes reported

- 3 Heterogeneity is evident in the adult populations, interventions, comparators and outcomes found in
- 4 the reviews (Table 2). All reviews consider one or more of the following; health service outcomes,
- 5 patient outcomes and family or caregiver outcomes. Patient and caregiver outcomes relate to physical
- 6 (e.g. physical symptoms), psychological (e.g. coping), social issues (e.g. place of care).

The range of models of palliative care

- 8 Models are often classified with reference to the setting in which they are delivered. Evidence
- 9 frequently describes home based palliative care or models that are delivered across care settings (i.e.
- 10 home, hospital, or inpatient hospice). Using descriptors of the models found in the included reviews for
- 11 fidelity, these models have been clustered together as follows:
- 1. home based palliative care ^{14, 15,16} (i.e. models of palliative care delivered within the patient or
- their carer's own home),
- models delivered across multiple settings.
- 15 Our approach to reporting on the models across settings is pragmatic due to the lack of detailed
- description of the models in the included publications. The terms used below to 'classify' the models
- 17 reflect those used in the reviews themselves as it is not possible to develop a typology of models from
- 18 the scant information available about these in the included reviews. It is not appropriate to re-define
- 19 these "clusters" as this involves making assumptions about the characteristics of the models identified.
- 20 Therefore models in this review are 'clustered' according to the terms used to describe the models in
- 21 the reviews themselves as this best reflects the focus of the included reviews as:

- palliative care ^{7,17,18} or a palliative care approach ¹⁹. This includes palliative care for patients with HIV / AIDS ¹⁷ and dementia ¹⁹ and outpatient palliative care ²⁰ for patients with various diagnoses, including cancer, Congestive Heart Failure and Chronic Obstructive Pulmonary Disease delivered in non-hospice settings, including specialist consultations and co-management in clinics, in home or residential home settings.
 - specialised palliative care ^{21,22} for patients with various diagnoses or specialist palliative care for
 patients with cancer²³ including hospice care²⁴ (again, for patients with various diagnoses);
 - a team approach defined as models which provide an integrated team based approach to
 providing palliative care. Models are described as a palliative care team²⁷ specialist palliative
 care team²⁶; palliative and hospice care teams (PCHCT)²⁸; an interdisciplinary team approach²⁵;
 hospital-based palliative care teams²⁹ or dedicated community teams³⁰.

Despite limitations in the reporting about models, it is clear that considerable heterogeneity exists in the models of palliative care and their components (Table 2). None-the-less, almost all models appear to involve some specialist palliative care provision (i.e. provision by delivery agents with training in palliative care), albeit that the level of the care providers' training is not explicitly stated in all publications. Often, differences between the models are unclear and models are potentially overlapping. Included reviews report that models are often not well defined or described in original studies, which explains the paucity of subsequent reporting in reviews. A key limitation of the evidence base is the lack of descriptive detail provided about the models which makes it difficult to know how these have been conceptualised and to identify similarities and differences.

The advantages and disadvantages of models of palliative care

20

1 Insights into causal pathways and mechanisms of action are not evident in the evidence base. Reviews 2 report a range of outcomes conceptualised and measured in different ways. This provides huge 3 challenges in making comparisons across outcomes. The varied reporting of evidence (i.e. by outcome, 4 study, setting or a combination of these) compounds difficulties in comparing review findings. The 5 reporting of the individual models and components is too scant, and too variable for synthesis of 6 findings about which components of palliative care models are most appropriate for different patient 7 groups and under what circumstances across different reviews to be feasible. None-the-less, it is 8 possible to report on the advantages and disadvantages of models as reported in the reviews. 9 10 Evidence for home based palliative care models Three reviews 14,15,16 report specifically on home based models of palliative care for patients with 11 12 advanced illness, including malignant and non-malignant conditions (Table 2). Positive benefits of 13 palliative home care services over comparator models (which varied) are reported (see Table 2). The 14 benefits include an increased likelihood of dying at home, as identified in two meta-analyses 14,16. A third meta-analysis¹⁵ reports inconclusive, but compelling trends in the evidence in favour of home services 15 16 increasing home deaths without compromising symptoms, QoL or costs compared to other models that 17 did not include access to home nursing. 18 19

Evidence for models of care involving provision across different settings:

- 1 One review¹⁸ specifically reports on the costs and cost effectiveness of palliative and / or hospice care
- 2 interventions in any setting (i.e. hospital-based, home-based and hospice care). This review includes
- 3 home, hospital and hospice based palliative care and therefore appears in more than one section below.
- 4 The remaining fourteen reviews 7,17,19,20,21,22,23,24,25,26,27,28,29,30 report on a range of heterogeneous
- 5 intervention and comparator models of palliative care which have been implemented across a range of
- 6 contexts and settings.
- 7 Additionally, the heterogeneity of these models, the limited volume of evidence relating to each service
- 8 model and the diverse reporting of findings across reviews makes synthesis difficult. Reviews report
- 9 findings with reference to the outcomes measured 7,14,15,16,18,22,23,25,30 both interventions and outcomes 29
- or outcomes and themes identified²⁴; method of analysis²⁸, evidence grade¹⁷, setting^{26, 27}, study^{19,20, 21} or
- 11 study type 26 .

14

15

16

17

18

19

20

21

22

13 "Palliative care or a palliative care approach, including outpatient palliative care":

Four reviews^{7,17,19,20} report some evidence suggesting that palliative care reduces total healthcare costs, with one review suggesting there is reduced healthcare utilization and a lengthening of survival for patients with lung cancer²⁰. Evidence from high quality RCTs indicate a reduction in direct costs for programmes including home care with Palliative Care Team (PCT) support compared to usual care⁷. Home care programmes also reduce the need for acute hospital care⁷. Harding et al (2005)¹⁷ and Sampson et al (2005)¹⁹ provide scant evidence to support their conclusion, possibly due to limitations in the reporting of this data in primary studies. None-the-less, Smith et al's (2014)¹⁸ more detailed findings which focus on the costs of palliative care concur with these reviews, indicating that, in most cases, palliative care is consistently found to be significantly less costly than comparator models. However,

- Smith et al (2014)¹⁸ acknowledge that their findings are based on variable cost data that often fails to consider 'out of pocket expenses' or informal care costs. The evidence base for cost-effectiveness is very limited as Smith et al (2014)¹⁸ report on only one cost effectiveness study, the results of which are inconclusive. This finding confirms Arora et al's (2011)⁷ conclusions that the cost-effectiveness of palliative care has not been rigorously assessed.

