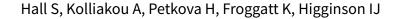


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# Interventions for improving palliative care for older people living in nursing care homes (Review)



Hall S, Kolliakou A, Petkova H, Froggatt K, Higginson IJ. Interventions for improving palliative care for older people living in nursing care homes. *Cochrane Database of Systematic Reviews* 2011, Issue 3. Art. No.: CD007132. DOI: 10.1002/14651858.CD007132.pub2.

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# TABLE OF CONTENTS

HEADER	1
ABSTRACT	1
PLAIN LANGUAGE SUMMARY	2
BACKGROUND	3
OBJECTIVES	3
METHODS	3
RESULTS	5
DISCUSSION	8
AUTHORS' CONCLUSIONS	10
ACKNOWLEDGEMENTS	11
REFERENCES	12
CHARACTERISTICS OF STUDIES	15
APPENDICES	20
WHAT'S NEW	28
HISTORY	28
CONTRIBUTIONS OF AUTHORS	28
DECLARATIONS OF INTEREST	29
SOURCES OF SUPPORT	29
DIFFERENCES BETWEEN PROTOCOL AND REVIEW	29
NOTES	29
INDEX TERMS	29



[Intervention Review]

# Interventions for improving palliative care for older people living in nursing care homes

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#### **ABSTRACT**

#### **Background**

Residents of nursing care homes for older people are highly likely to die there, making these places where palliative care is needed.

# Objectives

The primary objective was to determine effectiveness of multi-component palliative care service delivery interventions for residents of care homes for older people. The secondary objective was to describe the range and quality of outcome measures.

# **Search methods**

The grey literature and the following electronic databases were searched: Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effectiveness (all issue 1, 2010); MEDLINE, EMBASE, CINAHL, British Nursing Index, (1806 to February 2010), Science Citation Index Expanded & AMED (all to February 2010). Key journals were hand searched and a PubMed related articles link search was conducted on the final list of articles.

## **Selection criteria**

We planned to include Randomised Clinical Trials (RCTs), Controlled Clinical Trials (CCTs), controlled before-and-after studies and interrupted time series studies of multi-component palliative care service delivery interventions for residents of care homes for older people. These usually include the assessment and management of physical, psychological and spiritual symptoms and advance care planning. We did not include individual components of palliative care, such as advance care planning.

## **Data collection and analysis**

Two review authors independently assessed studies for inclusion, extracted data, and assessed quality and risk of bias. Meta analysis was not conducted due to heterogeneity of studies. The analysis comprised a structured narrative synthesis. Outcomes for residents and process of care measures were reported separately.

## **Main results**

Two RCTs and one controlled before-and-after study were included (735 participants). All were conducted in the USA and had several potential sources of bias. Few outcomes for residents were assessed. One study reported higher satisfaction with care and the other found lower observed discomfort in residents with end-stage dementia. Two studies reported group differences on some process measures. Both reported higher referral to hospice services in their intervention group, one found fewer hospital admissions and days in hospital in the intervention group, the other found an increase in do-not-resuscitate orders and documented advance care plan discussions.



#### **Authors' conclusions**

We found few studies, and all were in the USA. Although the results are potentially promising, high quality trials of palliative care service delivery interventions which assess outcomes for residents are needed, particularly outside the USA. These should focus on measuring standard outcomes, assessing cost-effectiveness, and reducing bias.

#### PLAIN LANGUAGE SUMMARY

## Improving palliative care for older people in care homes

People are living longer, however, the very old often have many health problems and disabilities which result in them living and eventually dying in care homes. Residents of such homes are highly likely to die there, making these places where palliative care is needed. Palliative care provides relief from pain and other distressing symptoms experienced by people reaching the end of life. Palliative care hopes to help people live as actively as possible until death, and their families cope with the illness and bereavement. The aim of this review was to see how effective palliative care interventions in care homes are, and to describe the outcome measures used in the studies. We found only three suitable studies (735 participants), all from the USA. There was little evidence that interventions to improve palliative care for older people in care homes improved outcomes for residents. One study found that palliative care increased bereaved family members' perceptions of the quality of care and another found lower discomfort for residents with dementia who were dying. There were problems with both of these findings. Two studies found that palliative care improved some of the ways in which care was given in the care home, however, we do not know if this resulted in better outcomes for residents. There is a need for more high quality research, particularly outside the USA.



#### BACKGROUND

### **Description of the intervention**

Palliative care has been defined by the World Health Organization (WHO 2002) as "an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual". Palliative care concentrates on the individual person rather than on the specific disease, affirms life and regards dying as a normal process, and intends neither to hasten nor to prolong death. Using a team approach, palliative care addresses the needs of patients and their families. This review focuses on multi-component palliative care service delivery interventions for residents in care homes for older people. These usually include the assessment and management of physical, psychological and spiritual symptoms and advance care planning. We did not include individual components of palliative care, such as advance care planning or the assessment or treatment of pain.

# How the intervention might work

Multi-component palliative care service delivery interventions aim to improve quality of life by providing relief from pain and other distressing symptoms experienced by people reaching the end of life. They also help patients' families cope with the illness and bereavement.

## Why it is important to do this review

More people are now living longer and the proportion of those living beyond 60 years has increased, and will continue to increase further until 2050 (Gomes 2008). The very oldest people (e.g. those aged 85+) often experience multiple chronic diseases, and in developed countries, are often cared for in long-term care facilities such as nursing or residential homes. Palliative care patients are increasingly admitted to care homes if their prognosis is too long for in-patient hospice care or acute palliative care beds. Although it is still a minority, a significant proportion of people die in these settings: ranging from 13% in Austria, 20% in England to 39% in Canada (Froggatt, in press). When people move to a care home they frequently experience multiple losses: physical, mental, social and spiritual. Although death may not necessarily be imminent, residents of care homes are highly likely to die there, making these settings where palliative care is needed (Cartwright 2002; Froggatt 2006; Parker-Oliver 2004).

A systematic review has shown the benefit of palliative and hospice care teams across a range of settings (Higginson 2003). Mean effect sizes (Cohen's *d*) were greatest for pain management (0.41), other symptoms (0.32), and satisfaction with care (0.38). A wide range of different measures were used and the clinical significance of these effects is not known. Older people do not have access to hospice and palliative care services in the proportions that might be expected (Davies 2004). Literature reviews have shown considerable need for palliative care in care homes. These include symptom management (Cartwright 2002; Gruenewald 2006; Parker-Oliver 2004), psychosocial and spiritual needs (Gruenewald 2006), resident involvement in decision-making (Cartwright 2002). End of life care for people living in care homes for older people may differ from palliative care, which was developed to reduce the suffering of people with advanced cancer.

For example: the former usually involves multiple rather than single disease processes; death may be seen as natural rather than a life cut short; prognosis may be unclear; and there is a higher incidence of cognitive impairment, making symptom assessment particularly difficult (Davies 2004). There is some evidence that interventions to improve palliative care for residents of care homes for older people are effective (Froggatt 2006). These tend to be complex interventions, including the provision of hospice services, the establishment of specialist palliative care units, consultation services, staff education, facilitating decision-making and care pathways. However, the search strategy used in the review by Froggatt 2006 was limited, many of the included studies were descriptive rather than evaluative, and quality and risk of bias were not assessed. Although an increasing number of studies are being conducted in this area, evidence of the effectiveness of these interventions is unclear.

#### **OBJECTIVES**

The primary objective of this review was to determine the effectiveness of multi-component palliative care service delivery interventions for residents of care homes for older people. We planned to include the provision of hospice services, establishment of specialist palliative care units, consultation services, and staff educational programmes.

The secondary objective was to describe the range and quality of outcome measures reported in the studies included in the review.

#### METHODS

# Criteria for considering studies for this review

# **Types of studies**

The following types of studies were included: randomised controlled trials (RCTs), controlled clinical trials (CCTs) (quasi-randomised trials); trials with double-blinding, but randomisation not mentioned, controlled before-and-after studies (CBA), and interrupted time series (ITS) analyses.

