

What is the evidence base for care models within care homes that improve the end of life for patients and their carers?

25/03/2020

Review Methods

Search Strategy: A systematic search was conducted across a wide-ranging set of databases: Ovid Medline, including In-Process & Other Non-Indexed Citations, Ovid Embase, Ovid HMIC, Ovid PsycINFO, SCIE Social Care Online, Cochrane Library and Ebsco CINAHL.

The preliminary search strategy was developed on Ovid Medline using both text words and Medical subject headings from January 2009 to October 2019 restricted to English language humans. The search strategy was modified to capture indexing systems of the other databases. (Search strategies available upon request). To identify additional papers, the following website was searched: Social Care Institute for Excellence, ENRICH, The Kings Fund. Furthermore electronic tables of content for the last two years were scanned for BMJ Supportive & Palliative Care, The Palliative Medicine and Gerontologist, Reference lists of systematic reviews were checked for any relevant studies. After removing duplicates and irrelevant records the searches generated 173 citations. Figure 1 represents the flow of information through the different phases of the review.

Inclusion: Studies published in the last 10 years, care home based model/intervention, end of life or palliative care model/intervention, set in a Organization for Economic Cooperation and Development (OECD) countries, outcome measures must include quality of life, preference for place of care, place of death, acute hospital admissions or narrative evidence based on the lived experience of patients. Secondary outcomes included carer burden, satisfaction with care, frequency of hospital admissions in the last 6 months of life and documented preferred place of care and whether this was achieved.

Exclusion: Studies set in non OECD countries, studies consisting of less than 25 patients, not care home based or studies excluding those with palliative care needs/ end of life.

Study selection/Quality Assessment/Data

Extraction: Study selection was based upon review of the abstract by two independent reviewers. The full text was then assessed using a pre-designed eligibility form according to inclusion criteria. Data extraction and critical appraisal was completed by 2 reviewers. Where consensus could not be achieved at any stage, an independent reviewer was consulted.

Context

Care homes are a common place of residence for older people who are nearing the end of their lives. Often those living in care or residential homes have multiple long-term conditions and palliative care needs and this can lead to poorer quality of life, quality of death and unnecessary hospital admissions.

There is anecdotal evidence from service evaluations that suggests there are benefits of implementing interventions within care homes for people at the end of life and their families/carers (Garden et al. 2016; Finucance et al. 2013). This rapid review aims to identify robust evidence for interventions/care models within care homes which improve quality of life and quality of care outcomes within the UK or comparable countries.

The findings from this rapid review will be presented to the Marie Curie care homes project group to inform future plans of how Marie Curie may support care homes in their provision of end of life care, to ensure everyone has the best end of life experience possible, irrespective of their place of death.

Key Findings

Of 696 records identified, 173 abstracts were screened, and 6 papers are included in this review. Our search did not focus on specific terminal diseases. However, the majority of the included papers focus specifically on palliative and end of life care interventions for those with dementia (n=4; Brazil et al., 2018; Sheaf et al., 2018; van Soest-Poortvliet et al., 2015; Verreault et al., 2018). This may reflect the difference in populations between community and care home settings, with the prevalence of dementia being higher in the latter group.

There does not appear to be strong evidence to date supporting one specific care model or intervention that is particularly effective in improving the end of life for patients within care homes and their families. Overall, there was quasi-experimental evidence that structured interventions with common domains of improved communication between staff, specialist palliative care and primary care - and associated end of life education - may reduce the number of admissions to acute hospitals, and length of hospital stay. Chapman's Australian care home study (2018) demonstrated that dedicated palliative care rounds using a nurse facilitator reduced overall length of hospital stay by 45% towards end of life and reduced the risk of admission when the individual's case was discussed. A UK study in London care homes (Sherlaw-Johnson et al., 2018), suggested that a complex care multi-professional hub using a chronic disease care model reduced end of life admissions by 36%, but outpatient visits increased and heterogeneity across homes was high.

Carer burden and satisfaction with care were specific domains of interest for the review. Three studies included carer outcomes of interest. For dementia patients there was limited evidence that early confirmation of a comfort care goal (van Soest-Poortvliet et al., 2015) and improved staff skills in symptom management and communication (Verreault et al., 2018) may improve family satisfaction with care.

Notably, Brazil et al. (2018) in a cluster randomised study found that advanced care planning with family carers of residents with dementia, who lacked capacity, resulted in reduction in carer uncertainty in decision making and a change in perceptions of care compared to controls. Rates of hospital admission were not affected.