 Three reviews^{7,17,20} conclude that there are benefits or trends indicating some benefits of palliative care, including an increase in patient and family / caregiver satisfaction and improvements in symptom
 - control. Rabow et al (2013)²⁰ also report that outpatient palliative care services improve clinician satisfaction. Harding et al's (2005) review¹⁷ reports data that patients with HIV / AIDS receiving home care value the emotional support and high quality of care received, as well as being able to remain at home and avoid hospital visits which was less disruptive of their daily routine. This review¹⁷ also suggests that both home and inpatient hospice care significantly improved anxiety, insight and spiritual wellbeing. Only Arora et al (2011)⁷ reports on place of death, finding inconclusive results in terms of whether patients died at home or not. This review⁷ also reports little evidence of benefits for patient survival, quality of life, patient satisfaction and resource use. A fourth¹⁹ review concludes that there is insufficient evidence to indicate benefits of a palliative care approach for patients with dementia. None of these four reviews^{7,17,19,20} found evidence to suggest that palliative care worsens patient or caregiver outcomes.
 - Specialised or specialist Palliative Care including models of hospice care:
- Four reviews^{21,22,23,24} report on specialised or specialist palliative care, including models of hospice care.

Three of these reviews report on the costs of specialist or specialised palliative care^{21,22,24}. Although limited cost data exist, reviews concur that the models are associated with cost savings, usually due to a reduction in general health care use²⁴, emergency care use²⁴, hospital costs (although this review also reports that home and hospice care costs increased when patients were referred to a palliative care programme)²² and inpatient stays²¹. Smith et al (2014)¹⁸ report that cost savings associated with palliative care are largely due to significant differences in hospital readmission rates compared to patients receiving 'usual care'. However, it is not clear whether the cost savings are attributable to specialist palliative care in Smith et al's (2014)¹⁸ review.

Although Candy et al (2011)²⁴ found that hospice care delivered at home increases death not occurring in hospital, effective pain relief and patient and family satisfaction with care, reviews of other specialised palliative care services do not concur with these findings. Garcia-Perez et al (2009)²¹ found that all reviews conclude that no specific model of specialised palliative care is more effective or cost effective than others with regard to symptom control, QoL, emotional support and satisfaction. Zimmermann et al (2008)²² concur with Garcia-Perez et al's (2009)²¹ findings for symptom control, QoL and patient satisfaction, but report consistent improvements in family satisfaction with specialised palliative care. Candy et al (2011)²⁴ concur reporting an increase in patient and family satisfaction when hospice care is provided in a variety of settings including hospital, nursing home or a patient's home. Qualitative findings in their review²⁴ also suggest that hospice care is highly valued by patients and families, whist hospice day care generates a renewed sense of meaning and purpose for patients. Home hospice services support families to sustain patient care at home.

Davies and Higginson, (2005)²³ also identify some advantages of specialist palliative care day services in 1 2 terms of high patient satisfaction and the value of social contact with staff and other patients. 3 4 5 **Palliative Care Teams:** 6 Six reviews report on palliative care teams 25,26,27,28,29,30. Although one meta synthesis reports wide 7 8 variations in the type of service delivered by such teams, there is no discernible difference in outcomes 9 between service delivery in cities, urban, and rural areas and evidence of benefit is strongest for home 10 care²⁴. Multidisciplinary teams are found to be more effective than unidisciplinary teams in one review²⁷. 11 12 Although five reviews ^{26,27,28,29,30} all identify some advantages of team based models of palliative care in 13 14 terms of effectiveness, one review based on four studies of varying quality reports little evidence to support the effectiveness of interdisciplinary teams²⁵. In terms of specific outcomes, a team approach is 15 found to improve pain and symptom control 26,27,28,29,30 and reduce anxiety in some cases 26. Additionally, 16 although some reviews report mixed findings about satisfaction 29,30, most report that palliative care 17 teams increase patient^{25,27}and especially carer satisfaction^{27,28,30}, with one not specifying whether 18

satisfaction increases for patients, carers or both groups²⁶.

19

20

21

Discussion

Reviews suggest that the impact of palliative care teams on home deaths was equivocal²⁸ but hospice at 1 home teams lead to more home deaths and fewer deaths in nursing homes³⁰. Although one review 2 3 indicates no differences in hospital use, others suggest that specialist palliative care teams have advantages in terms of reducing hospital admissions and length of hospital stays^{26,27}. One review 4 5 reports that home hospice reduces costs²⁷. Cost savings are attributed to transfer of costs from hospital to home in one review²⁹ and differences in length of stay in another review²⁸. Smith et al (2014)¹⁸ 6 7 support the latter finding reporting that the average length of stay was significantly shorter for palliative 8 care patients compared to the control group. 9 10 Evidence for the effectiveness, cost-effectiveness and appropriateness of the different models of 11 palliative care for different patient groups in different contexts 12 Heterogeneity and methodological limitations make it impossible to identify the relative advantages and 13 disadvantages of different models for different patient groups or in different contexts. However, all 14 reviews highlight a number of potential advantages and relatively few disadvantages for all models of 15 palliative care. Although all reviews identify the delivery agent(s) and care recipients, few details are 16 given about delivery mechanisms or the context and settings, timing, duration and circumstances in 17 which models are delivered. Comparator models are often described as 'usual care' but many reviews 18 provide no further detail about the components of these models, meaning that it is not possible to 19 determine which components of the models may influence outcomes. 20

1 The publications included in this systematic review of review level evidence report a range of 2 heterogeneous models of palliative care in terms of their definitions, descriptions, components and 3 outcome measures. Most reviews relate to specialist palliative care services, defined as those delivered 4 by staff working primarily in palliative care and with training in this speciality. Irrespective of setting or 5 patient group, models of palliative care included in the reviews appear to show potential benefits for 6 patients and their carers, with no evidence of negative effects. There is some evidence to suggest that 7 some models may result in reduced total healthcare costs. 8 The heterogeneous nature of the interventions across the various care settings means that there is little 9 evidence at review level relating to relevant settings such as nursing homes³¹. No reviews examining 10 palliative care for people with mental health issues or learning disabilities, who have specific needs and preferences ^{35,36} were identified. 11 12 'Usual,' 'standard' or 'conventional' care is often a comparator model but not well defined or described 13 and likely to vary considerably between countries given international differences in conceptualisations of palliative care³². The lack of detailed descriptions of both interventions and comparators at review 14 15 level may result from reporting restrictions (e.g. word limitations). However, the limited description of 16 models makes it difficult to discern differences between models of palliative care and draw firm 17 conclusions from our review, especially as we cannot be certain that there are no overlaps in the way 18 models have been 'clustered' in this review. Consequently, it was also difficult to draw conclusions 19 about the efficacy of the individual components of any model. In common with other reviews of review level evidence that focus on models of palliative care 7,33 heterogeneity in the study designs, populations, 20 21 interventions and outcomes of the included reviews precluded meta-analysis and meta synthesis.

