End of life care in UK care homes – controlled drugs: systematic review and narrative synthesis

Megha Majumder ,[1] Ben Bowers ,[1] Kristian Pollock,[2] Claire Goodman,[3] Isla Kuhn,[4] Stephen Barclay [1]

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[1]Public Health and Primary Care, University of Cambridge, Cambridge, UK
[2]Nottingham Centre for the Advancement of Research into Supportive, Palliative and End of Life Care, School of Health Sciences, University of Nottingham, Nottingham, UK
[3]Centre for Research in Primary and Community Care, University of Hertfordshire, Hatfield, UK
[4]Medical Library, University of Cambridge, Cambridge, UK

Correspondence to
Megha Majumder;
mm2426@medschl.cam.ac.uk

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ABSTRACT

Background Controlled drugs (CDs) such as opioids and midazolam are commonly used in end-of-life care symptom management for care home residents.

Aim To review the published evidence concerning the prescribing, storage, use and disposal of CDs for end-of-life care for care home residents in the UK.

Design Systematic review and narrative synthesis.

Methods Seven databases (Medline, CINAHL, Embase, PsycINFO, Web of Science, Cochrane Library, and Social Care Online) were searched from January 2000 to January 2021, alongside reference, citation and journal hand searches. Gough's 'Weight of Evidence' framework was used to appraise the relevance of studies to the review questions.

Results The search yielded 1279 titles, from which 125 abstracts and then 42 full-text papers were screened. 14 papers were included in the synthesis. Prescribing is primarily by general practitioners, with administration by nurses. Nurses frequently report feeling inadequately trained in the use of CDs. The storage, monitoring and disposal of end-of-life care CDs in UK care homes has not been researched to date. The attitudes and experiences of residents and family members regarding these medications also remain unknown.

Conclusion The current widespread use of CDs for end-of-life care in care homes has a limited evidence base. The lack of research concerning the storing, monitoring and disposing of CDs, alongside the limited evidence concerning resident and family members' perspectives, is a significant knowledge deficit that requires urgent attention.

PROSPERO registration number CRD42020173014.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The anticipatory prescribing of Schedule 1, 2 and 3 controlled drugs (CDs) including strong opioids and midazolam for adults at the end of their life is a recommended practice in UK care homes.
⇒ Anticipatory prescribing frequently presents challenges to care home staff with limited training and experience in end-of-life care, particularly concerning the appropriate use of these powerful drugs, their potential for hastening the end of life and the legal and regulatory frameworks for their storage, use and disposal.

WHAT THIS STUDY ADDS

⇒ The prescribing of end-of-life care CDs is primarily by general practitioners, with administration by nursing home and community nurses; however, nurses frequently report feeling inadequately trained in the use of CDs.
⇒ No studies have explored the storage and monitoring of end-of-life care CDs in UK care homes, and only one study has researched their disposal in this context; the attitudes and experiences of residents and family members regarding these medications are unknown.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE AND/OR POLICY

⇒ The current widespread use of CDs for end-of-life care in care homes has a limited evidence base; research is needed to evaluate the processes inherent to anticipatory prescribing in UK care homes.
⇒ The lack of research concerning the storing, monitoring and disposing of CDs, alongside the limited research concerning resident and family members' perspectives, is a significant knowledge deficit that requires urgent attention.

INTRODUCTION

Care homes are an important location for end-of-life care in the UK. Over 430 000 older people and vulnerable people in the UK live in care homes: of the 539 738 deaths in England and Wales in 2019, up to 137 998 (26%) occurred in care homes.[1] During the

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COVID-19 pandemic, the number of deaths within care homes increased by 134% in the first wave and 10% in the second wave.[2] By 2040, it is projected that care homes will be the most common place of death in the UK.[3]

Care homes are categorised as either 'residential homes' (social care staff but no on-site qualified nurses) or 'nursing homes' (social care staff and qualified nurses on-site at all times): many are dual registered. Additionally, there are specialist care homes for individuals with learning disabilities and mental health needs. For this review, we use the term 'care home' for all types of homes.

Care home residents are often older people, with multiple and complex medical conditions, leading to both physical and cognitive frailty: 80% are estimated to have a degree of dementia.[4] The mean survival of nursing home residents is 2.2 years with 31% annual mortality rates: the mean survival in residential homes is around 4.5 years and varies according to type of home and ages of residents, with 22% annual mortality.[5 6] Residents are often prescribed numerous medications, with additional drugs prescribed for the management of physical symptoms and distress as the end of life approaches.[7 8] In the UK, these include 'Schedule 1, 2 and 3 Controlled Drugs' (CDs) such as morphine and related opioids and the sedative medication midazolam. CDs are subject to regulations in addition to those for other prescription-only medications, as they are potentially open to misuse. National legislation controls the prescribing, dispensing, administration, storage and disposal of medications and CDs and is detailed in the guidelines of the National Institute for Health and Care Excellence,[9] reinforced by the regulatory inspector of care homes, the Care Quality Commission (CQC),[10] and guided by the principles outlined in the Enhanced Health in Care Homes Framework of National Health Service (NHS) England.[11]

CDs and other end-of-life care medications are commonly prescribed in the community in advance of need in a widespread practice known as 'Anticipatory Prescribing', to ensure that appropriate medications are in place if needed during the dying phase. These 'Anticipatory Medications' are stored in the home or care home 'just in case' they are needed at the end of life.[12 13]

Care homes are owned and run by corporate providers, charities, local authorities or individuals. Their residents are registered with one or more local general practitioner (GP) practice(s) who are responsible for providing and coordinating their medical care, in partnership with care home staff and other members of local health and social care services. GPs are responsible for prescribing residents' medication, which is supplied to the care home by a local community pharmacist, where staff store the medication according to the home's medicines management processes and are responsible for ensuring that residents receive their medications as prescribed. CDs are stored in separate locked cabinets in care homes, with strict regulations over their documentation and use.[10] The potential for errors in the storage and administration of CDs is a major concern for care home staff and CQC inspectors.[14 15] The storage capacity in care homes is often limited. Thus, the storage of such anticipatory medicines, prescribed in advance of possible need, may present challenges for care homes where they may be prescribed for several residents considered to be close to the end of life.

Towards the end of life, people can often no longer take oral medications for symptoms such as pain and agitation: a trained nurse may be needed to administer drugs by injection, either a visiting community nurse in a residential home or an in-house nurse in a nursing home. This requires the appropriate injectable drugs, frequently CDs, to have been prescribed for the person, which national guidance recommends should be in a personalised manner rather than a 'blanket-like fashion'.[16]

The decision to administer anticipatory medicines depends on nursing staff assessing that there are no reversible causes of a resident's deterioration,[17] that the end of life is approaching[17–19] and that symptomatic management and comfort care is appropriate.[17 20] These judgements are frequently challenging for nursing home nurses who may have limited training in end-of-life care and limited access to colleagues such as GPs and specialist nurses, particularly overnight and at weekends.[18] In residential homes, these decisions are made by visiting community nurses who may be more experienced in end-of-life care. The use of CDs such as morphine and midazolam at the end of life adds a further layer of concern for managers and nursing staff in both residential and nursing homes, with concerns over the appropriate use of such powerful drugs, their potential for hastening the end of life and the legal and regulatory frameworks for their storage, use and disposal.[7]

Alongside the marked increase in care home deaths during the COVID-19 pandemic, changes were made in UK legislation which permitted the repurposing of end-of-life care drugs in care homes. During the COVID-19 pandemic in England, drugs prescribed and stored for one resident could be repurposed for and administered to another resident if urgently needed to address issues regarding the timely supply of drugs in care homes.[21] The extent to which this legislation was used in practice is unclear at present and is under investigation by the authors.