## **Types of participants**

The participants were residents of care homes for older people. We did not select participants on the basis of age, diagnosis, prognosis or palliative care needs. We did not include studies of care home staff. Care homes were defined as collective institutional settings where care is provided for older people 24 hours a day, 7 days a week. The care provided includes on-site provision of personal assistance with activities of daily living. Nursing and medical care may be provided on-site or provided by nursing and medical professionals from services external to the setting. We therefore included nursing and residential homes and aged, skilled-care, or long-term care facilities. We did not select studies based on the healthcare systems in which they were carried out. The generalisability of evidence across different types of participants, care homes and healthcare systems was considered.

# **Types of interventions**

Palliative care service delivery interventions for residents of care homes for older people. These included referrals to external palliative care services and/or palliative care training for care home staff. They are multi-component interventions, usually including, for example, the assessment and management of



physical, psychological and spiritual symptoms and advance care planning. We did not include interventions which focused on individual components of palliative care, such as advance care planning or the assessment or treatment of specific symptoms such as pain. Including these would greatly increase the heterogeneity of the studies in the review. These interventions would benefit from systematic reviews focusing on these particular topics. For example, a Cochrane review to evaluate advance care planning for end of life in older people is planned (title registered).

#### Types of outcome measures

It was expected that a range of outcome measures would have been assessed in the included studies (e.g. quality of life, symptoms and satisfaction with care (residents and their family and friends). Since one of the aims of this review was to describe the range and quality of the outcome measures reported in the included studies, we did not specify primary and secondary outcomes. We extracted all measures reported as outcomes for individual residents, including process of care (e.g. completion of advance care plans and place of death). We initially planned to analyse objective and subjective outcomes separately and to include health care costs where these were reported, along with relevant aspects of the country's health system in order to place the reported findings in context.

## Search methods for identification of studies

# **Electronic searches**

#### Electronic databases searched (access via Ovid)

The following databases were searched:

- Cochrane Central Register of Controlled Trials (Issue 1, 2010).
- Cochrane Database of Systematic Reviews (Issue 1, 2010).
- Database of Abstracts of Reviews of Effectiveness (Issue 1, 2010).
- MEDLINE (1966 to February 2010).
- EMBASE (1980 to February 2010).
- CINAHL (1980 to February 2010).
- British Nursing Index (1985 to February 2010).
- PsycINFO (1806 to February 2010).
- Science Citation Index Expanded (1980 to February 2010).
- AMED (1985 to February 2010).

To identify studies for inclusion in this review, detailed search strategies were developed for each electronic database searched (Appendix 1). The subject search used a combination of controlled vocabulary and free text terms based on the search strategy developed to search MEDLINE via Ovid, and was revised appropriately for each database.

#### Searching other resources

#### **Hand searching**

The reference lists of all included studies were checked for further studies. Studies of designated authors in the field were checked (Froggatt K, Teno J, Kristjanson L). Relevant reviews, reports and guidelines were read and the reference lists checked (Australian Government 2004; Birch 2008; Blasi 2002; Bolmsjo 2008; Cartwright 2002; Froggatt 2006; Goodman 2010; Hines unpublished; Lorenz 2004; The National Council for Palliative Care 2006; Parker-Oliver 2004; Robinson 2006; Roger 2006; Sampson 2005; Thomas 2006; Zimmerman 2008). The following key journals were hand searched:

- American Journal of Hospice and Palliative Care (1984 February 2010).
- Annals of Long term Care (2001 February 2010).
- End of Life Care Journal (2007 February 2010).
- Journal of Hospice and Palliative Nursing (1999 February 2010).
- Journal of Palliative Care (1985 Spring 2010).
- Journal of Palliative Medicine (1998 February 2010).
- International Journal of Palliative Nursing (1996 February 2010).
- Nursing Homes: Long Term Care Management (1986 February 2010).
- Palliative Medicine (1987 January 2010).
- Palliative and Supportive Care (2003 December 2009).
- Progress in Palliative Care (2003 February 2010).

#### Related article search

A PubMed related articles link search was conducted on the final list of articles. This strategy has been shown to be useful for reviewing complex evidence (O'Leary 2007).

## Personal contact

Investigators known to be carrying out research in this area were contacted for unpublished data or knowledge of the grey literature (Albers G, Brazil K, Kristjanson L, Parker D, Pasman R, Ribbe M, Teno J). In addition, the 167 members of the National Care Home Research and Development Forum were also contacted. Authors' personal collections of articles were also searched (SH, AK, HP).

#### Language

There was no language restriction in the selection of studies. Non-English papers were assessed with the assistance of a native speaker.

# **Data collection and analysis**

# **Selection of studies**

First, the titles identified by the searches were assessed independently by two review authors (SH and either AK or HP) to determine whether each article might meet the eligibility criteria. If the title gave room for doubt, the abstract was read. If the abstract left room for doubt that the article could not definitely be rejected, the full text of the article was obtained. All disagreements were resolved by discussion. If the article was not rejected, information from it was formally extracted. All studies which failed to meet the inclusion criteria at 'full text' stage can be seen in the 'Characteristics of excluded studies' table. Reference Manager was used to keep track of any studies identified.

# **Data extraction and management**

A data extraction form was developed for the review. A double extraction process was used in which two independent assessments of each study were compared and reconciled if necessary (SH & HP). Any disagreements were resolved by discussion. If there was any missing data, authors were contacted to obtain full details. A record of contacts and responses was kept. The following data were extracted:

- Publication details (authors, year, journal).
- · Country of origin.



- · Verification of the study eligibility.
- Type of care home.
- Study aim.
- Type of intervention/control.
- Number of follow-ups.
- · Time of follow-ups.
- Inclusion/exclusion criteria.
- Sample size (number in each group).
- Sample size calculations.
- · Recruitment rate.
- Number of withdrawals.
- · Number of drop-outs.
- Study participant characteristics (e.g., age, sex).
- · Outcome measures.
- Results of the study.
- · Health care cost.
- · Handling of missing data.
- · Adverse effects of the intervention.
- Participants comments on the interventions.
- · Assessment of methodological quality.

#### Assessment of risk of bias in included studies

Risk of bias in included studies was assessed independently by two review authors (SH & HP) using the Cochrane risk of bias tool (Higgins 2008). All disagreements were resolved by discussion.

Each of the studies selected for the review was assessed independently by two review authors (SH & HP) for methodological quality. The Oxford Quality Scale was used (Jadad 1996). This considers randomisation, double-blinding and the extent to which participants are accounted for. The maximum score for this scale is five. A score of three is judged as high quality, a score of two or less as poor quality. However, the Oxford Quality Scale has been criticised for being of limited use (e.g. considerable importance is given to double-blinding although this may not be feasible in many studies (Jüni 2005).

#### **Measures of treatment effect**

Number needed to treat to benefit (NNT) and the 95% confidence intervals (CIs) for the NNT were calculated for dichotomous outcomes. Cohen's d was calculated for differences in means.

# **Data synthesis**

The included studies were not sufficiently homogeneous for meta-analysis to be undertaken. The results were extracted and summarised in a table. Means (with standard deviations), frequencies and proportions, test coefficients, 95% CIs and effect sizes were reported if data were available. The analysis comprises a structured narrative synthesis including a discussion of the studies' characteristics (e.g. methodological limitations, country and context in which the intervention was delivered, generalisability) and findings.

#### RESULTS

## **Description of studies**

#### Results of the search

The search of electronic databases yielded 14,936 titles once duplicates had been removed. We judged that 38 of these potentially met the inclusion criteria and full copies of these were obtained for more detailed assessment.

#### **Included studies**

Three studies: two RCTs (Casarett 2005; Kovach 1996) and one controlled before-and-after study (Hanson 2005) (including a total of 735 participants), met all the inclusion criteria and were included in the review. A summary of the characteristics of these studies and their interventions is below in the 'Characteristics of included studies' table.