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A. Reliability of evidence

The majority of the studies included used quasi-experimental or cohort designs with inherent significant limitations in terms of bias. Only two randomized trials were included. Brazil’s study used a cluster randomized design and was well described in terms of methodology and used a well validated primary outcome. However, an effect size and associated sample size was not described, and there was considerable heterogeneity in outcome between cluster pairs. Sheaf’s randomized study used a complex methodology. There was a high rate of attrition, inconsistent application of the intervention and significant missing data which made results interpretation difficult.

B. Consistency of evidence

It is particularly difficult to compare across studies which have different outcome measures, over different time periods and using different, often multidimensional, interventions. However, the use of single, designated facilitators or points of contact who directed care or coordinated professional and family communication (Chapman et al. 2018, Verreault et al. 2018, Sheaf et al 2018, Sherlaw-Johnson et al. 2018) provides a degree of consistency in approach across studies with low level evidence of impact on admission rates and/or family satisfaction with care. A degree of future care planning (Brazil et al. 2018, van Soest-Poortvliet et al.2015) may improve aspects of carer burden and satisfaction with care in caring for patients with dementia.

C. Relevance of evidence

We sought evidence of palliative and end of life care models and interventions used within care homes. We did not focus on one particular terminal condition and the evidence identified covers a range of conditions, although dementia predominates. All of the evidence identified is from health and social care economies with similarities to the UK. However, the definition of care home was not always clear and is likely to have differed between studies and geographical locations.

Glossary:

ACP – Advance care plan	SM-EOLD – Symptom management for end of life care in dementia
FPCS - Family Perceptions of Care Scale	DNR – Do not resuscitate
SPC – Specialist palliative care	GP – General practitioners
DLC – Dementia learning community	EOLD – End of life in dementia
PDSA – Plan-do-study-act	QOC – Quality of care
WIB – Well and ill being	QOD – Quality of dying
EOLD-SWC – End of life in dementia satisfaction with care	QoL – Quality of Life
EOL-CAD – End of life in dementia comfort assessment in dying	

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Evidence Implications:

Clinical:

Robust evidence is lacking on effective palliative interventions to improve end of life care in care homes. Identification of single GP practices per care home and designated palliative care nurse facilitators for case discussion and education may impact on some aspects of quality of care.

There is also a lack of clarity on the methodological approaches and outcomes of importance which will best assess domains of impact of multi-dimensional approaches to end of life care in care homes.

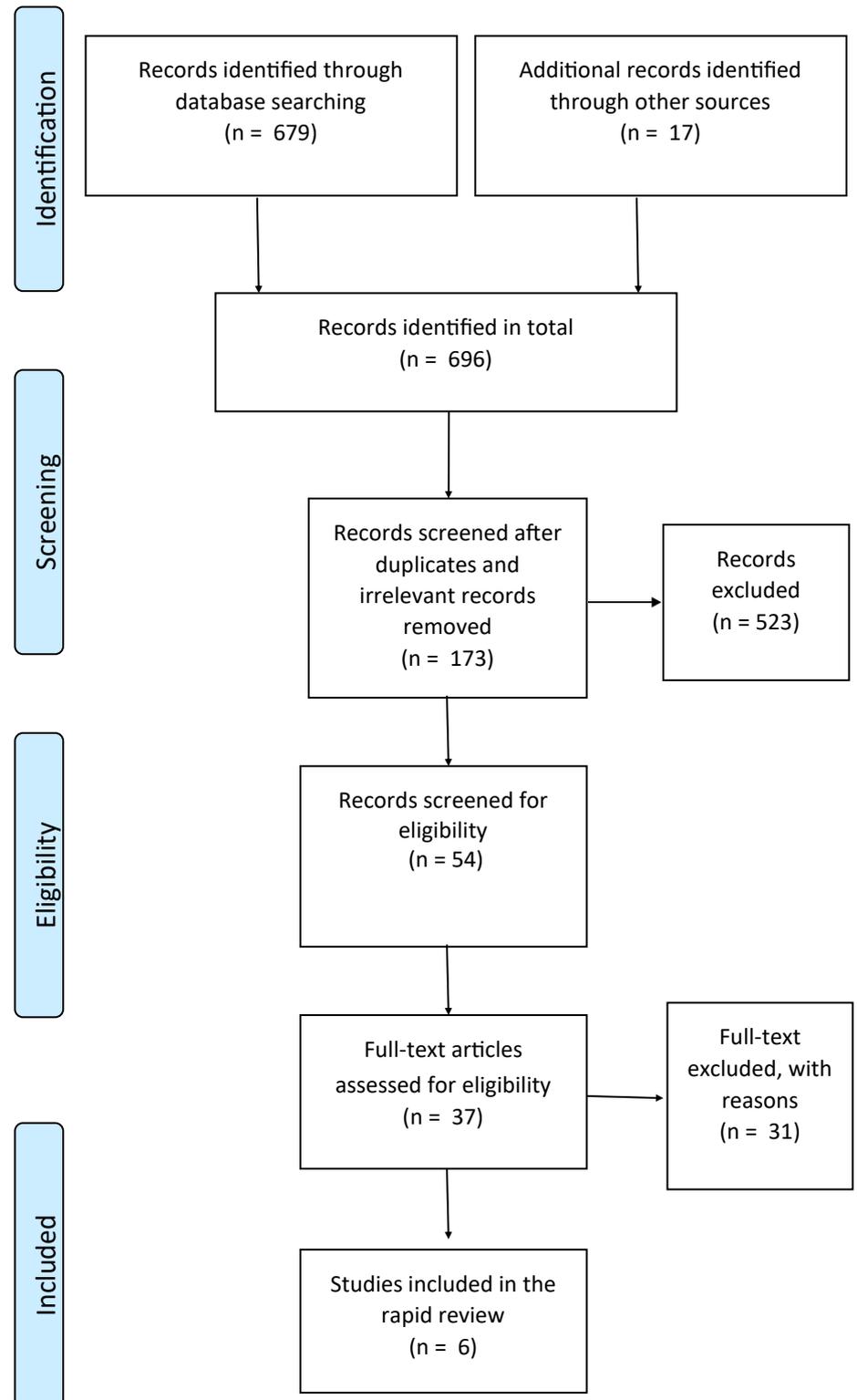
Cluster randomized studies may be appropriate to the environment and focus of care, but consensus is required on the key outcomes. Feasibility studies will be important in determining which multi-method approaches will best capture those outcomes and identify the specific domains of the intervention which are most effective.