Given the increasingly important role of care homes in end-of-life care in the UK, it was timely to review the published evidence concerning the prescribing, dispensing, storing, administration and disposal of end-of-life CDs in UK care homes. The focus is on oral, injectable and transdermal 'Schedule 1, 2 and 3 CDs', primarily strong opioids such as morphine, oxycodone

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and fentanyl (excluding codeine, dihydrocodeine and tramadol) and midazolam. These medicines are commonly prescribed for end-of-life symptom control, are subject to strict regulation due in part to their potential for misuse and abuse and require specific training in their use. There was considerable concern during the COVID-19 pandemic that they might be in short supply.[16 17]

Aim

This review builds on a previous review exploring anticipatory prescribing, the process of prescribing medications in advance of clinical need, in the community,[12] with a specific focus on end-of-life care CDs in the care home setting.

Review questions

With regard to end-of-life CDs in care homes in the UK:

1. For whom and by whom are they prescribed?
2. How are they stored and monitored?
3. For whom and by whom are they administered?
4. How are they disposed of after a resident's death?
5. What are the views of care home staff and other health and social care professionals concerning these issues?
6. What are the views of residents and their family members concerning these issues?

METHODS

A search strategy, developed with a specialist information technologist (IK), was developed for CINAHL (online supplemental file 1) and adapted for six subsequent databases (Medline, Embase, Web of Science, PsycINFO, Social Care Online and Cochrane Library). All databases were searched from January 2000 to January 2021: the start date was selected as the year of publication of the Care Standards Act (2000) which covered CD usage, storage and administration in care homes. Hand searches of two journals, *Palliative Medicine* and *British Medical Journal Supportive & Palliative Care*, from January 2000 to March 2021 were conducted, as well as reference and citation searches of all included papers.

Papers were included if they presented empirical data on CDs for UK adult care home residents. Due to the diversity of CD regulations internationally, only papers concerning UK care homes were included. Box 1 summarises the inclusion and exclusion criteria. The review questions were developed iteratively through discussions with the research team, with clinical and lay stakeholders and from initial readings of the policy and research literature.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram (figure 1) summarises paper selection. Following deduplication and title screening by MM, 81 abstracts were independently screened by MM and BB. Full-text papers were assessed for eligibility by MM with a second review by BB where eligibility was uncertain, leading to identification of 14 papers for data extraction. Disagreements were resolved by consensus.

Box 1 Inclusion and exclusion criteria

Inclusion criteria

⇒ Published papers presenting empirical research on the prescribing, storage, administration and disposal of these oral and injectable Schedule 1, 2 and 3 controlled drugs: strong opioids (excluding codeine, dihydrocodeine and tramadol) and midazolam primarily (oral or injectable).
⇒ Studies published between January 2000 and January 2021.
⇒ English language full text.
⇒ Study setting: UK care home, residential and/or nursing homes.
⇒ Peer-reviewed quantitative and qualitative studies, case studies.
⇒ Key areas for data extraction:
  1. For whom and by whom end-of-life CDs are prescribed.
  2. How CDs are stored and monitored.
  3. For whom and by whom CDs are administered.
  4. How are CDs disposed of following a resident's death.
  5. The views of care home staff and other health and social care professionals concerning these issues.
  6. The views of residents and their family members concerning these issues.

Exclusion criteria

⇒ Controlled drugs in non-terminal situations.
⇒ Controlled drugs not relevant to end-of-life symptom control.
⇒ Children (aged under 18 years).
⇒ Prescribing in hospital, hospice, home or prisons.
⇒ Papers with no new empirical data, for example, editorials.
⇒ Research examining assisted dying, euthanasia or continuous sedation until death.
⇒ Grey literature.

A review-specific data extraction form (online supplemental file 2) was used by MM and BB to extract publication details, study aims, participants, methods and results relevant to the review questions.

Two reviewers (MM and either BB or SB) independently assessed the quality and relevance of each study using Gough's 'Weight of Evidence' (WoE) framework (box 2) with disagreements resolved by consensus.[22]

The criteria given in box 2 are adapted from a study by Gough[22] and the box contents are adapted from a study by Bowers *et al*.[12]

To capture the range of qualitative and quantitative evidence a narrative synthesis was undertaken of the range of qualitative and quantitative evidence, involving three iterative phases. First, the primary researcher (MM) developed a preliminary synthesis, creating textual descriptions of each study from the data extraction forms, tabulated according to the review questions. MM explored heterogeneity across studies and conducted an initial inductive thematic

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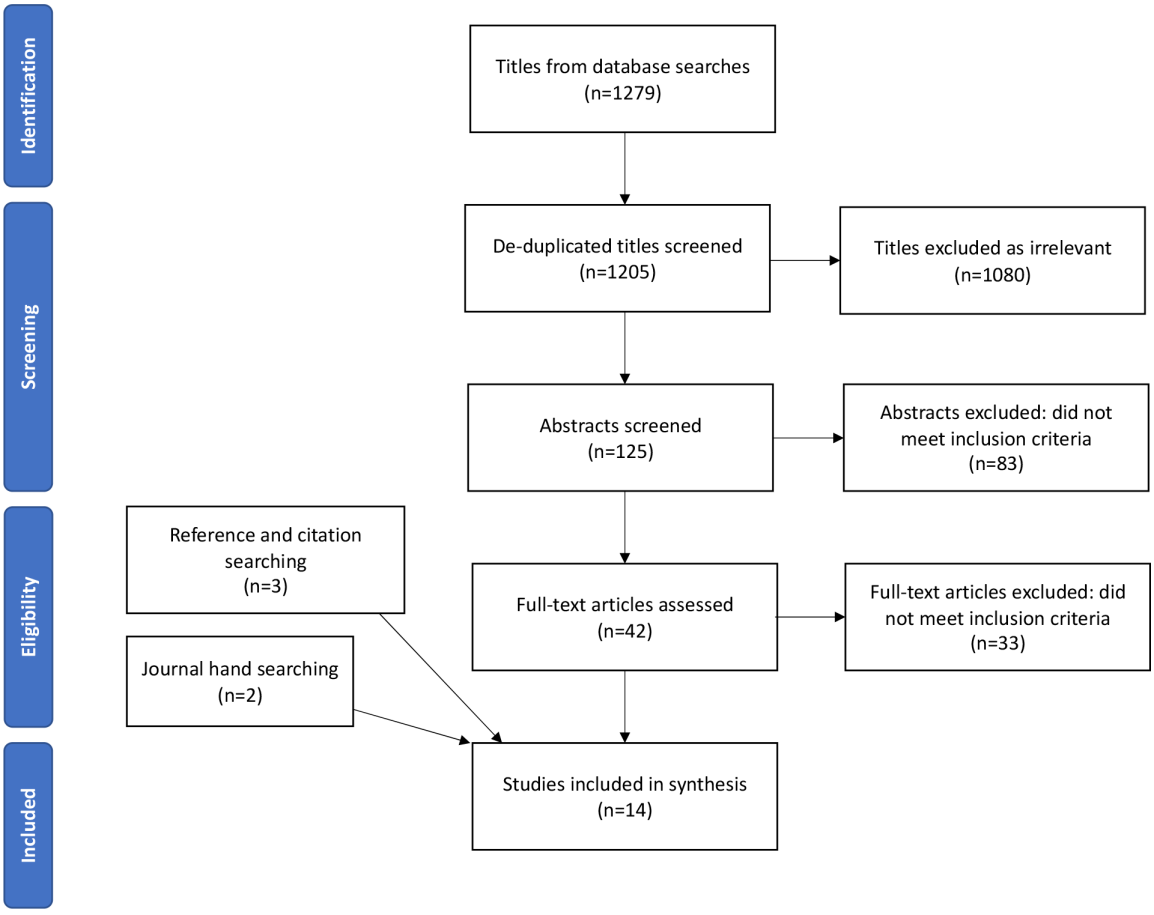

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram.

analysis. Second, MM and BB explored the relationships in the data and created an interpretive synthesis, independently reviewing the thematic analysis. In doing so, MM and BB investigated the similarities and differences between studies. Third, MM, BB and SB independently assessed the robustness of the synthesis, assessing quality and relevance using Gough's WoE framework. Papers deemed 'high WoE' were afforded greater weight throughout the synthesis.