22

Hoffman et al (2014)³⁴ offer suggestions about how better reporting of interventions can be achieved using the 12 item template for intervention description and replication (TIDieR) checklist and guide, an extension of the CONSORT 2010 statement (item 5)³¹ and the SPIRIT 2013 statement (item 11)³⁶. Developed for the reporting of all types of evaluative studies, the TIDieR checklist³⁴ could also be used when reporting on interventions in systematic and narrative reviews. Although the TIDiER checklist³⁴ prompt authors to describe interventions in enough detail to enable replication, the guidelines highlight issues that caused difficulty within this review. For example, in addition to the limited reporting about their components, models are not easy to find or recognise as few are known by specific names or described in a manner that allows identification. The lack of detail about the aim, rationale and the components of models reported in reviews perhaps reflects the lack of attention that has been given to the theoretical underpinning of these complex interventions³. The lack of conceptual underpinning for models may also explain the recognised variation in the outcomes measured³⁷. Some work to explain the mechanisms of action and causal pathways of the models developed and evaluated is fundamental to successfully determining what is likely to be effective⁸. Indeed, the complex nature of palliative care and the difficulties in identifying which components, if any, are important and has been recognised by McQuay (2011)³⁸.

17

18

19

20

21

22

1

2

3

4

5

6

7

8

9

10

11

12

13

14

15

16

Outcome reporting is also a key issue to address in palliative care practice and research^{37,39} especially in the evaluation of complex interventions⁴⁰ such as models of care where there is a need to explain mechanisms of action⁴¹ and identify how these relate to intermediate and final outcomes⁴⁰. Diverse outcomes are assessed for patients, family members and caregivers, staff members and professionals in palliative and hospice care using a wide range of assessment instruments in published studies³⁷.

- Agreement about important outcomes and consistency in outcome measures is essential if national and international comparisons are to be made in the evaluation of palliative care services³⁹. However,
- 3 irrespective of the well documented methodological challenges of outcome measurement in palliative
- 4 care³⁷, consensus will not be easy to establish, especially as the outcomes of interest are likely to vary
- 5 among stakeholders and levels (i.e. individual, family, community, societal). The EAPC (2015)³⁹
- 6 recognise outcome measurement as key to understanding different models of care and recommend the
- 7 introduction of outcomes that allow for national and international comparisons.

Comparison with findings of previous reviews of palliative care models:

The findings of our review are consistent with those reported in other reviews of review level evidence^{7,33,42,43}, despite differences in the scope and methods used. Both Luckett et al (2014)³³ and Arora et al (2011)⁷ completed both a review of reviews and a review of primary studies undertaken by a single researcher respectively. Our review included any type of review and any outcome, whereas Arora et al (2011)⁷ limited the review to eight commonly reported outcomes. The limitation of Arora et al's (2011)⁷ inclusion criteria seems apparent given that Stiel et al's (2012)³⁷ systematic review reported the existence of over 500instruments to measure outcomes. However, our findings indicate that the outcomes selected by Arora et al (2011)⁷ are those most frequently reported. In keeping with our findings, Keirse et al (2009)⁴³ found that most evidence relates to home models of palliative care (taking into account that home models are included in some models provided across settings), and conclude that heterogeneity in terms of the aims, caregivers, target populations and interventions make it

- difficult to compare models with regard to cost-effectiveness. In keeping with others^{7,33}, we found poor
- 2 quality information and a general lack of reporting about the components of the various types of
- 3 models. The difficulties associated with synthesising data about disparate models of palliative care has
- 4 also been previously acknowledged^{20,22}.

5

6

14

Quality of included reviews and primary studies:

- 7 The generally weak quality of evidence of the primary studies on which the included reviews were based
- 8 is largely due to the well documented methodological challenges faced by researchers within the field of
- 9 palliative care^{3,44,45}. These methodological difficulties consequently impact on the quality and
- usefulness of reviews in palliative care⁴⁶. None-the-less, Wee et al (2008)⁴⁶ acknowledge that reviews
- 11 can inform the palliative care community about the limited evidence base and indicate deficiencies in
- 12 the primary evidence base. The lack of controlled trials in palliative care makes use of findings from
- 13 well-designed nonrandomized controlled trials inevitable. 47.

Strengths and limitations of this review of reviews

- Restriction to English language searches introduces a potential bias 48, as does the mainly UK focus of the
- 16 grey literature searches. The broad aims and the inclusion of all outcomes in an attempt to provide
- 17 a comprehensive review of reviews may have generated additional challenges in terms of data
- analysis and reporting. However, despite ensuring that the Amstar criteria for a high quality review
- are met, this review is also weakened by the poor reporting of heterogeneous models of palliative care
- and the lack of standardised outcome measures, a known problem in the field of palliative care³⁷.

Poor reporting makes the development of a typology of models impossible. Although 'clustering' models provides some consistency of reporting between included reviews and our own, models are potentially overlapping as similarities and differences between models are not clear. Consequently, we cannot be sure of the effect that these clusters may have on the reporting of relevant outcomes. Irrespective of the clustering, it is evident that all reviews highlight some advantages of models and very few limitations.

The differences in palliative care provision between countries and contexts means that models vary considerably, making comparisons difficult. The wider generalisability of the review to low or middle income countries is limited, since the evidence originates from largely high income countries where populations are rapidly ageing and more is spent on health care ⁴⁶. A mapping review shows a paucity of research in international palliative care, and particularly highlights a lack of research from low to middle income regions ⁴⁹. This lack of evidence, combined with complexities in transferring evidence from different contexts, means that cross-country comparisons are likely to remain challenging.

Implications for policy and practice

This review of reviews shows a substantial body of evidence which, overall, supports the development and implementation of a range of different models for providing palliative care, across different settings and for different clinical conditions and patient groups. However, it remains difficult to conclude which models may be the most effective, cost-effective and appropriate to different contexts and therefore such decisions will still be largely based on the preferences of local providers and commissioners and the availability of the required staff, resources and facilities.

Implications for research

- 1 Better reporting of interventions and comparators in primary research is likely to subsequently increase
- 2 the value of systematic reviews in terms of providing the best evidence⁵⁰, improving the standard of
- 3 evaluative research³ (especially as Randomised Controlled Trials (RCTs) are often inadequate in palliative
- 4 care⁵¹), better understanding complexity⁸, mechanisms of action and critical components of models of
- 5 care.

Conclusions

- 7 A range of models of palliative care are reported in mainly medium to high quality published review
- 8 evidence, most of which are narrative reviews based on non-randomised studies. Most available
- 9 evidence relates to home care. Reviews highlight a number of potential advantages and few
- 10 disadvantages of models of palliative care. However, the heterogeneous nature and the poor quality of
- 11 reporting about the components of the models makes it difficult to draw any conclusions about which
- models are most appropriate in different contexts or for different patient groups. The under-reporting
- 13 of the components of intervention and comparator model is a major barrier to the evaluation and
- implementation of models of palliative care.
- 15 Acknowledgements:
- 16 We are grateful to our INTEGRATE-HTA partners who have advised on the protocol to complete the
- 17 review. We would like to thank Kate Chadwick for her assistance with internet searches, Jacqui Gath and
- 18 Simon Cork for the advice provided during the review.
- 19 Conflict of interest statement:
- The authors declare that there is no conflict of interest.