Policy:

Provision of a consistent approach to end of life care, and assessment of effectiveness, is very challenging when applied to environments which are operated independently and may differ significantly in terms of staff skill sets and access to support.

Consensus is required on the outcomes of most relevance to end of life care provision in care homes. Prospective approaches to evaluation are required, with agreed commitment to the robust collection of, and access to, data in advance.

Flow Diagram:



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Table 1: Characteristics of Included Studies

Brazil et al. (2018)	Study Setting & Design – Northern Ireland, UK. Nursing homes catering for dementia patients: single provider. Paired cluster randomized controlled trial
Study Objective	To evaluate the effectiveness of ACP with family carers of patients with dementia who were nursing home residents.
Participants	Family carers of nursing home residents classified as having dementia and not having decisional capacity. A total of 24 nursing homes run by a single independent provider were included in the cluster randomized design: 12 to intervention and 12 to control arm matched into pairs by number of dementia beds in facility.
Interventions/Comparators/Methods	The intervention comprised a trained facilitator, family education, two family meetings, documentation of advance care planning decisions and intervention orientation for general practitioners and nursing home staff. Usual care applied to the control group. Included in main analysis Intervention were 11 clusters in each arm [a total of (n = 51) individuals in intervention and (n = 91) in usual care].
Proposed Outcomes	<ul style="list-style-type: none"> Primary: Family carers uncertainty in decision making measured by the Decisional Conflict Scale Secondary: Family carer satisfaction with nursing home care; family carer distress; hospitalization rates; presence of DNR orders; place of death.
Summary of Results	Primary outcome on family carer uncertainty in decision-making about the care of the resident (Decisional Conflict Scale). There was evidence of a reduction in total Decisional Conflict Scale score in the intervention group compared with the usual care group (-10.5, 95% confidence interval: -16.4 to -4.7; p < 0.001). There was evidence of a difference in the total Family Perceptions of Care Scale (FPCS) total score between the intervention and usual care groups after adjusting for baseline (8.6, 95% CI: 2.3 to 14.8; p = 0.01), which was also fairly consistent across pairs (I ² = 14%, heterogeneity p = 0.31). There was no detectable impact on carer psychological distress. There were no significant differences in hospital admissions or DNR form completions between groups. Only 6 deaths occurred making 'place of death' assessment meaningless.
Appraisal Summary	The methods are robust with the use of a cluster randomised methodology and validated outcomes. The intervention was described in detail and standardised across sites. The primary outcome was chosen to assess the impact of ACP on carer decisional conflict which appeared appropriate in context of patients lacking capacity. Statistical methods were well described including the handling of missing data. Limitations include the lack of blinding to allocation at time of data collection, lack of description of potential contamination between groups (single provider for all sites) and lack of health economic analysis.
Chapman et al. (2018)	Study Setting & Design – 4 residential care home facilities in Canberra, Australia. Quasi-experimental design.
Study Objective	To examine whether the addition of a standardised specialist palliative care model reduces resident transfer to the acute care setting and reduce hospital deaths.
Participants	Care home residents in 4 residential care home facilities in Canberra.
Interventions/Comparators/Methods	The intervention involved a 'palliative care needs round' to support clinical decision making, education and training. This was facilitated by a specialist palliative care nurse facilitator who had received standardised training. The intervention occurred monthly between the facilitator and care home staff with individual care plans formulated via case based discussions and if required individual case conferences to include residents, families and GPs. The intervention group of residents in the care homes were compared to a historical control cohort made up of residents who had died during the 3 years prior to the intervention: 104 residents in the intervention group and 173 residents with complete data in a historical control group. Residents receiving the intervention met one or more of the following criteria – discussed at a palliative care needs round; received urgent SPC assessment due to uncontrolled symptom burden; died during the course of the study. Data was collected in the 3 months prior to death in the intervention and historical control groups.
Proposed Outcomes	<ul style="list-style-type: none"> Participant hospitalisation: number of episodes and length in days The preferred place of death and location of death
Summary of Results	Rates of hospitalisation were not significantly different between the groups. However when matched, the intervention group showed a 45% reduction in length of hospital stay from 4.8 days to 2.63 days (all decedents). This effect was even more significant for those who were specifically identified as in need and discussed at the palliative care needs rounds. There was a reduction in number of hospital deaths in the intervention group which reached statistical significance when those specifically discussed on needs rounds were included. It wasn't possible to compare completion of preferences for place of death due to lack of historical control data.