The review protocol was registered with PROSPERO (registration number: CRD42020173014) in June 2020.

RESULTS

Fourteen full papers, reporting on 12 studies, were included in the synthesis (online supplemental file 3). Methods included: interviews or surveys of healthcare professionals or care home staff (n=11), retrospective care home resident notes reviews (n=8), ethnographic observations of healthcare professionals across care homes (n=3) and documentary analyses of provider end-of-life care policy documents (n=2). One study was reported in three papers.[20 23 24] Each paper presented different findings and was therefore treated as an individual unit in the synthesis. Several papers answered more than one review question. In addressing review questions 1 and 3, studies included surveys, analyses of patient records and policy documents. In addressing review question 5, included studies drew on qualitative methods, namely interviewing. Studies that used more than one method contributed to more than one section of the synthesis. Table 1 summarises the included papers and their 'Weight of Evidence'; two were rated high, nine medium and three low WoE.

1. *For whom and by whom are CDs prescribed?*

Ten studies addressed this review question.[23 25–33] One study, a review of 80 deceased resident notes from eight care homes, found up to 53% of residents in three nursing homes were symptomatic in the final days of life (pain, agitation, secretions, dyspnoea, nausea and vomiting) and required access to end-of-life medicines including midazolam and morphine.[27] In one nursing home, of those who had anticipatory medicines, only 36% of residents had them prescribed prior to the study's anticipatory medicines stocking intervention: rather than doctors prescribing then pharmacists dispensing end-of-life medications to residents when they became symptomatic, Morris and Hockley worked alongside nurse managers and local pharmacists on a strategy to implement tailored stocks of end-of-life medications in the participating homes.[27] If prescribed for a symptomatic patient by an out-of-hours GP, care home staff experienced difficulty

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Box 2 Review-specific Gough's 'Weight of Evidence' (WoE) criteria

WoE A: judged against internal validity: whether study design was rigorous, whether this could be adequately assessed from a transparent, comprehensive and replicable method; accurate and understandable presentation and analysis; if samples and data collection tools were appropriate to the method. Papers scored as high/medium/low.

WoE B: relates to the appropriateness of the study design to the six review-specific questions. Papers were scored as high/medium/low.

Review questions 1, 2, 3 and 4: the fitness for the purpose of the study design in answering the questions was made on a paper-by-paper basis.

Review questions 5 and 6: inductive research designs interpreting the views directly reported by patients/carers/healthcare professions=high. Deductive research designs interpreting these views directly reported by patients/family carers/healthcare professionals=low.

WoE C: relates to detailed judgements about each study relating to the relevance of the focus of the evidence for answering the review questions. This includes: consideration of any sampling issues relating to the interpretation of the data; whether the study was undertaken in an appropriate context from which results can be generalised to answer the relevant review-specific questions. Papers were scored as high/medium/low.

WoE D: the above three sets of judgement scores are then combined to give the overall 'weight of evidence' as high/medium/low.

obtaining the medication.[23] Some GPs tried to overcome this difficulty by ensuring that medications were pre-emptively prescribed for individuals prior to weekends, but this did not provide a solution for residents who deteriorated unexpectedly.[32]

Another study found that of 77 residents who died in eight care homes, 54% had anticipatory medicines prescribed and 15% had prescriptions for all four nationally recommended anticipatory medicines. The study noted considerable variation in frequency of AP practice: 100% of residents in one care home and 13% in another.[25] Prescribing practices also varied regarding the frequency of prescriptions and the doses of anticipatory morphine for residents with no analgesic history.[30]

During the last month of life, residents were primarily prescribed oral medication for symptom control; for example, oral and/or transdermal analgesia were prescribed for 84% of residents, while only 37% of residents had anticipatory injectable medication prescribed to be administered as required (PRN).[26] During the last days of life, the only oral medication that was occasionally prescribed PRN across nursing homes in one study was oral morphine, whether or not residents were on a previous opiate analgesic.[33] Syringe pumps have been reported to be used in around a quarter of dying nursing home residents, usually for less than the final 24 hours of life.[30]

In all 10 studies, the prescriber was a GP; occasionally, anticipatory medicines were also prescribed by hospital teams on discharge or palliative care community specialists.[30] While most nurses felt that GPs were in general willing to prescribe anticipatory medicines, one large-scale survey found 20% of nurses reported some doctors to be reluctant to prescribe anticipatory medicines, leading to difficulty in obtaining these medications in a timely manner.[23]

2. *How are end-of-life CDs stored and monitored in UK care homes?*

No studies were identified that addressed this review question.

3. *For whom and by whom are CDs administered?*

Five studies addressed this question: in each, care home nurses administered the CDs.[27 29–31 34] Kinley and Hockley found that while up to 53% of the residents in three nursing homes were symptomatic at the end of life, not all symptomatic residents were prescribed or administered the medicines that the researchers assessed were needed from a postdeath notes review. In one care home, 16% of symptomatic residents died without anticipatory medicines either prescribed or administered.[30] In a cross-sectional survey study assessing pain and dyspnoea in long-term care facility residents, nurses reported opioid underuse in the last

Table 1 Number of papers included in the synthesis

With regard to end-of-life controlled drugs (CDs) in care homes in the UK Review question	Number of papers answering each review question
For whom and by whom are end-of-life CDs prescribed?	10 papers: 1 high, 7 medium, 2 low WoE
How are CDs stored and monitored?	No papers identified
For whom and by whom are CDs administered?	5 papers of medium WoE
How are CDs disposed of after a resident's death?	1 paper of medium WoE
What are the views of care home staff and other health and social care professionals concerning these issues?	9 papers: 2 high, 5 medium, 2 low WoE
What are the views of residents and their family members concerning these issues?	No papers identified

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3 days of life to be higher in residents with dyspnoea than those with pain.[34]

In another study of 11 nursing homes, nurses commonly administered CDs including midazolam (for agitation), and morphine, oxycodone or diamorphine (for pain); residents were reported to have been 'more comfortable and settled'.[29] Kinley and Hockley found that the majority of residents required three or fewer injectable medications for symptom control in their last few days of life.[30] Injectable medications were more likely to be used when the nursing homes were supported by a specialist palliative care service.[30]

A report from an ongoing project found that during the initial stages of the COVID-19 pandemic, care home staff experienced difficulties in accessing medicines to manage and control symptoms at end of life for residents. Timely administration was especially difficult during the pandemic peaks, creating localised shortages of end-of-life medicines for residents.[31]

4. *How are end-of-life care CDs disposed of after a resident's death?*

Only one study addressed this question. A survey of 56 care homes concerning the disposal practices of fentanyl patches found over half of staff (53%) to be unaware of regulations concerning appropriate disposal of fentanyl patches.[35–37] The authors suggested this indicates gaps in communicating changes in regulations to care homes, deficits of in-company communication strategies or both.