## Characteristics of the interventions

The content of the interventions differed in the three studies. One focused on identifying residents suitable for, or in need of, palliative care and asking physicians to refer them to specialist palliative care (Casarett 2005). A structured interview was conducted to identify residents whose goal for care, treatment preferences and palliative care needs made them appropriate for palliative care. Those determined as appropriate for such care expressed goals for care that focused on comfort, refused both cardiopulmonary resuscitation and mechanical ventilation, and had at least one need for palliative care identified. Physicians of residents deemed appropriate for palliative care were notified and asked to authorise a hospice informal visit and told they could learn more about palliative care by speaking with the resident's health care team. In contrast, the intervention evaluated by Hanson 2005 involved the recruitment and training of palliative care leadership teams in each facility. This was followed by six technical assistance meetings for team members. Hospice providers delivered six educational sessions for all the nursing home staff using a structured curriculum designed for nursing homes. Teams received feedback of performance data on hospice enrolment, pain management and advance care planning. The third focused on residents with endstage dementia (Kovach 1996). Those in the intervention group were transferred to special units in the homes where they took part in a range of therapeutic activities. Case managers led small interdisciplinary teams to develop individualised care plans. Care was holistic and focused on maintaining comfort and quality of life. Staff education included palliative care. Those in the control group received the usual care provided by the facility.

## **Participants**

Seven hundred and thirty five participants were included in the review. The average age of participants varied from 80.0 to 87.9 years. The majority were female (75 to 81%), reflecting the higher proportion of women living in most care homes. The inclusion and exclusion criteria varied. One study included only residents with end-stage dementia (Kovach 1996), whilst another excluded residents with cognitive impairment who had no proxy decision-maker (Casarett 2005). The third randomly selected it's participants from all residents of participating homes (outcomes obtained by chart review) (Hanson 2005).



# Settings

All three studies were conducted in the USA. Two were conducted in nursing homes and one in long-term care facilities. Both of the

nursing homes had their own hospice services or arrangements with external hospice services.

Table 1. Summary of the characteristics of included studies

Study charac-	Casarett 2005	Hanson 2005	Kovach 1996
teristic			
Study design	RCT	СВА	RCT
Sample size	205	458	72
	Intervention = 107	Intervention = 345	Intervention = 35
	Control = 98	Control = 113	Control = 37
Setting	3 nursing homes	9 nursing homes	3 long-term care facilities.
	With own hospice programmes, or re-	With existing hospice contracts.	All had religious affiliation
	lationships with community hospice programmes.	The 7 intervention homes were volunteers, the 2 control homes were randomly selected.	
Inclusion crite- ria	All residents in units at time of initial chart review	Non reported - probably all residents	Residents diagnosed with end- stage dementia, identified by staff as usually unable to en- gage in group programmes for residents with dementia, at least 2 symptoms, advance directives requesting no car- diopulmonary resuscitation
Exclusion cri- teria	Admitted for respite care, already receiving hospice care, cognitive impairment, no surrogate decision makers	None reported	None reported
Mean age of residents (years)	83.5	80.0	87.9
Sex of resi-	25	24	19
dents Male (%)	75	76	81
Female (%)			
Intervention	Structured interview to identify residents suitable for palliative care and asked their physicians to refer them to specialist palliative care	Development of palliative care leader- ship teams, technical assistance meet- ings for team members, education in palliative care for all staff, feedback on performance	Residents transferred to spe- cial units in the homes, inter- disciplinary teams to devel- op individualised care plans, holistic care, and staff educa- tion in palliative care
	Control aroun Como intervious as in	Control group: No intervention	Control group: No intervention
Control/com- parison inter- vention	Control group: Same interview as intervention group, but results not communicated to their physicians	control group. No intervention	control group. No men vention



	Bereaved relatives 2 months post- death		
Outcomes for residents	1. Six-month mortality	1. Resident in pain $^{\mathrm{1}}$	Behaviours associated with dementia
residents	2. Family rating of quality of care (N = 17)		2. Discomfort
			3. Physical complications
Processes as-	1. Hospice enrolment	1. With hospice or palliative care	None
sessed	2. Acute hospital admissions	2. With pain assessment <sup>1</sup>	
	3. Days in hospital	3. Pain medication <sup>1</sup>	
	4. Died in care home	4. Non-pharmacologiocal treatment of pain $^{\! 1}$	
		5. Do-not-resuscitate order	
		6. Easy to identify do-not-resuscitate indicator on chart	
		7. Has living will	
		8. Has health care powers of attorney	
		9. Advance care planning discussion documented	
Oxford Quality Scale	2	0	2
Number of sources of bias	4	5	3

<sup>1</sup> Although the Hanson study only published before-and-after data for the intervention group, we obtained additional information on the control group to compare the two groups. Since we had percentages only, we calculated frequencies and conducted Chi-square or Fisher's Exact tests as appropriate. However, as one facility did not provide data on pain, and we did not have any information on the amount of missing data, we were unable to calculate frequencies and conduct statistical tests on these four process of care measures.

#### **Excluded studies**

Thirty-five studies were excluded: 29 because of their study design (Arcand 2009; Armitage 2005; Badger 2009; Basson 2002; Brechling 1989; Casarett 2008; Deliens 2008; Duffy 2006; Easom 2006; Echteld 2008; Froggatt 2000; Heals 2008; Hirakawa 2009; Jerant 2006; Knight 2007; Knight 2008; Kortes-Miller 2007; Levy 2007; Levy 2008; Mathews 2006; Mitchell 2006; Murai 2008; Payne 2009; Phillips 2008; Rollins 2001; Suhrie 2009; Vandenberg 2005; Volicer 1986; Waldron 2008), two were not conducted in care homes (Ellershaw 2008; Garåsen 2005), three were not palliative care interventions (Chapman 2007; Gibb 1997; Kuske 2009), and one did not provide sufficient data on outcomes for residents (Strumpf 2004) (see 'Characteristics of excluded studies' table).

## Risk of bias in included studies

All three studies were graded on the Oxford Quality Scale as being of poor quality (a score of less than three) and were at some risk of bias.

## Allocation

One study was a non-RCT (Hanson 2005) and one of the RCTs did not conceal group allocation (Casarett 2005).

## **Blinding**

No study reported blinding of participants, personnel and outcome assessors.

#### Incomplete outcome data

No study addressed incomplete outcome data.

## **Selective reporting**

There was no evidence of selective outcome reporting, with all three studies reporting some non-significant comparisons, although they often did not provide the supporting data and statistics.



## Other potential sources of bias

All three studies had some other source of bias (see 'Characteristics of included studies' table).

#### **Effects of interventions**

The two studies that measured outcomes for residents found that the palliative care interventions improved the quality of care as assessed by bereaved families (Casarett 2005) and the discomfort observed for residents (Kovach 1996) (Appendix 2). There were no differences in mortality (Casarett 2005), behaviours associated with dementia and physical complications (Kovach 1996). However, in Casarett's study few participants died during the study, so this was based on a small sub-sample of 17 (11 intervention and six control), and the data needed to calculate the effect size were not reported. Although the effect size was large in the Kovach study, the researchers who assessed discomfort were not blinded to group allocation, which may have introduced bias. We have no comparisons between the intervention and control group on outcomes for residents for the Hanson 2005 study, however, pre and post-intervention comparisons showed no change in the proportion of residents recorded on their chart as being in pain (39% at baseline and 38% post-intervention). We do not have this data for the control group.

Two studies reported group differences on some process measures. Both Casarett 2005 and Hanson 2005 reported higher referral to hospice services in their intervention group six months post intervention. However, the effect sizes were not large. The Hanson study found no group difference in hospice enrolment at the time of death. The Casarett study also found fewer hospital admissions and days in hospital in the intervention group, furthermore, almost all (70/78) admissions in the intervention group occurred when the resident was not enrolled in hospice. The two groups did not differ on the proportion of residents who died in the nursing home rather than in an acute care setting. The Hanson 2005 study found that a higher proportion of residents in the intervention group had donot-resuscitate orders, had these easily identifiable on their chart, and had advance care plan discussions documented. The effect size for having an easy to identify do-not-resuscitate order on their chart was clinically significant. The groups did not differ in the proportion of residents with living wills or with health care powers of attorney.

#### **Additional study**

Another study (also conducted in the USA) was considered for inclusion in the review. Strumpf 2004 randomly allocated nursing homes to an intervention or control group. The intervention comprised staff training in palliative care and ongoing specialist guidance. The study was excluded because we were unable to obtain sufficient information on the analyses involving residents, including frequencies or proportions (only P-values were reported). Intervention homes had more residents with advance care plans (P < 0.01), more residents with pain managed by narcotics (P < 0.01), higher rates of symptoms recorded in the last weeks of life (P < 0.05)and higher rates of physician visits and X-rays in the last weeks of life (P < 0.01). The effects of clustering were not accounted for in the analyses. A staff survey was also conducted which showed that staff in the intervention group felt they were better at identifying three of 11 palliative care problems (Stillman 2005). However, they did not differ on nine attitudes towards caring of the dying. In view of the number of comparisons, the possibility of Type 1 errors cannot be ruled out.