Appraisal Summary	This research suggests that a defined model of case-based palliative needs rounds, education and training can be successful in reducing length of hospital admissions at the end of life for nursing home residents. However, this is a pilot study in a small number of care home settings, using historical controls and further limited by reliance on accessible data.

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Table 1: Characteristics of Included Studies

Sherlaw-Johnson et al. (2018)	Study Setting & Design - Four nursing homes in the London Borough of Havering. Cohort study
Study Objective	To assess the impact of a new complex care hub intervention for care homes, called Health 1000, on staff and use of hospital services.
Participants	Participants were those resident in four purposively chosen intervention nursing homes - and in 19 comparator nursing homes, all located across three London boroughs.
Interventions/Comparators/Methods	The intervention involved the assignment of a single GP practice to all residents in a care home; access to health care professionals with expertise in caring for older people with complex needs including a named geriatrician; extended access beyond normal GP hours (8am-8pm 7 days a week); care guidance to nursing home staff; improved medicines management; and new approaches for managing people who are at the end of life. The comparator group were residents of 19 usual care nursing homes. A mixed methods approach was used: prospective data capture and interviews with care home staff. A range of outcomes were assessed; we report here specifically on the end of life outcomes.
Proposed Outcomes	Impact of the new service Health 1000 <ul style="list-style-type: none"> on hospital inpatient admissions attendance at accident and emergency (A&E) departments outpatient appointments
Summary of Results	The full dataset for the study consisted of 431 in the intervention group and 1,926 in the comparator group. The numbers in the end of life cohort are not stated. In the last 3 months of life, compared to the wider non-end-of-life cohort, there was a five-fold increase in hospital admission rates across intervention and control groups, but the intervention group had statistically significantly fewer admissions than control. There was no difference in A&E attendance between the intervention and control groups. However the intervention group had a higher rate of outpatient visits.
Appraisal Summary	This project suggests that the implementation of a complex care hub, following a chronic disease management model, may impact on hospital admissions at the end of life. Key elements included having a single GP practice per nursing home, access to a multidisciplinary team and a named geriatrician. There were several limitations: a quasi-experimental design with four purposively chosen intervention homes; evidence of significant heterogeneity in outcomes across the four homes; only a sample of residents in the comparator homes had complete data; the data collection period was approximately 12 months so sustainability of findings is unclear.
Sheaf et al. (2018)	Study Setting & Design - 23 Care homes in England. Controlled trial.
Study Objective	To evaluate whether and how a dementia training intervention as part of a Dementia Learning Community (DLC) in care homes improved quality of life and reduced unplanned hospital admissions for residents with dementia.
Participants	Residents with dementia in 23 care homes across a single local authority area in England.
Interventions/Comparators/Methods	A dementia learning facilitator trained a dementia champion in each DLC care home. The dementia champion trained other staff in dementia awareness and change management with the aims of changing work routines, improving quality of life, and reducing demands on external services. These champions were trained on how to conduct 'Plan-Do-Study-Act' (PDSA) cycles with staff to improve resident's quality of life. Thirteen care homes were randomly assigned to the DLC intervention (288 residents) compared against ten control care homes (330 residents). Methodology consisted of a mixed methods realist evaluation examining the active components of the training intervention.
Proposed Outcomes	<ul style="list-style-type: none"> Resident Well and Ill-Being (WIB) and Quality of Life Scores using Dementia Care Mapping score and Quality of Life in Late Stage dementia (QUALID) scores respectively Number of ambulance call-outs Emergency hospital admission rates
Summary of Results	Data on QoL was only available for 246 residents (38% of the study population) and data on treatment escalation plans for 201 residents (31%). Dementia Care Mapping data was available across 10 intervention and 5 control sites. Residents' well-being (WIB) scores, measured by dementia care mapping, improved markedly in half of the intervention homes but not in the other half, where some deteriorated. There was no convincing evidence of an overall difference between intervention and control groups. There was also no difference between groups on quality of life scores, nor impact on the number of ambulance call-out or emergency hospital admission rates. The PDSA cycles appeared to be the most important component of the intervention, with staff encouragement and improvements in morale proving more important than changes in knowledge and attitudes.
Appraisal Summary	This was a complex, exploratory randomised study of a dementia learning intervention in care homes. The realist approach to assessing impact and implementation was commendable but the attrition rate amongst participating sites, inconsistent application of the model and variability in data capture makes the findings of limited value.