5. *What are the views of care home staff and other health and social care professionals concerning these issues?*

Nine studies addressed this question.[20 23 24 27 29–33] One survey of 180 care home managers found consensus that morphine, midazolam and haloperidol are essential drugs for symptom alleviation in the last 48 hours of life.[32] A survey of nurses found strong support for the view that AP was essential in both avoiding emergency hospitalisation of dying patients and effective symptom management.[29]

Despite this recognition of their importance, two studies reported persistent challenges in securing the necessary prescriptions and support from GPs, obtaining medications both at short notice and out of hours and accessing syringe pumps.[24 32] Problems included access to these medications out of hours, prescribing delays, medication availability at pharmacy, access to syringe pumps, variable GP support and reluctance of some GPs to prescribe.[24 32]

In a study of eight nursing homes, staff reported inadequate end-of-life symptom management when anticipatory medicines had not been prescribed, lack of knowledge of end-of-life symptoms and medications and difficulties recognising the dying phase.[33] Care home nurses and visiting community nurses report that while they did not want to leave symptoms undertreated, they also worried that anticipatory medicines might cause oversedation, and frequently started residents on the lowest prescribed dose.[20] If the resident died soon after administration of these medications, less experienced community nurses and care home staff were left uncomfortable and some worried that the medications may have hastened death.[20] Care home staff view training from local palliative care teams as essential in preparing frontline staff and promoting their confidence, particularly in medication administration.[33]

The importance of close team-working relationships between care home staff and GPs in end-of-life care is repeatedly emphasised.[20 23 24 27 29–33] Watson *et al* identified the lack of multidisciplinary team working in nursing homes as a barrier to implementing integrated care pathways for the last days of life in nursing homes.[33] Spilsbury *et al* emphasised the importance of close working relationships between care homes and community services which enabled access to wider ranges of end-of-life care medicines.[31] Reluctance by some GPs to prescribe anticipatory medicines is a cause of frustration for care home staff.[23 24 32] Nurses reported that GPs' attitudes towards prescribing anticipatory medicines were influenced by the potential wastage costs of unused medicines.[33]

Interviews with care home staff during the early stages of the COVID-19 pandemic revealed frustrations that end-of-life medications could not be accessed or repurposed.[31] Pressures on the medicines supply chain during the pandemic caused distress for both residents and staff members.[31] The introduction of changes in legislation in April 2020, permitting medicine repurposing in England, sought to address these concerns, although it is unknown to what extent this new process has been used.[21]

In a study of four care homes that implemented an intervention to keep a stock of end-of-life care medications in-home, staff reported feeling safer knowing that they could access the stock in the event of an emergency.[27] One nurse manager reported that being able to access the stock 'transformed' the practice of her nursing staff, who grew comfortable requesting prescriptions for dying residents knowing that the medications would not be wasted.[27]

6. *What are the views of residents and their family members concerning these issues?*

No studies have investigated this review question.

DISCUSSION

This is the first review to systematically identify and synthesise the literature concerning the use of end-of-life CDs in UK care homes. Searches of nine databases, developed with a professional medical librarian (IK), and supplemented by journal hand searches, robustly identified the published literature. The limited literature does not address all the review questions and is of mixed WoE. Notably, there were no studies which investigated the storage and monitoring of end-of-life

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care CDs in care homes, or the views of residents and their family members concerning these issues. Only one study addressed the questions regarding the disposal of end-of-life care CDs following a resident's death. At times it proved difficult to separate Schedule 1, 2 and 3 CDs such as morphine and midazolam from other analgesics such as codeine, dihydrocodeine and tramadol in papers. Further, it proved challenging to separate evidence pertaining to research questions 1 and 3: for whom end-of-life care CDs were prescribed and to whom they were administered. For example, one study in which nurses reported opioid underuse did not specify whether the underuse was a result of underprescribing or underadministration of end-of-life care CDs.[34] It was noted that most included studies did not distinguish between end-of-life care CDs and anticipatory medicines. In practice, this is not problematic because the majority of prescriptions for anticipatory medicines will include Schedule 1 and 2 CDs. Due to the diversity of CD regulations internationally the review findings are limited to the UK.

Care homes are an increasingly important setting for palliative and end-of-life care; they are the location of approximately a quarter of all deaths in England and Wales, a proportion that increased markedly during the first wave of the COVID-19 pandemic.[1 2] They provide care for many of the most vulnerable members of the community, often with advanced physical and cognitive frailties, for periods of many months. The COVID-19 pandemic has highlighted the extreme vulnerability to infection of care home residents and the challenges that the current division between health and social care provision in the UK presents for optimal care at the end of life. Recent UK legislation seeks to ensure that care home residents, as all other patients, will have access to NHS specialist palliative care services when needed.[38]

Difficulties in recognising the dying phase in frail older care home residents with non-cancer illness,[39–41] associated with concerns that CDs used for end-of-life symptom management might hasten death,[12 20] are frequent causes for concern for care home staff. Prognostication in advanced frailty and extreme old age is very challenging and requires multidisciplinary team assessment and decision-making and sensitive conversations with residents (where possible) and their families, with acknowledgement of the uncertainties involved.[40] For older people, there is limited discussion about the dose and frequency appropriate for symptom control using CDs, especially if they have not been taking such medications previously.[23 24] This exacerbates known staff anxieties about using CDs at the end of life in social care settings where there is no on-site medical cover.[23 32]

Close working relationships with GPs are highly valued by staff; when absent, or GPs are reluctant to prescribe CDs ahead of need, symptoms are often poorly managed at the end of life. Strong relationships with a supportive GP practice are of great importance to ensure that skilled clinical assessments are made with shared management decisions and that end-of-life CDs are available for administration in a timely manner. Where these are present, excellent symptom control and end-of-life care can be achieved in most cases: where absent, residents may suffer and care home staff struggle.

The current literature concerning the use of end-of-life CDs in UK care homes is limited and of mixed quality. The studies included in the synthesis demonstrate that prescribing of end-of-life care CDs is primarily by GPs with substantial variation in prescribing practices between GPs, while administration of end-of-life care CDs is primarily by nurses. However, nurses frequently report feeling inadequately trained in the use of CDs. Thus, this review highlights the need for training and support for nurses in the administration of end-of-life care CDs. Additionally, this review highlights notable gaps in the evidence base concerning the storage, monitoring, disposal and repurposing of end-of-life CDs. Thus, the absence of research concerning the storage, monitoring and disposal of end-of-life CDs in care homes, as well as the perspectives of residents and their family members on these issues, is a pressing research need.

CONCLUSION

There is a professional consensus that CDs are an essential part of end-of-life care for people dying in care homes. The prescribing, storage, monitoring, administration and disposal of end-of-life CDs is a common practice in care homes. However, the limited evidence that is available suggests that access to this important component of symptom management is variable and dependent on practitioner preference and whether staff have the necessary knowledge, support and confidence to administer medications. Established policy and practice lacks evidence concerning the crucial stages of storage, administration and disposal of CDs, as well as the perspectives of residents and their families. We are planning research to address these critical knowledge gaps.