The generalisability of the findings of these studies is considered in the 'Discussion' section.

#### **Outcome measures**

The secondary aim of this review was to describe the range and quality of outcome measures reported in the studies included in the review. A range of measures were reported as outcomes in the studies. We had planned to report objective and subjective outcomes separately, however, once we had a list of measures, we felt that it was more appropriate to differentiate outcomes for residents from process of care measures (Donabedian 1966). Outcomes are the desired states resulting from care processes (e.g. reduced pain or increased quality of life) whereas process measures of health care quality refer to the procedures done to and for patients when providing care (e.g. advance planning discussions and pain assessment). Although process measures are often reported as 'outcomes' in palliative care, they may, or may not, lead to improvements in outcomes for patients and their families. For example, pain may be assessed but not adequately treated, resulting in no reduction in pain.

Two studies used at least one validated outcome for residents: Casarett 2008 assessed family views on quality of care for residents in the last month of life using the Toolkit After Death Survey (Teno 2001); and Kovach 1996 assessed behaviours associated with dementia using the BEHAVE-AD (Patterson 1990) and comfort using the Discomfort Scale for Dementia of the Alzheimer's Type (Hurley 1992). Two studies collected some outcomes for residents from existing charts or records: Casarett 2005 collected data on 6-month mortality and Hanson 2005 on number of residents in pain. No outcome for residents was assessed in more than one study.

In addition to outcomes, a number of process of care measures were reported (shown in Table 1). These were usually abstracted from charts or records in the facilities. Just one was assessed in more than one study: the number of residents with hospice or palliative care involvement (assessed in Casarett 2005 and Hanson 2005). No health care costs of the interventions were reported.

# DISCUSSION

There is a need to improve palliative care for residents of care homes for older people. Residents who would benefit from such care are often not referred to specialist hospice or palliative care services, their symptoms are poorly managed, they are frequently hospitalised unnecessarily, advance care planning and communication is often inadequate, and their families are dissatisfied with their care (Parker-Oliver 2004). The main aim of this review was to determine the effectiveness of interventions to improve palliative care for older people in care homes. Three studies conducted in the USA were identified and included in the review. They were heterogenous in terms of the interventions evaluated, the populations studied, and the outcomes assessed. Although all three reported some positive effects, the quality of the studies was poor and all had sources of bias. One study showed higher family satisfaction with end of life care in the small sample of residents who had died during the study period (Casarett 2005) and another showed a decrease in discomfort in residents with advanced dementia (Kovach 1996). However, although the effect size reported in the latter study was large, there was a possibility of bias as the researchers assessing discomfort could not be blinded to group allocation. Increases in satisfaction with care



were also reported in a review of palliative and hospice care teams across a range of settings (Higginson 2003), although the overall standardised effect size was small. Since we did not have the data needed to calculate the standardised effect size for the study in our review, we were unable to compare findings with the previous review. Two studies reported significant effects of the intervention on the processes of giving care: increased enrolment in hospice, donot-resuscitate orders and advance care plans documented, and fewer hospital admissions and days in hospital. However, the effect sizes were generally small and, with the exception of having an easy to identify do-not-resuscitate order on their chart, may not be considered clinically significant.

# **Quality of the studies**

The three studies included in this review were heterogeneous and graded as poor quality with several sources of bias. Confounding may have been a problem in all three studies. For example, one study reported that the homes in the interventions and control group differed on 'some characteristics'. Another reported 'no significant differences' in characteristics of participants, although the relatively small sample would have resulted in lack of statistical power to detect possible confounders. The dearth of good quality studies evaluating interventions to improve palliative care in care homes has been noted in earlier reviews of such interventions (Cartwright 2002; Froggatt 2006; Parker-Oliver 2004). Our review shows that there has been little improvement in recent years. The shortage of good quality studies is not restricted to palliative care in a care home setting. A review of the effectiveness of specialised palliative care which concluded that "the evidence for a benefit from specialised palliative care is sparse and limited by methodological shortcomings" (Zimmerman 2008). Only four of the 13 studies assessing quality of life, and one of the 14 studies assessing symptoms showed a significant benefit of the intervention. There was consistent evidence only for higher caregiver satisfaction (no effect sizes reported). A systematic review of the impact of palliative care teams also showed increases in satisfaction Higginson 2003, although the overall effect was small, this provides some support for the findings of the Casarett 2005 study included in our review. The relative absence of good evidence has also been highlighted in reviews of end of life care for older people with dementia living in the community (Goodman 2010), a palliative care approach in advanced dementia (Sampson 2005), and end of life care for older people in a range of settings (Bolmsjo 2008). A survey of 25 Cochrane systematic reviews in palliative care found that 23 of the 25 reviewed interventions were judged as weak (Bee Wee 2008). As in our review, the studies in reviews were heterogeneous with respect to patients, interventions and outcomes. Review authors indicated that there were frequently major problems with the primary studies. Although the reviewing process was generally good, conclusions were limited by the number, size, quality and validity of the primary studies. It is, however, difficult to conduct double-blind studies in this area, as researchers and participants may be very aware of the nature of the intervention. Good quality studies should, however, include posttreatment assessment by assessors blind to treatment allocation.

# **Types of Intervention**

Although all three palliative care interventions were complex and multi-faceted, their approaches differed. One focused on identifying residents suitable for hospice care and referring them to external specialist services (Casarett 2005). Specialist palliative

care services are appropriate for residents with complex palliative care needs, and in the USA, for those who are in the last six months of life. This intervention may not benefit residents, who may have palliative care needs but do not fit these criteria. The impact of this intervention is also particularly dependent on effective communication between nursing home staff and hospice providers around residents' changing care needs. The three selected nursing homes taking part in this study already had their own hospice programmes, or existing relationships with community hospice programmes. There are a range of barriers which can impede the integration of external specialist palliative care services into nursing home care (Stevenson 2009), therefore, the generalisability of the findings of this study to other nursing homes both in the USA and in other countries is questionable. The other two interventions focused on care home staff to providing a 'palliative approach' to care of residents, potentially benefiting all residents, not just those in the last six months of life. One developed palliative care leadership teams (Hanson 2005), the other involved moving residents with end-stage dementia to special units in the facility (Kovach 1996). Both of these interventions included training staff to provide palliative care. In view of the large turnover of staff in many care homes, training needs to be readily available for new staff to sustain any improvements. Furthermore, the implications for continuity of care and maintaining relationships between residents and care home staff need to be considered when moving residents to specialist units.

We included only interventions which were described as palliative care: a holistic approach focusing on assessing and managing the physical and psychological symptoms and spiritual concerns of people reaching the end of life. However, there is considerable overlap between palliative and geriatric care (Goldstein 2005), and there may be other complex interventions, which were not labelled 'palliative', which also aim to address some of these issues. For example one of the excluded studies evaluating the effectiveness of advanced illness care teams for nursing home residents with dementia reported a significant reduction in pain (Chapman 2007). However, including such studies would have substantially increased the heterogeneity of the interventions included in this review.

## Generalisability

There are two key factors that influence the extent to which the findings of these studies are generalisable beyond the USA. Firstly, the privately financed health economy in the USA mirrors to an extent the situation in other more mixed health economies such as the UK. Here the independent sector is more dominant than in other areas of health care provision, but the care is undergirded by sources of public funding in circumstances where an individual cannot afford to pay. In the USA the Medicaid and Medicare systems can time limit funding for specialist forms of care which may influence services such as hospice care. Secondly, Hospice (Palliative Care) in the USA is primarily provided by freestanding agencies with contracts to provide care in people's homes. The prevalence of in-patient settings as seen in other parts of the world, especially the UK, means that the USA might be seen to be more equipped to engage with the needs of people residing in care homes, as all their services are delivered in other care settings. There are also differences in the settings in which the studies were conducted which may impact on the generalisability of their findings to other care homes in the USA. The facilities in



the Casarett 2005 and Hanson 2005 studies were selected because they had their own hospice programmes, or had relationships with community hospice programmes. All those in the Kovach 1996 study had some religious affiliation. The facilities taking part in the Strumpf 2004 study were owned by a single company and were selected for willingness to implement a palliative care programme and the relative stability of administrative staff.