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Table 1: Characteristics of Included Studies

van Soest Poortvliet et al. (2015)	Study Setting & Design - 28 long term care facilities in the Netherlands. Cohort study.
Study Objective	To investigate whether family satisfaction with end-of-life care and quality of dying is associated with whether or not dementia patients have a comfort goal shortly after admission.
Participants	Residents with dementia in 28 care homes, and their carers across the Netherlands.
Interventions/Comparators/Methods	The intervention was implementation of a comfort care goal shortly after admission compared with no comfort goal. Written questionnaires were completed 8 weeks after admission (baseline), every 6 months after that (semi-annually), and after death (family after 2months; physicians within 2weeks) for patients whose families had consented to participate upon admission. The study aimed to recruit sufficient participant numbers to have complete data on 160 patients who died. Of 372 participants recruited, 218 patients died. Of those, 148 patients were included who had complete data on care goals and a family 'after death assessment'. Outcome measures used were EOLD scales which are validated and demonstrated to be sensitive to change.
Proposed Outcomes	<ul style="list-style-type: none"> Family satisfaction (End-of-Life in Dementia Satisfaction with Care (EOLD-SWC) scale; range: 10–40) Quality of dying (End-of-Life in Dementia-Comfort Assessment in Dying (EOLD-CAD) scale; range: 14–42)
Summary of Results	Family members were more satisfied with care where a comfort goal was established shortly after admission to the care home but this was only significant for those who died within 6 months of admission. The mean EOLD-SWC score was 33.2 (SD: 4.7) and the mean EOLD-CAD score was 33.4 (SD: 5.9). Family perspectives on quality of dying (EOLD-CAD) was not related to early comfort goal setting.
Appraisal Summary	This prospective cohort study suggests an early comfort care goal for people with dementia may improve carer satisfaction with end of life care for a subgroup of patients resident for less than 6 months, but not for the wider patient cohort. The authors chose care homes across the Netherlands for geographical representation and generalisability. Limitations include the cohort design, lack of detail on all treatments provided, and missing data on 50 of the 218 participants who died.
Verreault et al. (2018)	Study Setting & Design - 4 Canadian care homes. Quasi-experimental study
Study Objective	To evaluate the impact of a multidimensional intervention to improve quality of care and quality of dying in advanced dementia in long-term care facilities.
Participants	Residents with advanced dementia and their close family members from 4 care homes in a single Canadian province.
Interventions/Comparators/Methods	The intervention had five components: <ol style="list-style-type: none"> training program to physicians and nursing staff, clinical monitoring of pain using an observational pain scale, implementation of a regular mouth care routine, early and systematic communication with families about end-of-life care issues with provision of an information booklet, involvement of a nurse facilitator to implement and monitor the intervention. From a convenience sample, 2 care homes received the intervention and outcomes were compared to 2 control care homes where residents received 'usual care'. A total of 193 residents who died during the study period were included: 97 in intervention group and 96 in the control group. Outcome measures used are validated and included the Family Perceptions of Care Scale and EOLD tools which demonstrated as being sensitive to change.
Proposed Outcomes	<ul style="list-style-type: none"> Quality of care (QOC) was measured using the Family Perceptions of Care Scale (FPCS). Quality of dying (QOD) was measured using Symptom Management for End-of-Life Care in Dementia (SM-EOLD) Scale and the Comfort Assessment in Dying (CAD-EOLD) Scale.
Summary of Results	Baseline scores for QOD and QOC were similar in both groups in the 6 months prior to implementation of the intervention. Following implementation, there were significantly higher scores on both the Family Perceptions of Care Scale and The Comfort Assessment and Symptom Management Scale in the intervention group compared to the control group: FPCS total score was significantly higher in the intervention group than in the control group (157.3 vs 149.1; p = 0.04). SM-EOLD scores were also significantly better in the intervention group (34.7 vs 29.8; p = 0.03).
Appraisal Summary	This research suggests that a multi-dimensional intervention can be successful in improving quality of care and quality of dying in people with dementia in care home settings compared to usual care. However the quasi-experimental design limits reliability of results. Although p values were described there were no confidence intervals provided, and the amount of missing data was high.