Twitter Megha Majumder @megmajumder, Ben Bowers @Ben_Bowers__ and Isla Kuhn @ilk21

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ORCID iDs
Megha Majumder http://orcid.org/0000-0003-4853-4178
Ben Bowers http://orcid.org/0000-0001-6772-2620
Stephen Barclay http://orcid.org/0000-0002-4505-7743

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Supplementary Information 1. Search strategy: CINAHL via Ebsco

#	Query	Limiters/Expanders	Last Run Via	Results
S18	S3 AND S6 AND S9 AND S17	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	51
S17	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,266,989
S16	TI ((armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's")) OR AB ((armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's")) OR AF ((armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's"))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	9,050
S15	TI ((aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's") OR AB ((aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's") OR AF ((aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	59,746
S14	TI ((bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's")) OR AB ((bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's")) OR AF ((bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's"))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	21,884

S13	TI ((bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*)))))) OR AB ((bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*)))))) OR AF ((bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	897,810

S12	TI ((gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*)) OR AB ((gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*)) OR AF ((gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	496,909
S11	(TI ((english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) N5 english)) OR AB ((english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) N5 english))) OR (TI (national health service* or nhs) OR AB (national health service* or nhs) OR AF (national health service* or nhs))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	134,827
S10	(MH "United Kingdom+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	322,557
S9	S7 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	109,517
S8	(MH "Terminal Care+") OR (MH "Terminally Ill Patients+") OR (MH "Hospice and Palliative Nursing") OR (MH "Palliative Care") OR (MH "Dying Care (Iowa NIC)")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	73,510
S7	((end N life) or ((final* or last*) N (hour* or day* or minute* or week* or month* or moment*)) or palliat* or terminal* or (end adj stage) or dying or (body N (shutdown or shut* down or deteriorat*)) or deathbed)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	97,742
S6	S4 OR S5	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	70,766
S5	(MH "Controlled Substances") OR (MH "Analgesics, Opioid+") OR (MH "Fentanyl+") OR (MH "Buprenorphine") OR (MH "Oxycodone") OR (MH "Codeine") OR (MH "Tramadol") OR (MH "Methadone") OR (MH "Dihydromorphinone") OR (MH "Phenobarbital+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	38,601
S4	("Controlled drug*" or "Controlled medic*" or "End of life drug*" or "End of life medic*" or anticipatory or pre-emptive or preemptive or "Just in case" or "Pro re nata" or PRN or "Core 4" or "Core four" or opioid* or morphine or diamorphine or oxycodone or methadone or midazolam or phenobarbital or tramadol or buprenorphine or codeine or fentanyl)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	68,614
S3	S1 OR S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	85,368
S2	(MH "Nursing Home Patients") OR (MH "Nursing Homes+") OR (MH "Residential Care+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	44,662
S1	("Care home*" or "Nursing home*" or "Residential home*" or "Long term care facilit*" or "Extended care facilit*" or "Care facilit*" or "Rest home*" or "Homes for the aged" or "Residential care" or "Geriatric home*" or "Geriatric facilit*" or "Geriatric institution*" or "Nursing center*" or "Nursing centre*")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	81,071

Searches in MEDLINE, Embase, PsycINFO, Web of Science, Cochrane Library, and Social Care Online were adapted from this strategy.
https://docs.google.com/document/d/1Yajy3uJKXpye4CCgZ7B8luY-8Ng1DRWEc2clzku1mWg/edit

Details of publication	
First author	
Reference	
Introduction	
Aims	
Study participants	
Country of study	
Recruitment	
Characteristics of participants: - Number - Setting (home, hospital, etc) - Age / sex / social class / ethnicity	
Methods	
Date of fieldwork	
Research methods	
Analysis	
Key findings relevant to review	
1) For whom and by whom are EoL CDs prescribed?	
2) How are CDs stored and monitored?	
3) For whom and by whom are CDs administered?	
4) How are CDs disposed of after a resident's death?	
5) What are the views of care home staff and other health and social care professionals concerning these issues?	
6) What are the views of residents and their family members concerning these issues?	
Author conclusions	
Reviewers' quality assessment of research (Gough WoE)	
WoE A: Coherence and integrity of the evidence in its own terms	
WoE B: Appropriateness of form of evidence for answering review question	
WoE C: Relevance of the evidence for answering review question	
WoE D: Overall assessment of study contribution to answering review question	

Supplementary Information 3.
Summary of included studies

Author, Year	Title	Reference	Aims	Research methods	Key Findings	Gough's WoE A + B + C = D
Finucane, 2014	Anticipatory prescribing at the end of life in Lothian care homes	Finucane A, et al. "Anticipatory prescribing at the end of life in Lothian care homes." British journal of community nursing 19.11 (2014): 544-547.	To investigate the extent to which residents in eight Lothian care homes had AMs prescribed prior to death.	AP intervention (training, multidisciplinary meetings, and new AM stocks) implemented in 8 care homes. Data collected in each care home at baseline, and once the intervention started. Quantitative analysis (counts, percentages).	RQ1: "Many care home residents do not have the recommended AMs in place in the last days of life and thus may experience inadequate symptom control. APs for analgesia were available to just over half of all deceased residents; however, less than one quarter had APs for nausea and respiratory secretions. There was a wide variety of AP across care homes, with all residents dying with AMs prescribed in one care home, compared to only 13% of residents dying with AMs prescribed in another care home. Of the 77 residents who died in the care homes, 54% had anticipatory medicines prescribed. Only 15% had prescriptions for all four nationally recommended anticipatory medications. Many care home residents do not have the recommended anticipatory medications in place in the last days of life and thus may experience inadequate symptom control. Interventions that increase the availability of AMs to manage common symptoms at the end of life for care home residents are necessary."	M M M = M
Kinley, 2016	Achieving symptom control not medication burden at the end of life	Kinley J, et al. (2016). "Achieving symptom control not medication burden at the end of life." Palliative Medicine 30 (6): NP331-NP332.	To identify the prescribing practice for symptom control in the last month of life for residents dying in nursing homes.	Thirty eight nursing homes implementing an end of life programme (GSFCH) took part in a trial. In order to complete this programme, the care home staff needed to evidence symptom control at the end of life. The data presented is from all items prescribed in the last month of life from all deceased residents' notes during the 2nd year of the GSFCH programme.	RQ1: "The medical administration charts were available for 50% of the 638 residents who died in the nursing home during the data collection period. In the last month of life the mean number of oral medication prescribed for residents was 10 (range 0-27). The residents who died had been prescribed oral medication for symptom control in their last month of life. For example 84% of residents had been prescribed oral and/or transdermal analgesia."	M L L = L
Morris, 2013	Implementing stock end-of-life medication in UK nursing homes	Morris K, et al. "Implementing stock end-of-life medication in UK nursing homes." End of life journal 3.3 (2013).	To assess the feasibility of nursing homes with Gold Standards Framework in Care Homes (GSFCH) accreditation keeping EoLC medications 'as stock', rather than having the medication prescribed and dispensed for individual residents when residents became symptomatic.	Qualitative interviews with nurse managers of four nursing homes with GSFCH accreditation, local pharmacists and the hospice pharmacist. A strategy to implement the stock medication was prepared. A baseline review of the notes of deceased residents was undertaken and information regarding symptoms and EoLC medication extracted. The review continued for 6 months after the stock EoLC medication was obtained.	RQ1: "Once the EoLC medication 'as stock' had been obtained, the number of deceased residents with a written order from the GP for anticipatory medication increased in each NCH.The number of orders increased in NCH 1 to 50%, in NCH 2 to 63% and in NCH 3 to 94%." RQ1: "Up to 53% of the residents were symptomatic in their last days of life, meaning that access to end-of-life medication is important. A total of 47% of frail older people were asymptomatic in the last days of their lives. If EoLC medications are stocked by nursing homes with EoLC training, there is a potential for dying residents to receive timely symptom control." RQ3: "As a result of anticipatory medication being immediately available once the stock had been obtained, more residents who were symptomatic had their symptoms managed promptly." RQ3: "Only four of the 92 residents reviewed required a syringe driver." RQ5: "Although during the study staff in NCH 1 did not use the EoLC 'as stock' drugs as much as the nurse manager had hoped, the number of residents having access to medication did increase significantly." RQ5: The staff in NCH 2 "did feel 'safer' in the knowledge that they had a supply of stock drugs that could be accessed in emergencies for residents who deteriorated unexpectedly." RQ5: "In NCH 3, the nurse manager reported that having access to stock medications had 'transformed' the practice of her nurses. They now felt comfortable requesting prescriptions for every dying resident, as they were more confident that there would be no wastage. She also reported an example of how having the stock medication had helped a busy GP."	M M M = M