#### **Outcomes**

A secondary aim of this review was to describe the range and quality of the outcome measures. Two studies used at least one validated outcome measure, and two collected some outcomes for residents from existing charts or records. No outcomes for residents were assessed in more than one study. In addition twelve process of care measures were reported. Just one (hospice enrolment) was assessed in more than one study. However, it cannot be assumed that these process measures are associated with patient outcomes. For example, completing advance directives rarely effect aspects of care such as improved communication between the patient and health care providers or care givers, reductions in aggressive medical care, or appropriate palliation (Lorenz 2004). There is a need to develop and test high quality instruments to assess outcomes for residents of care homes. These should be strongly related to the explicit aims of palliative care, as these are more sensitive to change and have been most useful in demonstrating the effects of such interventions (Lorenz 2004). Non-specific satisfaction measures often have ceiling effects which could explain the relatively small effects reported in a palliative and hospice care teams (Higginson 2003). In view of the holistic nature of palliative care, such measures should cover improvements in physical symptoms, psychological, existential and spiritual concerns as well as satisfaction with care. These outcomes (assessed using a range of different measures) have been frequently reported in evaluations of palliative care interventions in other settings (Higginson 2003). All are important at the end of life. None of the studies in the review looked at resident's views, probably because many residents have sensory or cognitive problems which makes these difficult to assess. Nevertheless, it is important to include their views on the care they have received. Ideally such measures could also be completed by proxies or surrogates for people who are unable to self-complete. Measures such as the Palliative Outcome Scale (Hearn 1999) are short and easy to apply in clinical and research settings, have options for completion by patients, families or other proxies in different conditions and settings (Bausewein 2005), and have been used in nursing homes among people with dementia (Brandt 2005). Further work on the development of the Palliative Outcome Scale is underway in a European Community Funded project: PRISMA (www.kcl.ac.uk/schools/medicine/depts/ palliative/arp/prisma/). Measures such as the Toolkit After Death Survey (Teno 2001) are comprehensive, but have limitations, for example few residents may die in the study period, and a substantial number have no family or friends who observed the care they received. Observational measures such as the Discomfort Scale for Dementia of the Alzheimer's Type (Hurley 1992) can be completed by suitably trained researchers, however, it is important that, to reduce the risk of bias, they are not aware of group allocation. Research in this area would benefit from consensus on outcome measures and the magnitudes of effect sizes that could be expected to make palliative care interventions in care homes clinically and cost-effective. The cost-effectiveness of palliative care and hospice interventions are rarely reported (Higginson 2003), and measures used in economic analyses of interventions delivered in other settings may not be suitable for care home settings. Both extra costs (e.g. provisions external specialist palliative care services) and cost savings (e.g. reduced hospital stays or the withdrawal of unnecessary treatments) would need to be considered.

## Strengths & limitations of this review

The main strength of this review is that we conducted a broad and highly sensitive search of electronic databases, and searched for additional studies using several other methods, including a related article link search shown to be useful in reviewing complex evidence (O'Leary 2007). Our search was not limited by date or language. Since we did not want to restrict the review to RCTs, we could not use a reliable study design filter. Our broad search strategy resulted in a very time-consuming check by two review authors of 14,936 titles and often their abstracts. We identified only three eligible studies, none of which were included in previous reviews of this literature. Another strength is that we followed standardised Cochrane review methods for selecting studies and assessing their risk of bias. The three main limitations are the generalisability of the findings (discussed earlier), heterogeneity of the three included studies which made combining and comparing their results difficult, and the small number of studies along with their risk of bias making it difficult to arrive at any firm conclusions. As discussed earlier, the relatively small number good quality studies and their heterogeneity seems to be a ubiquitous problem in palliative care (Bee Wee 2008). Our review highlights the need for more rigorous research on interventions to improve palliative care in care homes, and the need to show the impact of these in outcomes for residents.

## **AUTHORS' CONCLUSIONS**

# Implications for practice

There clearly is a need for effective palliative care interventions in care homes for older people, and the core principles and practices of palliative care, such as advance care planning and symptom management, could benefit all residents, not just those at the end of life (Morrison 2009). Our review found potentially promising results for three interventions: assessing residents' suitability for specialist palliative care and making recommendations to their physicians, developing palliative care expertise in care homes and moving residents with end-stage dementia to special units in the care home. However, without further evaluation, we cannot recommend the use of the interventions in clinical practice. There is an absence of a shared understanding in the literature of what a palliative care intervention for residents should look like. Some features of the interventions evaluated in this review are likely to be important, for example, relationships between care homes and specialist palliative care services who can provide specialist support for residents with complex needs. Specialist services can also provide training and advice to care home staff who could provide a general palliative approach to care which is appropriate for all residents, regardless of their diagnosis or prognosis. However, training is a necessary but not sufficient condition to improve the care of residents. Other components, such as the development of multidisciplinary teams, are also likely to be important. Such teams were included in two of the interventions and are a key aspect of a palliative approach to care (Australian Government 2004).



#### Implications for research

There are methodological and structural challenges to conducting research in palliative care (Kaasa 2006), and these may be greater in care homes (Hall 2009), which are often run by for-profit organizations and have no tradition of taking part in research. However, this review shows that it is possible to conduct controlled studies in these settings, at least in the USA. There is a need for high quality studies to be carried out in other cultural and geographical settings. Future studies need to take into account contamination of the control group in individually randomised studies, or the intra cluster correlation if cluster randomisation is used, identify and control for potential confounders, and avoid multiple significance testing or correct the P-values reported to reduce the possibility of Type 1 errors. It would be useful to look at the various components of these complex interventions and explore, if and how, each contributes to outcomes. It is important to demonstrate that interventions are beneficial to residents. A core outcome measure covering the key goals of palliative care in nursing homes is needed, so that the results of future studies can

be combined and compared. This needs to be short and easy to complete by residents or their proxies. It is important to report cost data so that the cost-effectiveness of different interventions could be explored in future reviews. Many of the issues raised in this review, for example: the need to develop and test high quality measures and determine the clinical significance of interventions, have been raised in relation to wider research literature on end of life care (Lorenz 2004).

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## CHARACTERISTICS OF STUDIES

**Characteristics of included studies** [ordered by study ID]

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Study characteristics	
Methods	Design: RCT
	Follow-up: residents for bi-weekly 6 months or until death, relatives of residents who died 2 months post-bereavement.
Participants	205 residents
	107 Intervention; 98 control
	Exclusion criteria: Admitted for respite, already receiving hospice care, too cognitively impaired to complete the interview and did not have a surrogate.
	Mean age: 83.5 years
	Sex: 25% male; 75% female



#### Casarett 2005 (Continued)

Inte			

Intervention: A structured interview to identify residents whose goal for care, treatment preferences and palliative care needs made them appropriate for hospice care. Those determined as appropriate for hospice care expressed goals for care that focused on comfort, refused both cardiopulmonary resuscitation and mechanical ventilation, identified at least 1 need for palliative care. Physicians of residents deemed appropriate for PC were notified and asked to authorise a hospice informal visit.

Control: Same interview as intervention group but results not communicated to their physician. Instead residents and their families were given a brief description of hospice and hospice services.

#### Outcomes

- 1. Six-month mortality
- 2. Families rating of care quality in last month (Toolkit After Death Survey)

#### Processes assessed

- 1. Hospice enrolment within 30 days of the intervention
- 2. Hospice enrolment at the end of 6 months
- 3. Hospice enrolment at time of death
- 4. Mean acute hospital admissions
- 5. Days in hospital
- 6. Died in nursing home

#### Setting

3 nursing homes in the U.S. These were selected for diversity of populations and because they had their own hospice programmes or relationships with community hospice programmes. One urban home had a high proportion of African Americans, another suburban home had a largely white affluent population and the third was a Veterans Affairs nursing home with an ethnically diverse population.