1	Funding:
2	This work was co-funded by the European Union [FP7-Health-2012-Innovation, grant agreement
3	306141].
4	Further information / supplementary material can be found at:
5	http://www.integrate-hta.eu
6	DISCLAIMER: The sole responsibility for the content of this manuscript lies with the authors. It does not
7	necessarily reflect the opinion of the European Union. The European Commission is not responsible for
8	any use that may be made of the information contained therein.
9	

Box 2 Search Terms

	Search Terms
1	Advance care planning/
2	Attitude to death/
3	Bereavement/
4	Death/
5	Hospices/
6	Hospice Care/
7	Palliative care/
8	Right to die/
9	Terminal care/
10	Terminally ill/
11	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12	(Attitude\$ adj2 (death\$ or dying or care or caring)).ti,ab.
13	Bereave*.ti,ab.
14	(EOL or end of life).ti,ab.
15	Hospice*.ti,ab.
16	(Imm* adj2 death).ti,ab.
17	(Incurabl* adj2 ill*).ti,ab.
18	(Limit* adj2 life).ti,ab.
19	Palliat*.ti,ab.)
20	((Respite or support*) adj2 (care or caring)).ti,ab.
21	(Terminal and (care or caring or ill* or disease*)).ti,ab.
22	12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
23	11 or 22
24	MEDLINE.tw.
25	Systematic review.tw.
26	Meta-analysis.pt.
27	Intervention\$.ti.
28	24 or 25 or 26 or 27
29	23 and 28
30	Limit 29 to (English language and humans and yr="2000 - 2014")

2 Table 1: Inclusion criteria:

Inclusion	Exclusion
Study type: Review level evidence reporting models of palliative care. Publications reporting systematic reviews of all types of original study (intervention, observational and qualitative studies). Reviews of reviews will be included when the findings related to the primary studies can be considered independently of the review of review findings in the publication.	Publications that are not review level evidence (i.e. primary studies). Publications or reviews that are <u>not</u> systematic in evidence search, retrieval appraisal, synthesis and analysis Opinion papers, editorials and conference abstracts.
Dates: Systematic & narrative reviews published between 2000- 2014.	Dates: Systematic & narrative reviews published outside of the date range 2000-2014.
Population: Reviews considering adults (defined as people aged 18 and over) with life-limiting illnesses as defined by the study authors. Reviews considering populations of varying ages will be included providing the focus of the research is adults, not children or adolescents.	Reviews solely considering children and adolescents (defined as those aged under 18 years of age)
Intervention: Reviews considering models of palliative care for any palliative care patient group.	Reviews will be excluded if focus is <u>not</u> a model of palliative care or is a single intervention used in palliative care. Models of palliative care provided at specific phases of the disease trajectory (e.g. bereavement services only).
Comparator: Any model of palliative care (specialist or generalist) provided at any point in the disease trajectory (i.e. from diagnosis to death) OR any form of 'usual' or 'routine' care. There may be no comparator.	We did not exclude reviews based on the comparator
Outcomes: All outcomes that are reported will be examined.	We did not exclude Reviews based on outcomes reported.
Language: written in English.	Language: Reviews not written in English,

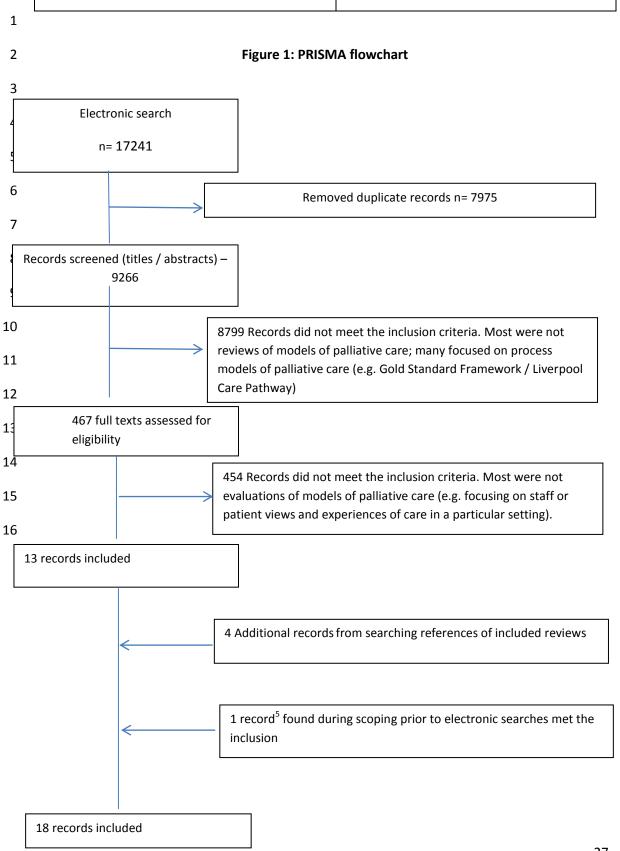


Table 2: Characteristics of included reviews:

Author, year, country or origin type of review & AMSTAR score	Review question/aim	Type and number of studies included	Population	Intervention	Comparator model(s) Or none	Primary Outcome	Key conclusions
HOME SETTING		<u> </u>	<u> </u>	<u> </u>	l.		-1
Gomes et al 2013 ¹⁴ UK Cochrane systematic review & meta analysis where appropriate. AMSTAR score - 11	To evaluate the impact of home palliative care services on outcomes for adults with advanced illness or their family caregivers or both.	Included controlled intervention studies. Identified 23 studies in 84 records	Adults with terminal illness, their family carers or both in receipt of home palliative care services	Home palliative care and 'reinforced' home palliative care (i.e. with an additional component of carer support)	Usual care' defined in various ways (comparator for Home palliative care) Care from specialist palliative care teams (comparator for 'reinforced' home palliative care).	Death at home	Home palliative care more than doubles the odds of dying at home
Luckett et al 2013 ¹⁵ Australia Systematic review & meta analysis AMSTAR score - 9	To compare the effect of Specialist Palliative care Services (SPCSs) providing home nursing vs. other models of service delivery on rates of home deaths.	Included comparative studies of any design that used quantitative evaluation. Identified 9 studies in 10 records.	Patients with life limiting illnesses; receiving nursing care exclusively at home.	Interventions delivering nursing care exclusively in the home rather than only through a day hospital or inpatient services.	an alternative that did not include access to home nursing.	Rates of home deaths	Inconclusive evidence that community SPCSs offering home nursing increase home deaths without compromising symptoms, QoL or increasing costs

Shepperd et al					Inpatient hospital		
2011 ¹⁶	To determine if home-	Included controlled	Adults aged 18 with	End of life care at home	or hospice care	Place of death	Patients receiving
UK	based end of life care	intervention studies.	various diagnoses			Patients' preferred	home-based end of
	reduces the likelihood	Identified 4 trials.	and over who			place of death	life care were more
Cochrane systematic	of dying in hospital		require terminal care				likely to die a home
review & Meta	and what effect this		at the end of life.				compared with those
analysis / narrative	has on patients'						receiving usual care
summary where mata	symptoms, quality of						(p=0.0002).
-analysis not possible	life, health service						
	costs and care giver's						
	satisfaction compared						
AMSTAR score - 11	with inpatient hospital						
	or hospice care.						