Owen, 2016	Pharmacy team led anticipatory prescribing in nursing homes: Increasing proportion of deaths in usual place of residence	Owen J, et al. "Pharmacy team led anticipatory prescribing in nursing homes: Increasing proportion of deaths in usual place of residence." International Journal of Pharmacy Practice 24 (Supplement 3): 12 (2016).	To determine if pharmacy team led end of life anticipatory prescribing for nursing homes decreases hospital admissions at end of life.	Data was assessed relating to 550 patients who died in 19 nursing homes between July 2014 and July 2015 and compiled into tables. Death certificates were accessed to determine place and reason of death. Supply of AMs was confirmed from prescribing software, and involvement of palliative care teams documented. Archived medicines administration records (MAR) and controlled drug (CD) registers were accessed to determine whether AMs were administered.	RQ1: "Embedding a pharmacy team managing prescribing in GP led nursing home service contributed to an increase in the proportion of deaths in nursing homes, avoiding hospital admission, from <40% to 75% in 2 years. The embedded nursing home pharmacy team worked alongside the local palliative care team to implement end of life initiatives such as teaching and support of nursing staff, development of a formulary of AMs and ensuring urgent supply from community pharmacies."	M M M = M
Perkins, 2016	The care of dying people in nursing homes and intensive care units: a qualitative mixed-methods study	Perkins E, et al. "The care of dying people in nursing homes and intensive care units: a qualitative mixed-methods study." (2016).	To gain an insight into how care in different settings was documented and described in the very last hours or days of life.	Data were collected from 12 ICUs and 11 nursing homes in England, though 3 of the 11 nursing homes did not participate in the observational aspect of the study: (1) documentary analysis of provider end-of-life care policy documents; (2) retrospective analysis of 10 deaths in each location using written case notes; (3) interviews with staff about end-of-life care; (4) observation of the care of dying patients; (5) analysis of the case notes pertaining to the observed patient's death; (6) interview with a member of staff providing care during the observed period; (7) interview with a bereaved relative present during the observation; (8) economic analysis focused on the observed patients; and (9) strict inclusion and selection criteria for nursing homes and ICUs applied to match sites on LCP use/non-LCP use.	RQ1, RQ3: "Where the LCP was used to support care, variances were recorded for agitation, respiratory tract secretions or pain. The most common action taken in response to these variances was the use of medication, namely midazolam, glycopyrronium (or hyoscine) and morphine (or oxycodone or diamorphine), respectively. Nurses administered AMs as advised and prescribed by GPs and in accordance with the LCP, even against family members' wishes." RQ3: "There was a strong emphasis in the nursing homes on being prepared for a patient's death. This did result in the prescribing of anticipatory drugs, just in case they were required, despite the fact that they were rarely used. Issues in achieving a timely visit from the general practitioner also created problems for the nursing homes and often meant that decisions relating to end-of-life care were taken by nurses." RQ3: Data from observations of last days of life care in nursing homes: "In the majority of cases where it was established, through either questioning or observation, that there was a symptom that needed relieving, the patient was given medication, with morphine and midazolam being the most common. The route of administration of these drugs was usually via a subcutaneous injection or a continuous subcutaneous infusion via a syringe driver. A small number of patients who were able to swallow were given oral medication. Over the course of the observations the route of administration was tailored to meet the patient's requirements; tablets were replaced with liquids, subcutaneous injection or continuous subcutaneous infusion via a syringe driver." RQ3: "A number of nurses also reported that very few of the deaths in their nursing home had required the administration of the drugs that had been prescribed." RQ5: "Respondents reported that GPs' attitudes toward anticipatory prescribing were influenced by the costs associated with throwing away the drugs that were not used." RQ5: "With the focus on avoiding the emergency hospitalisation of dying patients, and the importance of good pain and symptom control in these accounts of a 'good death', it was not surprising that many respondents in this study viewed anticipatory prescribing as essential in order to have the drugs available for use 'as needed.'" RQ5: "All nurses talked about a pain-free and peaceful death as the goal of care, and the ability to administer pain relief was seen as an important element in achieving this. However, the administration of drugs often left nurses feeling uncomfortable, particularly if the patient died soon after their administration."	M M M = M

Spilsbury, 2020	LESS COVID-19: Learning by Experience and Supporting the Care Home Sector during the COVID-19 pandemic: key lessons learnt, so far, by frontline care home and NHS staff	Spilsbury K, et al "LESS COVID-19: Learning by Experience and Supporting the Care Home Sector during the COVID-19 pandemic: key lessons learnt, so far, by frontline care home and NHS staff." Coventry, National Care Forum (2020).	To capture the experiences of frontline care home and NHS staff caring for older people with COVID-19 and to share the lessons learnt about the presentation, trajectories, and management of the infection with care homes that have and have not yet experienced the virus.	Phase 1: Interviews with frontline staff (objectives 1 to 3) in June and July to gather in- depth understanding of: • the clinical presentation and illness trajectory of COVID-19 in this population; • what had worked well, or what more was needed, for care and treatment; and • lessons learnt for supporting infected older people to recover or die well. Phase 2: Consultations with senior operational and quality managers in care homes (objectives 4-5) in September to establish: • the resonance, relevance, and any gaps in relation to Phase 1 findings; and • strategies for managing COVID-19 at an organisational level within the home for the mutual benefit of residents, relatives and staff.	RQ1: "The range of interventions used by frontline staff (in both care home and NHS settings) for symptom management included: Pain: small doses of lorazepam and/or oral morphine were prescribed (for some individuals) for pain relief. Frontline staff reported the variable effectiveness of these medicines for managing pain for older people." RQ5: "Peaks in the virus outbreak can create localised shortages of EOL medicines for care home residents." RQ3, RQ5: "Care home staff described that, where possible, they had in place anticipatory medicines (prescribed by a GP) for residents, where this was considered appropriate by staff, residents and, when relevant, family members. When these medicines were not in place then this created difficulties of access to, and timely administration of, medicines to manage and control symptoms at EOL. Participants described increased pressure placed on the medicines supply chain during the peak of the COVID-19 pandemic. When medicines were unavailable, then this caused distress for the older person and the staff caring for them. In the early stages of the pandemic, staff were not able to re-purpose medicines or to request a supply of medicines for storage in the care home (in case required). This caused frustration and upset for care home staff." RQ5: "Frontline staff working in, or with, care homes without nursing (also known as residential homes) described situations where an older person with COVID-19 deteriorated at a rapid rate (covered in the illness trajectory section). Delays in access to a health care professional (for example a community nurse, or a palliative care specialist) often delayed the timely administration of EOL medicines. Some participants reported delays of up to 6 hours." RQ5: "Participants highlighted the importance of cross sector working to ensure older people received appropriate interventions and care in a timely manner. For example, relationships between a care home and primary and community services enabled access to a wider range of medicines to manage symptoms (described in more detail in the section focused on promoting partnership through cross sector working and support)."	M M M = M
Tanghe, 2020	Opioid underuse in terminal care of long-term care facility residents with pain and/or dyspnoea: A cross-sectional PACE-survey in six European countries	Tanghe M, et al. "Opioid underuse in terminal care of long-term care facility residents with pain and/or dyspnoea: A cross-sectional PACE-survey in six European countries." Palliative Medicine 34.6 (2020): 784-794.	To examine the perception of barriers and their impact concerning opioid medicines, comparing policy makers, healthcare professionals working in the field of pain management, palliative care or harm reduction and other stakeholders.	A cross-sectional survey describing the dying phase in long-term care facility residents in six European countries. Nurses assessed pain/dyspnoea with Comfort Assessment in Dying with Dementia scale and checked opioid prescription by chart review. Opioid underuse per country and per symptom estimated. Associations of opioid underuse calculated by multilevel, multivariable analysis.	RQ3: Estimated percentage of overall opioid underuse by country: 29.3% (95% CI: 16.9–45.8) in England. Calculated as the estimated prevalence of diseased residents with pain and/or dyspnoea in the last week of life. The estimated prevalence of opioid underuse in the last 3 days of life was higher in residents with dyspnoea than in residents with pain. RQ3: Opioid underuse is strongly associated with the absence of symptom assessment. Opioid underuse estimated to be (in England) 33.7% (26.2–42.2) in long-term care facilities (opioid underuse defined as residents without opioid prescription despite pain and/or dyspnoea, 3 days prior to death). Implementing palliative care in long-term care facilities with robust symptom assessment programs and clearer indications for opioid use can contribute to improving symptom management in the dying phase for patients at these facilities.	M M M = M