#### Oxford Quality Score

2 (randomised and method to generate sequence described)

## Notes

# Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Blocked randomisation using a random-number list generated by the study statistician. Stratified by site of care.
Allocation concealment (selection bias)	High risk	Research assistants revealed each resident's assignment at the beginning of the interview. Participants were informed at the end of the interview.
Blinding (performance bias and detection bias) All outcomes	High risk	Not possible as researchers needed to ask those in the intervention group for permission to share the results of the interview with the physician. This is the main component of the intervention.
Incomplete outcome data (attrition bias) All outcomes	High risk	6/23 surrogates of the residents who died not included in Table 3. No information given on these.
Selective reporting (reporting bias)	Low risk	Probably not, also reported non-significant comparisons.
Other bias	High risk	The effect of the intervention may have been underestimated because there were fewer hospice appropriate residents in the intervention group and physicians cared for both groups which may have contaminated the control group.



## Hanson 2005

10115011 2000			
Study characteristics			
Methods	seven volunteer homes	ore-and-after study. Participants allocated to groups on the basis of location: s in the intervention group and two randomly selected homes in the control rts of residents in each home was randomly selected at baseline and follow-up.	
	Follow-up: 6 months po	ost intervention	
Participants	458 residents (no inclu	sion/exclusion criteria reported)	
	345 intervention; 113 c	ontrol	
	Mean age: 80 years		
	24% male, 76% female		
Interventions	care leadership teams Hospice providers deliv curriculum designed fo	nprovement to increase palliative care. Recruitment and training of palliative in each facility, followed by six technical assistance meetings for team members. wered six educational sessions for all the nursing home staff using a structured or nursing homes. Teams received feedback of performance data on hospice enment and advance care planning.	
	Control: No intervention	on (no information given)	
Outcomes	1. In pain (abstracted fi	rom charts)	
Processes assessed	1. With hospice or palliative care		
	2. With pain assessmer	nt	
	3. Pain medication		
	4. Non-pharmacologica	al treatment for pain	
	5. With do-not-resuscit	ate order on chart	
	6. Advance care planni	ng discussion documented	
Setting		U.S. 7 were volunteer homes, a further 2 were randomly selected as control isting hospice contracts.	
Oxford Quality Score	0		
Notes	-		
Risk of bias			
Bias	Authors' judgement	Support for judgement	
Random sequence generation (selection bias)	High risk	Not RCT	
Allocation concealment (selection bias)	High risk	Not RCT	
Blinding (performance bias and detection bias) All outcomes	High risk	Not RCT	



Hanson 2005 (Continued)		
Incomplete outcome data (attrition bias) All outcomes	High risk	Pain treatment data for one of the homes missing. No other information on missing data.
Selective reporting (reporting bias)	Low risk	Non-significant results reported
Other bias	High risk	Intervention and control homes differed on 'some characteristics', however, no information given. However, since control and intervention homes were not compared, these were not controlled for.

# Kovach 1996

Study characteristics			
Methods	Design: RCT		
	Follow-up: 2 months post-intervention (baseline assessed 2 months prior to intervention)		
Participants	72 residents in the end stages of a dementing illness, identified by staff as usually unable to engage in group programming designed for residents with dementia, and have advance directives that request no cardiopulmonary resuscitation.		
	35 intervention; 37 control		
	Exclusion criteria: none given		
	Mean age: 87.92 years		
	Sex: 19% male; 81% female		
Interventions	Intervention group: Hospice-oriented care. Residents were transferred to special units where they took part in a range of therapeutic activities. Case managers led small interdisciplinary teams to develop individualised care plans. Care was holistic and focused on maintaining comfort and quality of life. Staff education included hospice (palliative care).		
	Control group: Traditional care offered by the facility. This was not described.		
Outcomes	1. Behaviours associated with dementia (BEHAVE-AD)		
	2. Comfort (DS-DAT)		
	3. Physical complications (Data collection form developed for the study)		
Processes assessed	None		
Setting	A convenience sample of three long-term care facilities in the USA. All had some religious affiliation		
Oxford Quality Score	2 (randomisation and description of drop-outs)		
Notes	Outcomes were assessed by graduate nursing students not blinded to group allocation		
Risk of bias			
Bias	Authors' judgement Support for judgement		



Kovach 1996 (Continued)		
Random sequence generation (selection bias)	Low risk	"were randomly assigned to the treatment or control group". A random numbers table was used (additional information from author).
Allocation concealment (selection bias)	Low risk	Allocation completely concealed (additional information from author).
Blinding (performance bias and detection bias) All outcomes	High risk	Not possible as residents in the intervention group were moved to specific unit.
Incomplete outcome data (attrition bias) All outcomes	High risk	No analysis of drop-outs (although only 5 deaths in each group).
Selective reporting (reporting bias)	Low risk	Non-significant comparisons reported
Other bias	High risk	Intervention and control group were compared on demographic and baseline measures. Reported as non-significant. However, study would not have had power to detect small/moderate differences. These measures were not controlled in the analyses.

# **Characteristics of excluded studies** [ordered by study ID]

Study	Reason for exclusion	
Arcand 2009	Study design: historically controlled study	
Armitage 2005	Study design: uncontrolled study	
Badger 2009	Study design: uncontrolled study	
Basson 2002	Study design: survey, no intervention	
Brechling 1989	Study design: service description, no evaluation	
Casarett 2008	Study design: uncontrolled study	
Chapman 2007	Intervention: not palliative or end of life care	
Deliens 2008	Study design: uncontrolled study	
Duffy 2006	Study design: uncontrolled study	
Easom 2006	Study design: uncontrolled study	
Echteld 2008	Study design: uncontrolled study	
Ellershaw 2008	Setting: not care homes	
Froggatt 2000	Study design: uncontrolled study	
Garåsen 2005	Setting: control group not in care home	



Study	Reason for exclusion	
Gibb 1997	Intervention: not palliative or end of life care	
Heals 2008	Study design: uncontrolled study	
Hirakawa 2009	Study design: uncontrolled study	
Jerant 2006	Study design: uncontrolled study (intensive compared with less intensive intervention)	
Knight 2007	Study design: uncontrolled study	
Knight 2008	Study design: survey, no intervention	
Kortes-Miller 2007	Study design: uncontrolled study	
Kuske 2009	Intervention: not palliative or end of life care	
Levy 2007	Study design: observational, no intervention	
Levy 2008	Study design: historically controlled study	
Mathews 2006	Study design: uncontrolled study	
Mitchell 2006	Study design: observational, no intervention	
Murai 2008	Study design: uncontrolled study	
Payne 2009	Study design: description of model, no intervention	
Phillips 2008	Study design: uncontrolled study	
Rollins 2001	Study design: uncontrolled study	
Strumpf 2004	Insufficient data available on outcomes for residents	
Suhrie 2009	Study design: uncontrolled study	
Vandenberg 2005	Study design: uncontrolled study	
Volicer 1986	Study design: uncontrolled study	
Waldron 2008	Study design: uncontrolled study	

# APPENDICES

# **Appendix 1. Search strategies**

# Medline 1966 to February 2010

- 1 exp palliative care/
- 2 palliative care.mp.
- 3 (palliative treatment or palliative medicine).mp.
- 4 exp terminal care/
- 5 terminal care.mp.
- 6 exp terminally ill/



- 7 terminally ill.mp.
- 8 end-of-life care.mp.
- 9 end-of-life.mp.
- 10 exp hospice care/
- 11 hospice care.mp.
- 12 exp heart failure congestive/
- 13 heart failure.mp.
- 14 exp dementia/
- 15 dementia.mp.
- 16 exp Alzheimer Disease/
- 17 alzheimer\$ disease.mp.
- 18 exp kidney failure/
- 19 kidney failure.mp.
- 20 exp cerebrovascular accident/
- 21 cerebrovascular accident\$.mp.
- 22 stroke.mp.
- 23 exp neurodegenerative diseases/
- 24 neurodegenerative disease\$.mp.
- 25 exp cardiovascular diseases/
- 26 cardiovascular disease\$.mp.
- 27 exp parkinson disease/
- 28 parkinson disease.mp.
- 29 or/1-28
- 32 exp hospices/
- 31 hospice\$.mp.
- 32 nursing home\$.mp.
- 33 exp homes for the aged/
- 34 home\$ for the aged.mp.
- 35 care home\$.mp.
- 55 care nomes.mp
- 36 old age home\$.mp.
- 37 or/30-36
- 38 exp aged/
- 39 aged.mp.
- 40 elder\$.mp.
- 41 older people.mp.
- 42 senior citizen\$.mp.
- 43 exp frail elderly/
- 44 frail elderly.mp.
- 45 exp geriatrics/
- 46 geriatric\$.mp.
- 47 or/38-46
- 48 29 and 37 and 47

## **British Nursing Index 1985 to February 2010**

- 1 palliative care.mp.
- 2 (palliative treatment or palliative medicine).mp.
- 3 exp terminal care/
- 4 terminal care.mp.
- 5 terminally ill.mp.
- 6 end-of-life care.mp.
- 7 end-of-life.mp.
- 8 exp hospice care/
- 9 hospice care.mp.
- 10 heart failure.mp.



