Title: End-of-Life Care in UK Care homes: A systematic Review of the Literature.

Abstract:

The number of people requiring end of life care provision in care homes has grown significantly. There is a need for a systematic examination of individual studies to provide more comprehensive information about contemporary care provision. The aim of this study was to systematically review studies that describe end of life care in UK care homes. A systematic PRISMA review of the literature published between 2008 and April 2017 was carried out. Fourteen studies were included in the review. A number of areas of concern were identified in the literature in relation to the phases of dying during end of life care; end of life preplanning processes; understandings of end of life care; and interprofessional end of life care provision. Given that the problems identified in the literature concerning end of life care of residents in care homes are similar to those encountered in other healthcare environments, there is logic in considering how generalised solutions that have been proposed could be applied to the specifics of care homes. Further research is necessary to explore how barriers to good End of Life care can be mitigated, and facilitators strengthened.

Key words

Palliative care, advance care planning, interprofessional practice, residential homes, nursing homes

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Introduction

Due to an increasing ageing population in the UK, the number of older people who are cared for and dying in care homes is increasing significantly (Gomes and Higginson, 2008; Office for National Statistics, 2017). Therefore, the number of people requiring end of life (EoL) care provision in institutions that cater largely for the older person has grown significantly. It is also important to understand that most people would prefer to die at home and for permanent care home residents, the care home is their home, making it for most, their preferred place of death (National End of Life Care Intelligence Network, 2012).

EoL care for older adults aims to support and comfort individuals with a progressive chronic illness from which they are dying in the last stages of their life. The NICE Quality Standard for End of Life Care for Adults mandates:

> high-quality care that … should contribute to improving the effectiveness, safety and experience of care for adults approaching the end of life and the experience of their families and carers. This will be done in the following ways, regardless of condition or setting:
>   - Enhancing quality of life for people with long-term conditions.
>   - Ensuring that people have a positive experience of (health) care (NICE, 2011).

The care provided should acknowledge spiritual, cultural and personal beliefs and support both family and friends during and after the period of bereavement (Fisher et al., 2000).

Ensuring dignity and care quality at the end of life were key priorities of the End of Life Care Strategy (DH, 2008). Much has improved since the publication of the report, although some inadequacies persist (NHS England, 2014). These are indicated by persisting levels of inappropriate admissions from care homes to hospitals for residents at the end of their lives (Mason et al., 2016), and less than optimal levels of integrated working between care homes and external services (Davies et al., 2011). However, given the absence of an overall view of current practice in UK care homes, there is a need for a systematic examination of individual studies to provide more comprehensive information about contemporary EoL care provision. The following review aims to achieve this by synthesising the descriptive elements of literature in the field to uncover how EoL care is being delivered in UK care homes.

Methods

Preliminary searches were conducted using the EBSCO database. This provided insight into key terminology and relevant databases. Following on from the preliminary search, four main databases were systematically searched: ScienceDirect; MEDLINE; PSYCINFO; and CINAHL. These databases were included because they had been identified in the preliminary search as containing the journals relevant to the research topic. Boolean techniques (Appendix, Table 1) were used to ensure no relevant literature was missed in the search strategy (Gerrish and Lathlean, 2015; Boland and Dickson, 2014). Using this search strategy, the key components were entered into the database with their alternative subject headings.

The search was conducted on 25th April 2017, with the exclusion and inclusion criteria applied (Appendix, Table: 2). The search also included manual searching of the reference

Table 1 – Search strategy

Element	Alternatives
1. "End-of Life care"	Pallia* "Terminal care"
2. "Care Home*"	"Nursing home*" "Residential home*" "Long term care facili*"
3. "United Kingdom"	"United Kingdom" UK England "Great Britain" GB Wales Scotland "Northern Ireland"
Boolean Operators	1. "End of life care" OR Pallia* OR "Terminal care"
	2. "Care home*" OR "Nursing home*" OR "Residential home*"

| | OR "Long term care facili*" |
| | 3. "United Kingdom" OR UK OR England OR "Great Britain" OR GB OR Wales OR Scotland OR "Northern Ireland" |