Wilson, 2015	Administering anticipatory medications in end-of-life care: a qualitative study of nursing practice in the community and in nursing homes	Wilson E, et al. "Administering anticipatory medications in end-of-life care: a qualitative study of nursing practice in the community and in nursing homes." Palliative Medicine 29.1 (2015): 60-70.	To examine nurses' decisions, aims and concerns when using anticipatory medications.	An ethnographic study in two UK regions, using observations and interviews with nurses working in community and nursing home teams (n = 8). Observations (n = 83) and interviews (n = 61) with community nurses. Coding of field notes and thematic analysis of interviews.	RQ5: "Throughout this study, nurses reported working in pairs or liaising with colleagues during the decision-making and administration process. Education, training, experience, and clear access to and good communication with nursing colleagues/managers, GPs, disease-specific and specialist palliative care services are important for building nurses' confidence and ensuring a safe, comprehensive AM culture in nursing homes. However, a fear about hastening death and a lack of consensus about what the 'end-of-life' phase means may restrict the use of AMs in groups of patients with uncertain prognoses such as heart failure or COPD, potentially leaving some with their pain and symptoms under- or untreated." RQ5: "In accounts reported here, some nurses advocated the use of prescriptions that allowed drugs to be administered within a small range. Yet many did not want or feel it was appropriate for them to have decision-making responsibilities about dose ranges. Some considered such decisions to be emotionally burdensome, especially those with less training and experience. A number of other UK studies have illustrated the emotional strain felt by district nurses providing palliative and end-of-life care. This burden can be heightened by communication issues, limited knowledge, experience of some conditions, a lack of support and time pressures. Nurses working in care homes can often face similar barriers to providing good quality end-of-life care. There is now increasing evidence that symptoms are often undertreated, especially in older patients and in those with conditions other than cancer. The effects of the murders committed by Shipman continue to influence public and professional attitudes." RQ5: "Administering the medication raised a number of concerns for nurses. First, they were keen to distinguish between pain and agitation so as to administer the most appropriate drug but sometimes found this difficult." RQ5: "Despite all participants stating that they would always start on the lowest prescribed dose of the medication, some raised a fourth area of concern about over medicating patients and this resulting in unwanted side effects." RQ5: "Nurses acknowledged that although relatives often provided the majority of personal care to patients and had considerable insight into their needs, they took great care not to be 'unduly' swayed by relatives' judgements or requests."	H H H = H
Wilson, 2017	The importance of interdisciplinary communication in the process of anticipatory prescribing	Wilson E et al. "The importance of interdisciplinary communication in the process of anticipatory prescribing." International Journal of Palliative Nursing, 23 (3) (2017): 129-135.	To determine the nature and importance of interdisciplinary communication is to the process of anticipatory prescribing and end of life care.	Ethnography of healthcare professionals across four care homes and four community sites in England (83 episodes of observation and 72 interviews).	RQ5: "When interdisciplinary communication worked well, the AP process was smooth and optimised patient care. However, when communication was impaired between nurses and GPs, care home nurses reported a reluctance on behalf of the GPs to prescribe anticipatory medications and attributed it to a lack of experience and/or training." RQ5: "Trust, access and clarification of responsibilities were considered to be interlinked and comprise a central component of successful anticipatory prescribing." RQ5: "Good interdisciplinary communication has been shown to support all elements of the process of anticipatory prescribing." RQ5: "GPs seemed to be willing to work within a small level of risk and reported being frustrated by nurses continually bringing prescriptions back to be rewritten because of small errors." RQ5: "Having a clear understanding of each other's responsibilities in the anticipatory prescribing process was perceived to be an important factor in good interdisciplinary communication."	M L L = L

Wilson, 2016	Anticipatory prescribing for end of life care in the community: a survey of community nurses in England	Wilson E, et al. "Anticipatory prescribing for end of life care in the community: a survey of community nurses in England." Primary Health Care 26.9 (2016): 22-27.	To gain insight into the roles and experiences of a wide range of community nurses in end of life medication decisions.	Postal questionnaires to 1,558 English nursing home, community/district, and palliative care nurses. Collected data subject to quantitative and qualitative analysis. Descriptive statistics and thematic analysis to analyse questionnaire responses.	RQ1, RQ5: "Nurses reported working well with GPs and perceived that they had good access to the medications needed. Figure 1 shows that 79.2% (n=427/539) of nurses reported that they 'infrequently or never' found doctors reluctant to prescribe anticipatory medication, and 11.1% (n=60/539) reported this as 'neither frequent nor infrequent'. But it was evident there was some variation. A small proportion, 9.6% (n=52/539), agreed that some doctors were reluctant to provide anticipatory prescriptions..." RQ1, RQ5: "Not all practices in my location are happy to prescribe anticipatory medications, as they feel this is a waste of their budget and that out-of-hours doctors are there to be called upon for the prescribing of anticipatory drugs. In the main, the reluctance of GPs in prescribing is improving." Manager in a nursing home. RQ5: "Similarly, a few nurses (8.6%; n=45/525) said they 'always or frequently' experienced significant difficulties in obtaining the drugs specified in anticipatory prescriptions used in end-of-life care. For a further 11.2% (n=59/525) this was reported as 'neither frequent nor infrequent'. However, the majority of nurses (80.2%; n=421/525) said they encountered these difficulties 'infrequently or never'." RQ5: "I have real problems with GPs prescribing [end of life] drugs, they are usually unable to estimate doses correctly, have no idea how to prescribe when a patient has a fentanyl patch, or is a slow release morphine. This weekend, in 1 day, two prescriptions were written incorrectly." Palliative care nurse. RQ5: "Nurses reported that the anticipatory medications successfully controlled those symptoms they were intended to relieve in 89.6% of the patient cases they recalled. In a more general sense, most respondents (96.0%; n=504/525) agreed that when anticipatory prescriptions were in place they 'always or frequently' enabled respondents to improve the quality of end of life care they provided."	M M M = M
Seymour, Jane E., 2011	Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England	Seymour J, et al. "Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England." Palliative Medicine 25.2 (2011): 125-138.	To identify key factors in the larger health and social care system impacting the quality of end- of-life care provided in English nursing homes.	Mixed methods: 2 in-depth qualitative studies of nursing homes; a postal survey of 180 nursing homes surrounding the case study sites.	RQ1: "Rural home also reported that accessing GP support, prescribed medication and transferring a resident to the hospital during out of hours was very difficult. Some GPs endeavoured to overcome problems by ensuring medication was pre-emptively prescribed for individuals prior to the weekends, but this did not always provide the solution to unexpected problems among residents." RQ5: "Participants emphasized the importance of mutual trust between nursing staff and prescribers." RQ5: "GPs not always keen to issue end-of-life drugs or to visit promptly." Care home manager RQ5: "And she begged me not to send her into hospital and she ended up going to the hospice because we hadn't a clue where to get a syringe driver from. The doctor didn't know anything about the drugs or what we should be using." Care home manager RQ5: "One or two GPs I think sometimes may be less geared up to end-of-life care than others. So I think that's a challenge for the staff and we are working on that. I mean, generally, I think things have improved a great deal but there are just a few GPs that do hold back probably more than others . . . I think whether they [don't] know the patient very well, whether they're aware of the drugs they need to be prescribing, time probably as well, you know." Macmillan Nurse RQ5: ". . .Very often the question of end-of-life pathway drugs has been brought to us by the nursing staff [here] and always appropriately, as far as I'm concerned . . . I mean we're probably more familiar to them here than any other practices because we spend so much time here. So I think that helps really because the more you know people the more you come to trust them, or you could put it the other way, I suppose." GP RQ5: "Problems for nursing home personnel in accessing support for end-of-life care included variable support by general practitioners (GPs), reluctance among GPs to prescribe appropriate medication, lack of out of hours support, cost of syringe drivers and lack of access to training." RQ5: "Interviews with nursing home staff suggest that critical factors in improving care include developing clinical leadership, developing relationships with GPs, the support of 'key' external advocates and leverage of additional resources by adoption of care pathway tools." RQ5: "This study has demonstrated how the delivery of good quality end-of-life care in care homes requires an effective balance of external support, such as systems to access medication and syringe drivers, with internal resources, such as staff who are well trained and who work in a supportive culture in which they are able to make residents' and their relatives' needs and concerns their first priority."	H H H = H