11 exp dementia/ 12 dementia.mp. 13 exp Alzheimer disease/ 14 alzheimer\$ disease.mp. 15 kidney failure.mp. 16 exp cerebrovascular accident/ 17 cerebrovascular accident\$.mp. 18 stroke.mp. 19 neurodegenerative disease\$.mp. 20 cardiovascular disease\$.mp. 21 exp Parkinson disease/ 22 parkinson disease\$.mp. 23 exp hospice/ 24 hospice\$.mp. 25 nursing home\$.mp. 26 home\$ for the aged.mp. 27 care home\$.mp. 28 old age home\$.mp. 29 aged/ 30 aged.mp. 31 elder\$.mp. 32 older people.mp. 33 senior citizen\$.mp. 34 frail elderly.mp. 35 exp geriatrics/ 36 geriatric\$.mp. 37 or/1-22 38 or/23-28 39 or/29-36 40 and/37-39 EMBASE 1980 to February 2010 1 exp palliative therapy/ 2 palliative care.mp. 3 (palliative treatment or palliative medicine).mp.

4 exp terminal care/



5 terminal care.mp.		
6 exp terminally ill patient/		
7 terminally ill.mp.		
8 end-of-life care.mp.		
9 end-of-life.mp.		
10 exp hospice care/		
11 hospice care.mp.		
12 exp heart failure/		
13 heart failure.mp.		
14 exp dementia/		
15 dementia.mp.		
16 exp Alzheimer disease/		
17 alzheimer\$ disease.mp.		
18 kidney failure/		
19 kidney failure.mp.		
20 exp cerebrovascular accident/		
21 cerebrovascular accident\$.mp.		
22 stroke.mp.		
23 exp degenerative disease/		
24 neurodegenerative disease\$.mp.		
25 exp cardiovascular disease/		
26 cardiovascular disease\$.mp.		
27 exp Parkinson disease/		
28 parkinson disease\$.mp.		
29 or/1-28		
30 exp hospice/		
31 hospice\$.mp.		
32 nursing home\$.mp.		
33 exp home for the aged/		
34 home\$ for the aged.mp.		
35 care home\$.mp.		
36 old age home\$.mp.		
37 or/30-36		
38 aged/		

39 aged.mp.



40 elder\$.mp.
41 older people.mp.
42 senior citizen\$.mp.
43 exp frail elderly/
44 frail elderly.mp.
45 exp geriatrics/
46 geriatric\$.mp.
47 or/38-46
48 29 and 37 and 47
PsychINFO 1806 to February 2010
1 palliative care.mp.
2 (palliative treatment or palliative medicine).mp.
3 exp Palliative Care/
4 exp Terminally III/
5 exp Neurodegenerative Diseases/
6 terminal care.mp.
7 terminally ill.mp.
8 end-of-life care.mp.
9 end-of-life.mp.
10 hospice care.mp.
11 heart failure.mp.
12 exp dementia/
13 dementia.mp.
14 exp Alzheimer disease/
15 alzheimer\$ disease.mp.
16 kidney failure.mp.
17 exp cerebrovascular accident/
18 cerebrovascular accident\$.mp.
19 stroke.mp.
20 neurodegenerative disease\$.mp.
21 cardiovascular disease\$.mp.
22 parkinson disease\$.mp.
23 exp hospice/

25 nursing home\$.mp.



- 26 home\$ for the aged.mp.
  27 care home\$.mp.
- 28 old age home\$.mp.
- 29 aged/
- 30 aged.mp.
- 31 elder\$.mp.
- 32 older people.mp.
- 33 senior citizen\$.mp.
- 34 frail elderly.mp.
- 35 exp geriatrics/
- 36 geriatric\$.mp.
- 37 exp Palliative Care/
- 38 exp Terminally Ill/
- 39 exp Neurodegenerative Diseases/
- 40 Or/1-22, 37,38,39
- 41 Or/23-28
- 42 Or/29-36
- 43 And/ 40,41,42

# AMED 1985 to February 2010

- 1 palliative care.mp. [mp=abstract, heading words, title]
- 2 (palliative treatment or palliative medicine).mp. [mp=abstract, heading words, title]
- 3 exp terminal care/
- 4 terminal care.mp. [mp=abstract, heading words, title]
- 5 terminally ill.mp. [mp=abstract, heading words, title]
- 6 end-of-life care.mp. [mp=abstract, heading words, title]
- 7 end-of-life.mp. [mp=abstract, heading words, title]
- 8 exp hospice care/
- 9 hospice care.mp. [mp=abstract, heading words, title]
- 10 heart failure.mp. [mp=abstract, heading words, title]
- 11 exp dementia/
- 12 dementia.mp. [mp=abstract, heading words, title]
- 13 alzheimer\$ disease.mp. [mp=abstract, heading words, title]
- 14 kidney failure.mp. [mp=abstract, heading words, title]
- 15 exp cerebrovascular accident/
- 16 cerebrovascular accident\$.mp. [mp=abstract, heading words, title]



17 stroke.mp. [mp=abstract, heading words, title]

18 neurodegenerative disease\$.mp. [mp=abstract, heading words, title]

19 cardiovascular disease\$.mp. [mp=abstract, heading words, title]

20 exp Parkinson disease/

21 parkinson disease\$.mp. [mp=abstract, heading words, title]

22 hospice\$.mp. [mp=abstract, heading words, title]

23 nursing home\$.mp. [mp=abstract, heading words, title]

24 home\$ for the aged.mp. [mp=abstract, heading words, title]

25 care home\$.mp. [mp=abstract, heading words, title]

26 old age home\$.mp. [mp=abstract, heading words, title]

27 aged/

28 aged.mp. [mp=abstract, heading words, title]

29 elder\$.mp. [mp=abstract, heading words, title]

30 older people.mp. [mp=abstract, heading words, title]

31 senior citizen\$.mp. [mp=abstract, heading words, title]

32 frail elderly.mp. [mp=abstract, heading words, title]

33 exp geriatrics/

34 geriatric\$.mp. [mp=abstract, heading words, title]

35 exp Palliative Care/

36 exp Heart Failure/

37 exp Homes for the Aged/

38 or/1-21,35-36

39 or/22-26,37

40 or/27-34

41 and/38-40

Cochrane Database of Systematic Reviews (Cochrane Reviews) Issue 1 2010  $\,$ 

Database of Abstracts of Reviews of Effects (Other Reviews) Issue 1 2010

Cochrane Central Register of Controlled Trials (Clinical Trials) Issue 1 2010

Science Citation Index (1980 to February 2010)

CINAHL (1980 to February 2010)

(palliative care) or (terminal care) or (end of life care) or (terminally ill) or (hospice care) or (heart failure) or (cardiovascular disease) or (parkinson) or (alzheimer) or (stroke) or (neurodegenerative disease) or (kidney failure) or (dementia)

AND

(hospice) or (care home) or (nursing home)

AND



(aged) or (elder) or (older) or (senior citizen) or (geriatrics)

## Appendix 2. Summary of results of studies

## Study Results

#### Casarett 2005

#### **Outcomes for residents**

Families of residents in the intervention group rated the resident's care more highly than families of residents in the control group (4.3 [range 2-5] compared with 2.2 [range 1-5], Wilcoxon rank sum test = 3.33, difference in means = 2.1, 95% CI for difference = 0.69 to 5.97). Standard deviations were not reported, therefore, we were unable to calculate the standardised effect size. The two groups did not differ on six month mortality (15/107 [14%] in the intervention group compared with 8/98 [8%] in the control group, chi-square = 1.22, absolute risk reduction = 5.86%, 95% C I = -2.67% to +14.38%, NNT = 18).