(asterisk) represents any string of characters used in truncation

Table 2: Inclusion and exclusion criteria

Inclusion Criteria	Rationale
Studies must include a descriptive element regarding the nature of EoL care in care homes	To ascertain how EoL care is currently being delivered in care homes in the UK.
Must be UK based	EoL care policy and guidelines are national-specific, and this study is specific to UK care homes.
Exclusion Criteria	**Rationale**
Pre-dates 2008	July 2008 was the date of a seminal policy publication which significantly changed the focus of EoL care delivery and research in the UK.
Includes an EoL intervention	Studies exploring interventions which describe EoL care in the context of the intervention thus may not be representative of practice.
Studies specifically only exploring the acute hospital setting.	This review is focused on exploring the nature of EoL care in care home, not acute services.

lists of papers and by hand searching the grey literature. The search was limited to papers published after the date of The End of Life Care Strategy (DH, 2008), which have heavily influenced the contemporary focus of policy and practice (NHS England, 2014). A range of study types, including both qualitative and quantitative evidence were sought to explore how EoL care is currently being delivered in care homes in the UK. Critical Appraisal Skills Programme (CASP, 2014) frameworks were applied but no studies were excluded on this basis.

Due to the mythological diversity of research conducted in this area, this systematic review adopted a mixed methods synthesis. Mixed research synthesis aims to integrate the results from both qualitative and quantitative studies in a shared sphere of empirical research (Sandelowski et al., 2006). Moreover, mixed method synthesis has the potential to enhance both the significance and utility for practice by bringing together qualitative and quantitative studies to get 'more' of a picture of a phenomenon by looking at it from a number of different perspectives (Pope, Mays and Popay, 2007; Sandelowski et al., 2006). Analysis was carried out by means of thematic synthesis, a method that is recommended when the findings have relevance to practice and policy (Booth et al., 2016).

Comment [AS1]: Have I put this in the right place?

Summary of included literature

Fourteen studies were included in total: seven qualitative, five mixed method designs and two quantitative studies. Participants for the qualitative and quantitative studies included healthcare professionals, general practitioners (GPs), carers, care home managers, bereaved relatives and residents in care homes. The care homes included both residential and nursing homes, and all of the studies were conducted in the United Kingdom. All of the included

studies had descriptive elements which described the nature of EoL care in UK care homes. Most of the selected literature explored EoL care from the healthcare professionals' perspective. See figure 1 for a summary of the selection stages.

The seven included qualitative studies used the data collection method of in depth semi-structured interviews (Stone et al., 2013; Livingston et al., 2012; Lawrence et al., 2011; Goddard et al., 2013; Mathie et al., 2012; Kupeli et al., 2016a; Kupeli et al., 2016b). Four of the five included mixed method studies also utilised one to one individual interviews (Wye et al., 2014; Froggatt et al., 2009; Handley et al., 2014; Barclay et al., 2014). Wye et al used observations and analysed documentation (referral databases) (Wye et al., 2014), and Froggatt et al. (2009) used surveys alongside interviews. Kinley et al., 2014 analysed the case notes and daily records of all residents who died in the participating 8 care home from 2008-2011. Handley et al. (2014) and Barclay et al., 2014 both used a mixed methods approaches to analyse care home notes as well as qualitative interviews.

Both quantitative papers included the use of questionnaires. Mitchell and McGreevy (2016) and Ong et al. (2011) both used questionnaires to explore aspects of EoL care practice in care homes.

Results

Following systematic identification of the literature describing the nature of EoL care provision in UK care homes, thematic synthesis of identified findings revealed four key themes. These key themes are: the phases of dying during EoL care; EoL preplanning processes; understandings of EoL care; and interprofessional EoL care provision.