ACROSS SETTINGS: PALLIATIVE CARE OR A PALLIATIVE CARE APPROACH										
Arora et al 2011 ⁷ New Zealand Part 2 – Narrative review of original studies AMSTAR score - 7	To compare the efficacy of different models of palliative care	Included adequately powered comparative studies.Identified 27 eligible studies eligible studies in 34 records.	Adult palliative care patients as defined by the NZ Palliative Care Strategy (2001). Most had advanced cancer. Some study populations focused on family members / carers.	Any international structures, programs, systems or models of palliative care from different settings.	Any alternative structure, program, system or model of palliative care (including no structured program).	A range of outcomes including: 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	Heterogeneous models of palliative care with inconsistent results were found. Little evidence of benefits in favour of the intervention for home deaths, patient survival, quality of life, patient satisfaction and resource use. Home-care programmes reduced the need for acute hospital care. Some high-quality RCTs reported reduced costs for home care programs with PCT support.			

Harding et al 2005 ¹⁷ UK Narrative review presented by evidence grade AMSTAR score - 6	To appraise the effect of models of palliative care on patient outcomes.	Included original research of any design. Identified 22 services that had in 17 records.	Population infected with any stage of HIV / AIDS (or HIV infected subsample analysed and reported separately).	Home based care; home palliative care/hospice at home; hospice inpatient; hospital inpatient palliative care; specialist AIDS inpatient unit; and hospital inpatient and outpatient care.	Not stated	Various outcomes measured including pain and symptom control, patient and family anxiety, patient and family insight, communication and spiritual well-being Satisfaction with care, medical procedures and investigations, perceived quality of care, patient involvement, support, and quality of life.	Both home palliative care and inpatient hospice care significantly improved pain and symptom control, anxiety, insight, and spiritual wellbeing.
Sampson et al. 2005 ¹⁹ UK Narrative review presented by study AMSTAR score - 5	A systematic review assessing the efficacy of a palliative care model in patients with dementia.	Included any evaluative study design. Identified 2 studies- A randomized control trial & a prospective cohort study	Adults with a diagnosis of dementia.	Palliative care - Dementia Special Care Unit and an unidentified intervention in the 2 nd study.	Dementia Special Care Unit compared to traditional long- term care comparator not stated in the 2 nd study	Patient discomfort, medical resource utilization and mortality rates.	Equivocal (uncertain) evidence of the efficacy for a palliative model of care in dementia.

Rabow et al 2013 ²⁰ UK Narrative review presented by study AMSTAR score - 5	To assess the evidence of the impact of non-hospice outpatient palliative care services (defined as including specialty consultations and co-management in clinics, homes, or residential living facilities)	Included prospective, randomised controlled trials. Identified 4 studies.	Patients with late stage COPD, CHF and cancer; advanced cancer and metatastic non-small cell lung cancer and their family caregivers.	Outpatient palliative care services for terminally ill patients (i.e. in outpatient clinics, primary care clinics; in home or via telephone).	Usual care which included usual primary care and usual oncology care. Usual care was not described.	Impact of outpatient palliative care on patient, family caregiver, and clinician satisfaction; clinical outcomes including symptom management, quality of life, and mortality; and heath care utilization outcomes	Outpatient palliative care services can: improve patient satisfaction, symptom control and quality of life. These services also reduce health care utilization& costs and lengthens survival in lung cancer patients
						outcomes.	patients. Family and clinician satisfaction improved.

ACROSS SETTINGS: SPEC	ACROSS SETTINGS: SPECIALIST PALLIATIVE CARE & HOSPICE										
Garcia-Perez et al. 2009 ²¹ Spain.	To assess & synthesise evidence on the effectiveness and cost effectiveness of specialised palliative	Included comparative study designs examining two or more specialised palliative care	Adults (18 years and older) with terminal illness included in a palliative care programme.	Specialised palliative care programmes (i.e. Full palliative care team; Telephone palliative care team; In	Comparing different organisational models of specialised	Pain and other symptom control, psychological symptoms, health- related quality	None of the programmes studied are more effective (in terms of symptom control, QoL,				
Narrative review presented by study.	care for terminally ill patients, comparing different organisational models	programmes in adults with terminal illness. Identified 2 studies.		patient and home hospices and specialist palliative care unit).	palliative care provision with each other.	of life, well-being, functional state, satisfaction, place of death, number of	emotional support or satisfaction) or cost- effective than another.				
AMSTAR score - 6	with one another.					patients cared, number of home visits, number of days at hospital.					

Zimmermann et al. 2009 ²² . Canada Qualitative narrative synthesis. AMSTAR score - 8	To systematically examine the evidence for the effectiveness of specialized palliative care in improving quality of life, satisfaction with care, and economic cost.	Included randomised controlled trials. Identified 22 records.	Population with mixed diagnoses including cancer, COPD, Congestive Heart Failure (CHF) Motor Neurone Disease & AIDS	A specialized palliative care service was defined as a service of professionals that provides or coordinates comprehensive care for patients with a terminal illness.	'Usual care' in a variety of settings. 'Standard' hospital, hospice or home care. Mailed self help materials. Office care; Telephone consultation or 4 week waiting list.	Patient or caregiver quality of life, satisfaction with care, or economic cost. (Quality-of-life measures were not specific for terminally ill patients.)	Little evidence for benefit with regard to quality of life, symptom control and patient satisfaction or cost. However, specialized palliative care (SPC) consistently improves family satisfaction with care.
Davies & Higginson 2005 ²³ . UK Systematic review quantitative and qualitative analysis. AMSTAR score - 4	To systematically review the evidence for how the structure and process of palliative day care relate to outcomes for adults with cancer.	Included qualitative and quantitative studies examining the outcomes of interest. Identified 12 records.	Adults with cancer.	Specialist palliative day- care	Where stated, 'usual palliative care (not defined)	Symptom control, quality of life, social and psychological support, and patient and relative satisfaction with care	Patient satisfaction is high among those attending day-care. No model of care was found to be better than any other in terms of outcomes. Patients seem to value the social contact with staff and other patients that day care visits provide.