Watson, 2006	Barriers to implementing an integrated care pathway for the last days of life in nursing homes	Watson J, et al. "Barriers to implementing an integrated care pathway for the last days of life in nursing homes." International journal of palliative nursing 12.5 (2006): 234-240.	To explore the barriers that needed to be overcome during the process of implementing an integrated care pathway for the last days of life as a way of developing quality end-of-life care in nursing homes.	Qualitative and quantitative data were collected in eight nursing homes before, during and after the implementation of a care pathway. Documentary analysis, baseline audit of notes around the last days of life; group interviews; field notes; participant observation; and interviews were conducted.	RQ1: “When the notes of the last five residents to die in each nursing home before the study were reviewed, it was clear that the loss of the swallowing reflex in a dying resident was seldom anticipated and thus, subcutaneous or rectal medication rarely prescribed. Also the prescribing of prn medication in anticipation of symptoms was infrequent.” RQ1: “Nursing homes are not permitted to hold stock drugs unless they are for a named resident; it was often felt that prescribing prn medication was potentially a waste of money as drugs were destroyed if not used.” RQ1: “The only drug that was occasionally prescribed prn across the nursing homes in the last days of life before the study was oral morphine, whether or not the residents were on a previous opiate analgesic.” RQ5: "Nursing homes are not permitted to hold stock drugs unless they are for a named resident; it was often felt that prescribing prn medication was potentially a waste of money as drugs were destroyed if not used. However, the financial implications of this are negligible compared to the unnecessary length of time a resident has to wait if prn medication is not available. The only drug that was occasionally prescribed prn across the nursing homes in the last days of life before the study was oral morphine, whether or not the residents were on a previous opiate analgesic." RQ5: "Six main barriers were identified: a lack of knowledge of palliative care drugs and control of symptoms at the end of life; lack of preparation for approaching death; not knowing when someone is dying or understanding the dying process; lack of multidisciplinary team working in nursing homes; lack of confidence in communicating about dying; some nursing homes are not ready or able to change."	M L L = L
Kinley, 2010	A baseline review of medication provided to older people in nursing care homes in the last month of life	Kinley J et al. "A baseline review of medication provided to older people in nursing care homes in the last month of life." International journal of palliative nursing 16.5 (2010): 216-223.	To understand the medication needs of the very old and frail in the last weeks of life and how they might differ from a model of care developed for people dying from cancer	Questionnaires to 67 trained nurses, medication reviews of 48 deceased residents’ notes in the last month of life in seven nursing care homes, and coding. Quantitative and thematic analysis.	RQ1: Regarding EoLC symptom management requirements of frail older people in care homes: "Syringe drivers were used in 23% of cases; however, only three residents required a syringe driver for more than a day and a half and nurses’ confidence and competence in setting up syringe drivers varied. The use of syringe drivers may not be the most suitable way of managing end of life symptoms in very frail and old people." RQ1: "Out of the 11 residents who had a syringe driver in the last days of life, eight of the syringe drivers were in place for less than 1.5 days. That indicates that in the last days of life, symptom control needs of older people may be more appropriately managed through the use of bolus subcutaneous medication or rectal suppositories." RQ1: "As syringe drivers are rarely used in nursing homes, nurses working in these settings lack competence in setting up a syringe driver." RQ1: “Provision and administration of medication in NCHs varied considerably. In NCH-A, for example, the GP reviewed residents regularly, there was recognition when residents were dying, information was well recorded, residents’ relatives were contacted and the situation discussed with them and the full nursing team. Even though preparations were changed to liquid, no injectable medication was prescribed in anticipation of the resident becoming unable to swallow. In contrast, in NCH-D, nine out of 10 residents were prescribed injectable medication for symptom control when they became unable to swallow their oral medication.” RQ1: “There was evidence that variation occurred by prescriber preference. For example, some residents with no previous analgesic history were prescribed PRN morphine sulphate 1.25 mg as a starting dose and others 2.5 mg. Glycopyrronium and morphine sulphate were the most frequently used subcutaneous medication.” RQ3: “The use of injectable medication by residents with non-malignant disease was small (n=7).” RQ3: “Eleven residents additionally had parenteral medication administered as a continuous 24-hour infusion via a syringe driver. What is of note is the length of time residents received medication via the syringe driver. Eight of the 11 residents (73%) received medication via this route for 1.5 days or less. These figures suggest that for the majority of NCH residents the use of PRN medication to control residents’ symptoms in the last few days may have sufficed.” RQ3: “The use of injectable medication most often occurred where the NCH was supported by a specialist palliative care service.” RQ5: “The majority of nurses stated that they did not have difficulties in obtaining medication for residents in the last days of life. However, nurses from two of the homes (NCH-D and NCH-E) found that prescriptions for medication got delayed. These delays were at different levels: delay with prescribing, lack of immediate availability at pharmacy, and difficulty with delivering medication to the NCH.”	M M M = M

					RQ5: “There was also considerable variety in the RGNs’ recent experience of caring for a resident receiving medication via a syringe driver and in education regarding its use. While 11 nurses had looked after a resident with a syringe driver recently (within the last 3 months) for 11 others it had been over 1 year ago.”	
Breen, 2018	DOOP Kit, Domestic Bin Or Watery Grave? A Study Investigating Disposal Practices Of Transdermal Drug Delivery Products In Care Homes	Breen L, et al. "DOOP Kit, Domestic Bin Or Watery Grave? A Study Investigating Disposal Practices Of Transdermal Drug Delivery Products In Care Homes." (2018).	To 1) gain insight into current practices of healthcare professionals regarding opioid transdermal patches (OTPs) (fentanyl and buprenorphine) disposal practices and 2) identify knowledge and system awareness surrounding the disposal of these products in care home settings.	Google forms / paper questionnaires sent out to the nurses of 85 care homes; 36 online responses, 20 paper responses, for a total of 56 responses. Descriptive statistics and thematic analysis to analyse questionnaire responses.	RQ4: "More education and training is necessary regarding safe disposal practices of OTPs, informed by pharmacist-led interventions, in order to minimise confusion, reinforce safe disposal practices and support the reduction of unsafe disposal practices (domestic waste or flushing. Study results indicate that 52.8% of care staff were unaware of the recent safety update issued in July 2014 by the MHRA with regard to fentanyl patches, which suggests a gap in communication between healthcare professionals and external governing bodies, a lack of effective intra-company communication strategies, or both."	M M M = M