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Table 3 – Selected Studies

Study	Aim	Study type	Methods and participants	Results	*Quality score
Barclay et al., (2014)	**Aim:** To describe care home residents' trajectories to death and care provision in their final weeks of life.	Mixed method design	Case note reviews and interviews with residents, care home staff, and healthcare professionals. Location: six residential care homes in three English localities.	For some care home residents there was an identifiable period when they were approaching the end-of-life and planned care was put in place. For others, death came unexpectedly or during a period of considerable uncertainty, with care largely unplanned and reactive to events.	16/22 15/20
Froggatt et al., (2009)	**Aim:** To describe current advanced care planning practice	Mixed method	The study used questionnaire surveys (n = 213) with care home	Advanced care planning helped inform care home staffs' end of	18/22 15/20

	in care homes for older people.	design	staff, and 15 qualitative interviews with care home managers.	life care decisions. However, the number of advanced care plans completed by residents varied.	
Goddard et al., (2013)	**Aim:** To explore the views of care home staff and community nurses on providing end-of-life care in care homes.	Qualitative	Qualitative interviews conducted with 80 care home staff and 10 community nurses. Care homes providing care for older people (65 years or older) in two London boroughs took part in the study.	Care home staff acknowledged that improvements in their skills and the resources available to them were needed to manage end of life care effectively.	17/20
Handley et al., (2014)	**Aim:** To describe the expectations and experiences of	Mixed method	121 residents from six care homes in the East of England were	An ongoing lack of clarity about roles and responsibilities in	14/22 16/20

end-of-life care of older people in care homes.	design	tracked; 63 residents, 30 care home staff with assorted roles and 19 NHS staff from different disciplines were interviewed and the case notes of residents were analysed.	providing end-of-life care, and doubts from care home and primary healthcare staff about their capacity to work together was uncovered.	
Kinley et al., (2014)	**Aim:** To identify the care currently provided to residents dying in UK nursing care homes.	Mixed method design	Review of case notes took place for study participants who were residents who had died within 38 nursing care homes in southeast England over a 3-year period.	Nursing care homes have established links with some external healthcare providers. These links included the GP, palliative care nurses and physiotherapy. However, with 56% residents dying within a year	17/22 16/20

				of admission these links need to be expanded.	
Kupeli et al., (2016a)	**Aim:** To explore the context, mechanisms and outcomes for providing good palliative care to people with advanced dementia residing in UK care homes from the perspective of health and social care providers.	Qualitative	Qualitative interviews with 14 health and social care professionals including care home managers, commissioners for older adults' services and nursing staff.	Changes to the care home environment are necessary to promote consistent, sustainable high quality end of life dementia care. For example, how care staff understand and use advanced care plans.	16/20
Kupeli et al., (2016b)	**Aim:** To improve our understanding of health care professionals' attitudes and knowledge of the barriers to integrated care for	Qualitative	Qualitative interviews were carried out with 14 healthcare professionals including care home managers, care assistants and nurses.	Barriers to effective end of life care included poor relationships between care homes and external services, care home often felt undervalued by external	16/20