Candy et al 2011 ²⁴ UK Systematic review quantitative and qualitative analysis AMSTAR score - 8	To identify evidence for the effectiveness, including cost-effectiveness, of hospices, and hospice care in a patient's home and in nursing homes and for the experiences of those who use and of those who provide such services.	Included quantitative comparative study designs for evaluation of effectiveness and qualitative thematic evaluations to identify patient, family and service providers' experience of hospice type services. Identified 22 records.	Patients with a variety of cancer and non-cancer diagnoses in the final phases of terminal disease and family caregivers or family members.	Hospice (defined as holistic provision to patient and family by MDT at a dedicated hospice facility) at home, in a nursing home or other care facility in the community	Usual generalist care for comparative studies	Symptom management, pain assessment and other aspects of patient care, satisfaction with services, family carer well-being such as care burden and bereavement /grief, health service use, costs, and place of death, patients' emotional well-being	Quantitative evidence shows that hospice care reduces general health service use and costs, and increases effective pain relief, death not occurring in hospital and patient and family satisfaction with care Qualitative findings suggest that hospice care is highly valued by patients and families. Home hospice services support families to sustain patient care at home. Hospice day care services generate a renewed sense of meaning and purpose for patients.
--	---	---	---	---	---	--	---

ACROSS SETTINGS: TEAM	M APPROACH						
Leclerc et al 2014 ²⁵ Canada Narrative review	To determine the effectiveness, harms and adverse effects of the interdisciplinary team approach to	Included comparative studies of any quantitative or qualitative design. Identified 4 studies	In-patients or community dwelling patients aged 18 or over with stage III or IV cancer or a	'Interdisciplinary' teams or interventions	A group that did not receive care from an interdisciplinary team.	Outcomes relate to patients, patients' family members, home caregivers, healthcare providers or the	Interdisciplinary palliative care teams can improve patients' satisfaction with palliative care,
AMSTAR score - 9	providing end of life palliative care to adult patients and their home caregivers compared to other approaches.	in 5 records.	terminal condition with a prognosis of a year or less to live who received care in any setting.		ccum	healthcare system as well as adverse effects related to y aspect	hospital care and health providers' communication Patients were satisfied with the chances of dying at
							home and were less likely to visit the emergency department or be hospitalised.

Finlay et al 2002 ²⁷	To assess whether there was an effect of	Included grade I – III evidence (qualitative	Not clearly stated, although adults mentioned in	Palliative care teams / subgroups of teams in	Usual generalist care for	15 outcomes in 5 areas: 1) Patient group	Small positive benefits for hospice
UK	palliative care teams.	and quantitative		hospital, home and	comparative	2) Carer (pre-	and palliative care
Customatic rouisuu		reports). Identified 43 studies.	included tables.	hospice (not defined).	studies. Conventional care.	bereavement) group - 3) Carer (post-	teams exist. Palliative
Systematic review quantitative and		identified 43 studies.			Conventional care.	bereavement.) -	care teams seem effective in differing
qualitative analysis						4) Patient/carer group -	settings.
qualitative allalysis						5) Professionals group -	Multidisciplinary
						3) i Totessionais group -	teams have
AMSTAR score – 2							advantages over uni-
711101711130010 2							disciplinary
							teams(e.g. reduce
							length of hospital
							stay) Improved pain
							and symptom control,
							satisfaction for carers
							and patients.Home
							care reduced costs. In
							patient hospice
							resulted in greater
							satisfaction
							(especially for carers).
							In patient hospice
							and palliative care
							services either
							improved symptom
							control or had no
							effect and findings were equivocal
							regarding QoL.
					1		regarding QUL.

Higginson et al 2003 ²⁸ UK Meta-analysis, meta- synthesis and meta- regression AMSTAR score – 10	To determine the effectiveness of palliative and hospice care teams (PCHCT),	Included evaluative controlled, comparative and observational studies. Identified 44 studies in 69 records.	Patients with a progressive life threatening illness and their caregivers (defined as family, friends, or significant others).	Palliative and hospice care teams (PCHCT) defined as two or more health care workers, at least one of whom had specialist training or worked mainly in palliative or hospice care. PCHCT were home care, hospital-based combined home/hospital care, inpatient units, and integrated teams.	Usual care was routine community and general hospital/oncology services.	Range of patient and caregiver outcomes:	A meta-regression of 26 studies indicated a slight positive effect on patient outcomes, but no effect on caregiver outcomes. Meta-analysis of 19 RCTs or quasi-experimental studies demonstrated small but significant benefit on patients' pain other symptoms and a non-significant trend towards benefits for satisfaction.
---	--	---	--	---	--	--	--

Higginson Finlay et al 2002 ²⁹ Do hospital based teams UK meta-analysis, meta- synthesis	To determine whether hospital-based palliative care teams improve the process or outcomes of care for patients and families at the end of life.	Included evaluative – trial design comparing hospital-based palliative care with usual care delivery (present or historical). Identified 13 studies.	Patients with a progressive life-threatening illness, and their family, carers, or close friends.	Palliative Care Teams working in hospitals (defined as two or more health care workers at least one of whom had specialist training or worked mainly in palliative care). Interventions were very varied.	Usual care (either current or historical)	A broad range of outcomes and process measures related to: Patients, Carer/family member pre/postbereavement, Population, Professionals	Hospital-based palliative care teams offer some benefits e.g reduced time in hospital and improved symptom management. Satisfaction and quality of life improved in some studies. Some benefits exist for carers and the service.
Thomas et al, 2006 ³⁰ Canada Dedicated community teams Narrative review AMSTAR score – 6	To identify and analyse all published RCTs that focus on the organization of EOL care provided to persons who are terminally ill, near death, or dying.	Included 23 RCTs of palliative care – 12 of which focused on examined the effect of Providing Palliative Care through Dedicated Community Teams.	Terminally ill people near death, or dying, including patients with advanced cancer. Close family members were included in 1 study	Dedicated Community Teams (described in various ways)	Routine or standard care usual EOL care; customary Veterans Affairs post discharge Care; conventional care; standard home care or to office care	a. ratings of QoL and symptom management b. satisfaction with care c. the duration of the palliative period and the place of death d. costs of palliative are compared to usual care	Community or home- based EOL care associated with improved QoL and symptom management. There were mixed findings about patient/carer satisfaction Cost data were inconclusive

ACROSS ALL SETTINGS	– COSTS AND COST EFFECT	IVENESS		Τ	T	T	T
Smith et al 2014 ¹⁸ Ireland Narrative review of cost and cost	Identify studies that investigate the cost or resource use implications or costeffectiveness of a 'palliative care	Included any comparative study design examining the cost and/or utilisation implications of a	Limited information was provided about study population. Where stated, cancer & non cancer Patients with	A range of hospital- based, home-based and hospice care) models of palliative care	A range of models described in various ways as usual care; conventional care or non-PC hospital-	Costs or resource use implications and cost-effectiveness (n=1): point estimates that indicate that the intervention is cost-	Palliative care is most often less costly than comparators Palliative care has a mixed impact on resource utilisation
effectiveness	intervention' relative to some type of	palliative care intervention. Identified 46 eligible	advanced illness		based care.	saving	resource utilisation
AMSTAR score - 7	comparator or control.	studies.					