#### **Process of care**

Significantly more residents in the intervention group were enrolled in hospice within 30 days of the intervention (21/107 [20%] compared with 1/98 [1%], Fisher's exact test = 3.16, absolute risk reduction = 18.61%, 95% CI = 10.82% to 26.39%, NNT = 6, 95% CI for NNT = 3.8 to 9.2) and within six months of the intervention (27/107 [25%] compared with 6/98 [6%], chi-square = 13.83, absolute risk reduction = 19.11%, 95% CI = 9.61% to 28.61%, NNT = 6, 95% CI for NNT = 3.5 to 10.4), but not at the time of death (5/15 [33%]) compared with 3/8 [38%], chi-square = 0.040, absolute risk increase = 4.17%, 95% CI = -37.00% to +45.33%, NNH = 24). Mean hospital admissions and days in hospital were also lower in the intervention group (0.28 [range 0-4] compared with 0.49 [range 0.4] and 1.2 [range 0-18] compared with 3.0 [range 0-29] respectively). Wilcoxon rank sum coefficients were not reported, and since standard deviations were also not reported, we were unable to calculate standardised effect sizes or 95% Cls. Differences in means were 0.21 (hospital admissions) and 1.8 days in hospital. Reported P values were 0.04 and 0.03 respectively. Almost all (70/78) of admissions in the intervention group occurred when the resident was not enrolled in hospice. The two groups did not differ in the proportion of residents who died in the care home (9/15 [66%] in the intervention group compared with 5/8 [62%] in the control group, chi-square = 0.014, absolute risk reduction = 2.5%, 95% CI =-39.21% to +44.21%, NNH = 40).

# **Risk of bias**

No allocation concealment or blinding, incomplete outcome data, other bias (The effect of the intervention may have been underestimated because there were fewer hospice appropriate residents in the intervention group and physicians cared for both groups which may have contaminated the control group).

## Hanson 2005

## Process of care

Significantly more residents in the intervention group were receiving hospice care (24/346 [6.8%] compared with 2/113 [2%], Fisher's exact test, absolute risk reduction = 5.17%, 95% CI = 1.55% to 8.78%, NNT = 20, 95% CI for NNT = 11.4 to 64.5), had do-not-resuscitate orders (225/346 [65%] compared with 50/113 [44%], chi-square = 15.32, absolute risk reduction = 20.78%, 95% CI = 10.34% to 31.23%, NNT = 5, 95% CI for NNT = 3.2 to 9.7), had an easy to identify do-not-resuscitate indicator on their chart (208/346 [60%] compared with 29/113 [25%], chi-square = 40.49, absolute risk reduction = 34.45%, 95% CI = 24.89% to 24.89% to 24.89% CI for NNT = 2.3 to 2.99% CI for NNT = 2.99

## **Risk of bias**

Non RCT. No appropriate sequence generation, allocation concealment or blinding, incomplete outcome data, other bias (Intervention and control homes differed on 'some characteristics', how-



(Continued)

ever, no information given. However, since control and intervention homes were not compared, these were not controlled for).

#### Kovach 1996

#### **Outcomes for residents**

Residents in the intervention group were observed to have significantly less discomfort than those in the control group (mean [SD] 218.10 [142.10] and 368.88 [168.30] respectively, t = 3.80, difference in means = 150.78, 95% CI for difference = 77.38 to 230.18, effect size (Cohen's d = 0.97). There were no significant group differences in behaviours associated with dementia (mean [SD] 4.5 [5.2] and 6.6 [6.0] respectively, t = 1.55, difference in means = 2.06, 95% CI for difference = -4.92 to +0.80, effect size (Cohen's d = 0.37)) or physical complications (mean [SD] 1.7 [1.7] and 1.7 [1.3] respectively, t = 0.05, difference in means = 0.02, 95% CI for difference = -0.76 to +0.80, effect size (Cohen's d = 0.01)).

# **Risk of bias**

No blinding, incomplete outcome data, other bias (Intervention and control group were compared on demographic and baseline measures. Reported as non-significant. However, study would not have had power to detect small/moderate differences. These measures were not controlled in the analyses).

#### WHAT'S NEW

Date	Event	Description
22 June 2020	Review declared as stable	See Published notes.

## HISTORY

Protocol first published: Issue 2, 2008 Review first published: Issue 3, 2011

Date	Event	Description
17 May 2018	Review declared as stable	See Published notes
19 July 2013	Review declared as stable	This review will be assessed for updating in 2018 as it is unlikely that new evidence will be published before then.
15 April 2008	Amended	Converted to new review format.

# CONTRIBUTIONS OF AUTHORS

SH: wrote the protocol and will be responsible for conducting the update.

IH & KF: commented on the draft protocol and final review.

SH, AK & HP: developed the search strategy; conducted the searches, obtained copies of studies and selected which studies to include.

IH: agreed included/excluded studies.

SH & HP: extracted the data from studies.

SH & AK: conducted the analysis and wrote the final review.



#### **DECLARATIONS OF INTEREST**

None known

#### SOURCES OF SUPPORT

#### Internal sources

No sources of support supplied

#### **External sources**

• The Dunhill Medical Trust, UK

Funding for Dr Sue Hall

• Fondazione Maruzza Lefebvre DOvidio Onlus, Italy

Funding for Anna Kolliakou and Dr Hristina Petkova

#### DIFFERENCES BETWEEN PROTOCOL AND REVIEW

These differences are mainly due to the small number of studies identified for the review.

- In the 'Participants' section, we have included a definition of 'care home', which includes nursing and residential homes and aged or long-term care facilities.
- We had expected to include more than three studies in the review and we expected the interventions to be heterogeneous. In the 'types of intervention' section we had planned to make the findings easier to present by basing the review on a series of more narrowly focused criteria grouping different types of intervention together. With only three relevant studies, this was not necessary. Instead we more clearly defined palliative care interventions.
- In the 'Personal contact' section we have added contacting the 167 members of the National Care Home Research and Development Forum. This was to improve our search for unpublished data or grey literature
- In the 'Language' section we have added that non-English papers were assessed with the assistance of a native speaker.
- We had planned to develop a manual to help with the data extraction process, however, since only two review authors were involved
  in data extraction from the three studies, and both were involved in the development of the data extraction sheet, a manual was not
  necessary.
- We have included 'Assessment of methodological quality' under a separate heading. In addition to the Oxford Quality score, we have assessed risk of bias according to the criteria described in the Cochrane Handbook for Systematic Reviews.
- In the analysis we had planned to first group studies by the nature of the intervention and to present the results in a table of comparisons, however, there were too few studies and they were too diverse for this to be done in any meaningful way. We have summarised the results in a table.

## NOTES

# Assessed for updating in 2018

A restricted search in May 2018 did not identify any potentially relevant studies likely to change the conclusions. Therefore, this review has now been stabilised following disucssion with the authors and editors. The review will be assessed for updating in two years time. If appropriate we will update the review before this date if new evidence likely to change the conclusions is published, or if standards change substantially which necessitates major revisions.

# Assessed for updating in 2020

A restricted search in May 2020 did not identify any potentially relevant studies likely to change the conclusions, although we are aware of some ongoing studies. Therefore, this review has now been stabilised following discussion with the authors and editors. The review will be re-assessed for updating in two years when it is likely the new studies will be published. If appropriate, we will update the review before this date if new evidence likely to change the conclusions is published, or if standards change substantially which necessitate major revisions.

# INDEX TERMS

# **Medical Subject Headings (MeSH)**

Controlled Clinical Trials as Topic; \*Homes for the Aged; Hospice Care [statistics & numerical data]; \*Nursing Homes; \*Outcome Assessment, Health Care; Palliative Care [\*organization & administration] [standards]; Patient Satisfaction



# **MeSH check words**

Aged; Humans