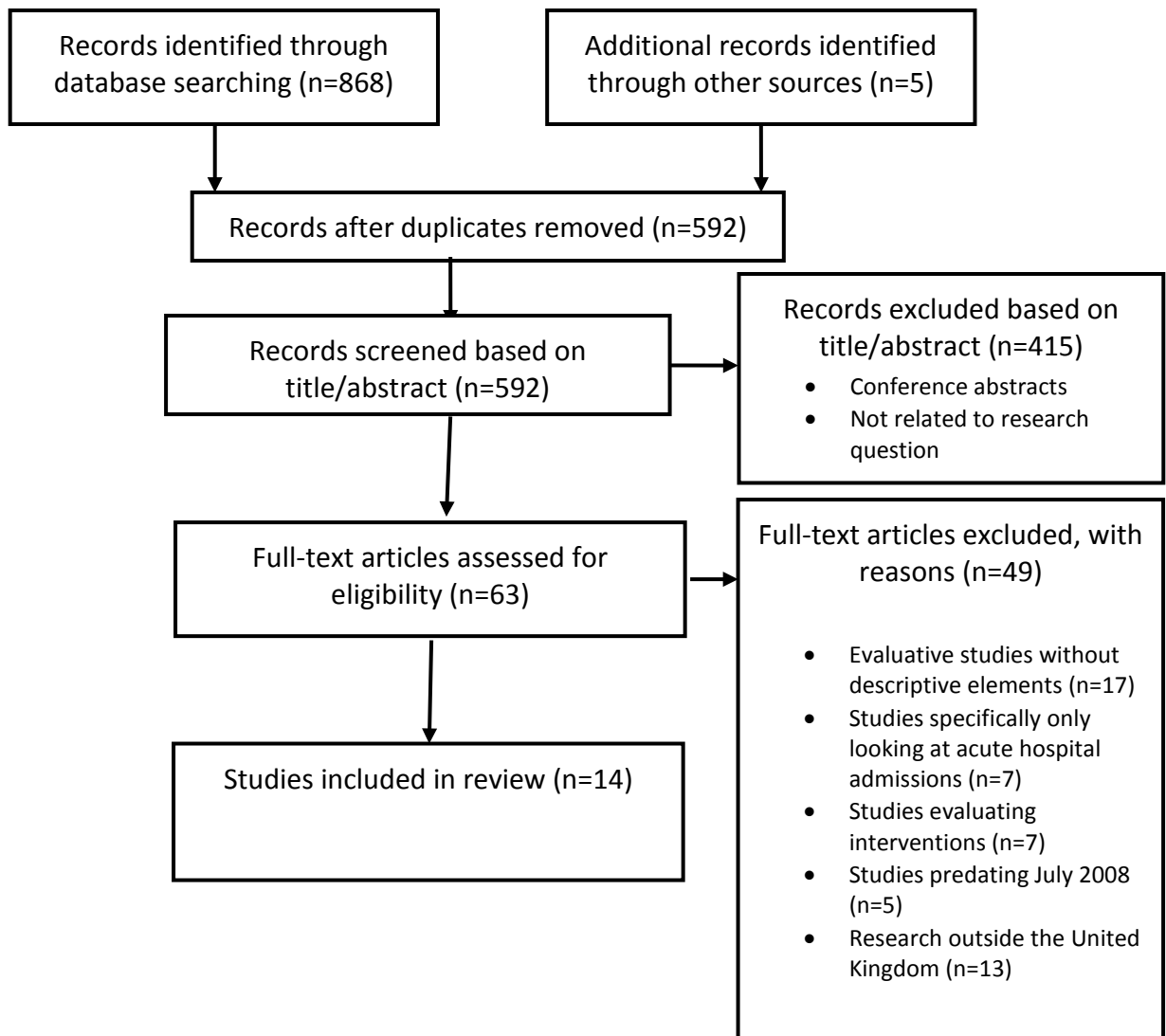|				healthcare professionals.	
	people with advanced dementia.				
Lawrence et al., (2011)	**Aim:** To define and describe good end-of-life care for people with dementia and identify how it can be delivered across care settings in the UK.	Qualitative	Qualitative interviews were conducted with 27 bereaved family carers and 23 care professionals recruited from the community, care homes and general hospitals.	The data reveal key elements of good end-of-life care and that staff education, supervision and specialist input can enable its provision.	14/20
Livingston et al., (2012)	**Aim:** To examine barriers and facilitators to providing effective end-of-life care for people with dementia in care homes.	Qualitative	Qualitative interviews of 58 staff in a 120-bed nursing home where the staff and the residents' religion differed were carried out.	Care staff, nurses and doctors did not see themselves as a team and communicated poorly with relatives about approaching	16/20