Review of models of palliative care

Table 3: Quality appraisal* of included reviews

*Adapted from the AMSTAR tool

Criteria	7	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
1. Was an a priori design provided?	CA	Υ	Υ	Y	Υ	CA	CA	Υ	Y	Υ	Y	CA	CA	Υ	CA	Y	Υ	CA
2. Was there duplicate study selection and data extraction?	N	Υ	N	Υ	Y	CA	Y	CA	Υ	Y	CA	Y	У	CA	CA	Y	Y	Y
3. Was a comprehensive literature search performed?	Υ	Y	Y	Υ	Y	Υ	Υ	N	Y	Y	Υ	Y	У	Υ	CA	Y	Y	У
4. Was the status of publication (i.e. grey literature) used as an inclusion criteria?	N	N	Y	N	CA	Y	N	N	CA	Y	Υ	CA	N	CA	CA	N	N	Υ

5. Was a list of studies (included and excluded) provided?	N	Y	Y	Y	N	Y	Y	N	N	N	N	Y	Y	Y	N	Y	Y	Y
6. Were the characteristics of the included studies provided?	Y	Y	Υ	Υ	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
7. Was the scientific quality of the included studies assessed and documented?	Y	Y	Y	Y	Y	Y	N	N	Y	Y	N	Y	Y	Y	N	Y	Y	Υ
8. Was the scientific quality of the included studies used appropriately in formulating conclusions?	Y	Y	Y	Y	Y	Y	N	N	N	Y	N	Y	Y	Y	Y	Y	Y	N
9. Were the methods used to combine the findings of the studies appropriate?	Y	Y	Y	Υ	N/A	Y	N	Y	Y	Y	Y	Y	Y	Y	CA	Y	Y	Y
10. Was the likelihood of publication bias assessed?	Y	Υ	Y	Υ	N	N	N	N	N	N	N	N	Y	Y	N	Υ	Y	N
11. Was the conflict of interest	N	Y	Υ	Υ	N	Y	Υ	Υ	Υ	Y	N	Υ	N	N	N	N	Υ	N

AMSTAR scores: 7 11 9 11 6 7 5 5 6 8 4 8 9 8 2 10 11 6	stated?																		
	AMSTAR scores:	7	11	9	11	6	7	5	5	6	8	4	8	9	8	2	10	11	6

Y = Yes, N= No, CA = Can't Answer, N/A= Not applicable

Quality Scores Yes scores 1 point, except for question 4 where No scores 1 point .

Quality is described as: High – 8-11; Medium – 4-7; Low - 3 or lower

References

- 1. Kirk, T. W. (2011). The meaning, limitations and possibilities of making palliative care a public health priority by declaring it a human right. *Public Health Ethics*, *4*(1), 84-92.
- 2. Centeno, C et al., (2013) "EAPC Atlas of Palliative Care in Europe 2013 Full Edition" Milano: EAPC (European Association for Palliative Care), http://hdl.handle.net/10171/29291.
- 3. Higginson, I. J., Evans, C. J., Grande, G., Preston, N., Morgan, M., McCrone, P., ... & Murray, S. A. (2013). Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC medicine*, *11*(1), 1.
- 4. Centeno C, Clark D, Lynch T, et al. Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC Task Force. *Palliat Med* 2007; 21: 463–471.
- 5. Higginson, I.J., Gomes, B., Calanzani, N., Gao, W., Bausewein, C., Daveson, B.A., Deliens, L., Ferreira, P.L., Toscani, F., Gysels, M. and Ceulemans, L. (2014). Priorities for treatment, care and information if faced with serious illness: A comparative population-based survey in seven European countries. *Palliative medicine*, *28*(2), 101-110.
- 6. World Health Assembly (2014) Item 15.5: Strengthening of palliative care as a component of comprehensive care throughout the life course. Minutes of the SIXTY-SEVENTH WORLD HEALTH ASSEMBLY http://apps.who.int/gb/ebwha/pdf files/WHA67/A67 R19-en.pdf (accessed 16 January 12017)
- 7. Arora, N., Standfield, L. and Weston (2011) A. Systematic review of systems of palliative

Care HSAC Report; 4 (22).

- 8. Craig P, Dieppe P, Macintyre S et al (2008) Developing and evaluating complex interventions:

 New guidance 2008. Medical Research Council [on-line]. Available at

 http://www.mrc.ac.uk/complexinterventionsguicance.
- 9. Davidson P, Halcomb E, Hickman L, Phillips J, Graham B (2006) Beyond the rhetoric: what do we mean by a 'model of care'? Australian Journal Advanced Nursing 23(3):47-55
- 10. Lee, E., Dobbins, M., DeCorby, K., McRae, L., Tirilis, D., & Husson, H. (2012). An optimal search filter for retrieving systematic reviews and meta-analyses. *BMC medical research methodology*, *12*(1), 51.
- 11. Shea, B.J., Hamel, C., Wells, G.A., Bouter, L.M., Kristjansson, E., Grimshaw, J., Henry, D.A. and Boers, M. (2009). AMSTAR is a reliable and valid measurement tool to assess the methodological quality of systematic reviews. *Journal of clinical epidemiology*, *62*(10), 1013-1020.
- 12. Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M. and Britten, N. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme. Version 1. Lancaster: Institute of Health Research.*
- 13. Moher D, Liberati A, Tetzlaff J, Altmann D, and the Prisma Group. Preferred reporting items for systematic reviews and meta-anlyses: the PRISMA guidelines. BMJ, 2009; 339: 332-336.

 14 Gomes, B., Calanzani, N., Curiale, V., McCrone, P., & Higginson, I. J. (2013). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev*, *6*(6).

- 15 Luckett, T., Davidson, P. M., Lam, L., Phillips, J., Currow, D. C., & Agar, M. (2013). Do community specialist palliative care services that provide home nursing increase rates of home death for people with life-limiting illnesses? A systematic review and meta-analysis of comparative studies. *Journal of pain and symptom management*, *45*(2), 279-297.

 16 Shepperd, S., Wee, B., & Straus, S. E. (2011). Hospital at home: home-based end of life care.
- 16 Shepperd, S., Wee, B., & Straus, S. E. (2011). Hospital at home: home-based end of life care Cochrane Database of Systematic Reviews, 7.
- 17. Harding, R., Karus, D., Easterbrook, P., Raveis, V. H., Higginson, I. J., & Marconi, K. (2005). Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. *Sexually Transmitted Infections*, *81*(1), 5-14.
- 18. Smith, S., Brick, A., O'Hara, S., & Normand, C. (2014). Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative medicine*, *28*(2), 130-150

 19. Sampson, E. L., Ritchie, C. W., Lai, R., Raven, P. W., & Blanchard, M. R. (2005). A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogeriatrics*, *17*(01), 31-40.
- 20. Rabow, M., Kvale, E., Barbour, L., Cassel, J. B., Cohen, S., Jackson, V., ... & Weissman, D. (2013). Moving upstream: a review of the evidence of the impact of outpatient palliative care. *Journal of palliative medicine*, *16*(12), 1540-1549.
- 21. García-Pérez, L., Linertová, R., Martín-Olivera, R., Serrano-Aguilar, P., & Benítez-Rosario, M. A. (2008). A systematic review of specialised palliative care for terminal patients: which model is better?. *Palliative medicine*.