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Included Studies:

Studies were included where it was reported a care model intervention within care homes improved the end of life for patients and their carers

1. Brazil, K., et al. (2018). "Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial." *Palliative Medicine* 32(3): 603-612. Chapman, M., Johnston, N., Lovell, C., Forbat, L., & Liu, W.-M. (2018). Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults. *BMJ Supportive & Palliative Care*, 8(1), 102-109. doi:10.1136/bmjspcare-2015-001071
2. Chapman, M., Johnston, N., Lovell, C., Forbat, L., & Liu, W.-M. (2018). Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults. *BMJ Supportive & Palliative Care*, 8(1), 102-109. doi:10.1136/bmjspcare-2015-001071
3. Sherlaw-Johnson, C., Crump, H., Curry, N., Paddison, C., & Meaker, R. (2018). Transforming health care in nursing homes. An evaluation of a dedicated primary care service in outer east London. Nuffield Trust. xxxx
4. Sheaff, R., Sherriff, I., & Hennessy, C. H. (2018). Evaluating a dementia learning community: exploratory study and research implications. *BMC Health Services Research*, 18, 1-1. doi:10.1186/s12913-018-2894-3
5. van Soest-Poortvliet, M. C., van der Steen, J. T., de Vet, H. C. W., Hertogh, C. M. P. M., Deliëns, L., & Onwuteaka-Philipsen, B. D. (2015). Comfort goal of care and end-of-life outcomes in dementia: A prospective study. *Palliative Medicine*, 29(6), 538-546. doi:10.1177/0269216315570409
6. Verreault, R., Arcand, M., Misson, L., Durand, P. J., Kroger, E., Aubin, M., . . . Carmichael, P.-H. (2018). Quasi-experimental evaluation of a multi-faceted intervention to improve quality of end-of-life care and quality of dying for patients with advanced dementia in long-term care institutions. *Palliative Medicine*, 32(3), 613-621. doi:10.1177/0269216317719588

Excluded Studies:

A number of studies have been excluded due to various reasons including the following:

- No intervention is implemented in the study
- Study participants were external stakeholders not patients and their carers
- Literature consisted of service evaluations and discussion articles.

Additional materials available upon request:

- Critical appraisal / data extraction forms
- Search strategies
- List of excluded studies

This report should be cited as follows: Palliative Care Evidence Review Service. What is the evidence base for care models within care homes that improve the end of life for patients and their carers? A rapid review: Cardiff: Palliative Care Evidence Review Service (PaCERS) & Marie Curie; 2020 March.

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Disclaimer: Palliative Care Evidence Review Service (PaCERS) is an information service for those involved in planning and providing palliative care in Wales. Rapid reviews are based on a limited literature search and are not comprehensive, systematic reviews. This review is current as of the date of the literature search specified in the Review Methods section. PaCERS makes no representation that the literature search captured every publication that was or could be applicable to the subject matter of the report. The aim is to provide an overview of the best available evidence on a specified topic using our documented methodological framework within the agreed timeframe.