- 22. Zimmermann, C., Riechelmann, R., Krzyzanowska, M., Rodin, G., & Tannock, I. (2008).
 Effectiveness of specialized palliative care: a systematic review. *Jama*, *299*(14), 1698-1709.
 23. Davies, E., & Higginson, I. J. (2005). Systematic review of specialist palliative day-care for
- 23. Davies, E., & Higginson, I. J. (2005). Systematic review of specialist palliative day-care for adults with cancer. *Supportive care in cancer*, *13*(8), 607-627.
- 24. Candy, B., Holman, A., Leurent, B., Davis, S., & Jones, L. (2011). Hospice care delivered at home, in nursing homes and in dedicated hospice facilities: A systematic review of quantitative and qualitative evidence. *International journal of nursing studies*, 48(1), 121-133.
- 25. Leclerc, B. S., Blanchard, L., Cantinotti, M., Couturier, Y., Gervais, D., Lessard, S., & Mongeau, S. (2014). The effectiveness of interdisciplinary teams in end-of-life palliative care: a systematic review of comparative studies. *Journal of palliative care*, *30*(1), 44-54.
- 26. Higginson, I. J., & Evans, C. J. (2010). What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *The Cancer Journal*, *16*(5), 423-435.
- 27 Finlay, I. G., Higginson, I. J., Goodwin, D. M., Cook, A. M., Edwards, A. G. K., Hood, K., ... & Normand, C. E. (2002). Palliative care in hospital, hospice, at home: results from a systematic review. *Annals of Oncology*, *13*(suppl 4), 257-264
- 28 Higginson, I. J., Finlay, I. G., Goodwin, D. M., Hood, K., Edwards, A. G., Cook, A., ... & Normand, C. E. (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*(2), 150-168. 29 Higginson, I. J., Finlay, I., Goodwin, D. M., Cook, A. M., Hood, K., Edwards, A. G., ... & Norman, C. E. (2002). Do hospital-based palliative teams improve care for patients or families

at the end of life?. Journal of pain and symptom management, 23(2), 96-106.

- 30 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.
- 31. Seymour, J. E., Kumar, A., & Froggatt, K. (2011). Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. *Palliative Medicine*, 0269216310387964.
- 32. Radbruch, L., & Payne, S. (2009). White paper on standards and norms for hospice and palliative care in Europe: part 1. *European journal of palliative care*, *16*(6), 278-289.
- 33. Luckett, T., Phillips, J., Agar, M., Virdun, C., Green, A., & Davidson, P. M. (2014). Elements of effective palliative care models: a rapid review. *BMC health services research*, *14*(1), 136.
- 34. Hoffmann, T. C., Glasziou, P. P., Boutron, I., Milne, R., Perera, R., Moher, D., ... & Lamb, S. E. (2014). Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *Bmj*,348, g1687.
- 35. Schulz K, Altman D, Moher D, CONSORT Group. CONSORT 2010 Statement: updated guidelines for reporting parallel group randomised trials. *BMJ* 2010;340:c332.
- 36. Chan A, Tetzlaff J, Gøtzsche P, Altman D, Mann H, Berlin J, et al. SPIRIT 2013 explanation and elaboration: guidance for protocols of clinical trials. *BMJ* 2013;346:e7586.

33.

37. Stiel, S., Pastrana, T., Balzer, C., Elsner, F., Ostgathe, C., & Radbruch, L. (2012). Outcome assessment instruments in palliative and hospice care—a review of the literature. *Supportive care in cancer*, *20*(11), 2879-2.

- 38. McQuay, H. (2011). Evidence-based medicine: What is the evidence that it has made a difference?. *Palliative medicine*, *25*(5), 394-397.
- 39. Bausewein, Claudia, Barbara A. Daveson, David C. Currow, Julia Downing, Luc Deliens, Lukas Radbruch, Kath Defilippi et al. "EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services—Recommendations from the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement." *Palliative medicine* (2015): 0269216315589898
- 40. Petticrew, M., Anderson, L., Elder, R., Grimshaw, J., Hopkins, D., Hahn, R., Krause, L., Kristjansson, E., Mercer, S., Sipe, T. and Tugwell, P., 2013. Complex interventions and their implications for systematic reviews: a pragmatic approach. *Journal of clinical epidemiology*, *66*(11), pp.1209-1214.
- 41. Anderson, L.M., Oliver, S.R., Michie, S., Rehfuess, E., Noyes, J. and Shemilt, I., 2013. Investigating complexity in systematic reviews of interventions by using a spectrum of methods. *Journal of clinical epidemiology*, *66*(11), pp.1223-1229.
- 42. Francke, A. L. (2000). Evaluative research on palliative support teams: a literature review. *Patient education and counseling*, *41*(1), 83-91.
- 43. 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. Available from: https://kce.fgov.be/sites/default/files/page_documents/d20091027342.pdf (2009)

 accessed 22 March 2016).

- 44. McMillan, S. C., & Weitzner, M. A. (2003, January). Methodologic issues in collecting data from debilitated patients with cancer near the end of life. In *Oncology nursing forum* (Vol. 30, No. 1).
- 45. Higginson, I. J., McCrone, P., Hart, S. R., Burman, R., Silber, E., & Edmonds, P. M. (2009). Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. *Journal of pain and symptom management*, *38*(6), 816-826.
- 46. Wee, B., Hadley, G., & Derry, S. (2008). How useful are systematic reviews for informing palliative care practice? Survey of 25 Cochrane systematic reviews. *BMC palliative care*, 7(1), 13.
- 47. Kongsgaard, U. E., & Werner, M. U. (2009). Evidence-based medicine works best when there is evidence: challenges in palliative medicine when randomized controlled trials are not possible. *Journal of pain & palliative care pharmacotherapy*, 23(1), 48-50.
- 48. Egger, M., Juni, P., Bartlett, C., Holenstein, F., and Sterne, J. (2003). How important are comprehensive literature searches and the assessment of trial quality in systematic reviews?: Health Technology Assessment 7 (1).
- 49. Clark J, Gardiner C, Barnes A. International palliative care research in the context of global development: a systematic mapping review. BMJ Supportive & Palliative Care (in press).

50. Evans, D. (2003) Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. *Journal of clinical nursing*, *12*(1), 77-84.

51. Aoun, S. M., & Kristjanson, L. J. (2005). Challenging the framework for evidence in palliative care research. *Palliative Medicine*, *19*(6), 461-465.

Review of models of palliative care