				death. The staff used opaque euphemisms and worried about being blamed.	
Mathie et al., (2012)	**Aim:** To explore the views, experiences and expectations of end-of-life care among care home residents to understand if key events or living in a care home.	Qualitative	The paper draws on the qualitative interviews of 63 care home residents who were interviewed up to three times over a year.	The study highlighted the importance of ongoing discussions with care home residents and their relatives.	15/20
Mitchell and McGreevy, (2016)	**Aim:** To determine and describe care home managers' knowledge of palliative care.	Mixed method design	56 care home managers (all nurses) completed a validated questionnaire that is used to assess a nurse's knowledge of palliative care.	The average score was 12.89 correct answers out of a possible 20 (64.45%). This study uncovered a need to develop care home managers knowledge of palliative	13/22 14/20

				care.	
Ong et al., (2011)	**Aim:** To better understand and gain deeper insight into the reasons/rationales that leads to a decision to admit a care home resident to hospital.	Mixed method design	Questionnaires were used to explore current practice in care homes, eight care homes were included.	Lack of advance care plans, and poor access to General Practitioners was uncovered ass being the most common reason leading to admission.	16/22 17/20
Stone, Kinley and Hockley, (2013)	**Aim:** To explore and describe the experiences of stakeholders initiating and completing EoL care discussions in care homes.	Qualitative	A qualitative descriptive study was carried out in three nursing care homes. Qualitative interviews were conducted with the resident, a family member, and the staff member.	Staff understanding of advanced care planning varied, affecting the depth of their discussions. Education was identified as being important, and role modelling advance care planning enabled a member of staff to develop their skills and confidence.	14/20

Wye et al., (2014)	**Aim:** To discuss and evaluate end of life services in care homes in English counties.	Mixed method design	Data collection included documentation (e.g. referral databases), 15 observations of services and interviews with 43 family carers and 105 professionals.	Results showed that time restrictions and poor staffing levels forced care home staff to rush and miss out or avoid vital aspects of end of life care, such as discussions with residents and family.	17/22 16/20

* Qualitative studies were scored out of 20. Mixed method studies were scored on their qualitative quality (out of 20) and their quantitative quality (out of 22), and therefore have two scores.

Figure 1: Selection flow chart

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┌─────────────────────────────┐        ┌─────────────────────────────┐
│  Records identified through │        │  Additional records identified │
│  database searching (n=868) │        │  through other sources (n=5)   │
└─────────────────────────────┘        └─────────────────────────────┘
              │                                        │
              ▼                                        ▼
        ┌───────────────────────────────────────────────┐
        │  Records after duplicates removed (n=592)      │
        └───────────────────────────────────────────────┘
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        ┌─────────────────────────────┐        ┌─────────────────────────────┐
        │  Records screened based on  │───────▶│  Records excluded based on  │
        │  title/abstract (n=592)     │        │  title/abstract (n=415)     │
        └─────────────────────────────┘        │   • Conference abstracts    │
                          │                     │   • Not related to research │
                          │                     │     question                │
                          ▼                     └─────────────────────────────┘
        ┌─────────────────────────────┐        ┌─────────────────────────────┐
        │  Full-text articles assessed│───────▶│  Full-text articles excluded, with │
        │  for eligibility (n=63)     │        │  reasons (n=49)             │
        └─────────────────────────────┘        │                             │
                          │                     │   • Evaluative studies without │
                          │                     │     descriptive elements (n=17)│
                          ▼                     │   • Studies specifically only  │
        ┌─────────────────────────────┐        │     looking at acute hospital  │
        │  Studies included in review │        │     admissions (n=7)           │
        │  (n=14)                     │        │   • Studies evaluating         │
        │                             │        │     interventions (n=7)        │
        │                             │        │   • Studies predating July 2008│
        │                             │        │     (n=5)                      │
        │                             │        │   • Research outside the United│
        └─────────────────────────────┘        │     Kingdom (n=13)             │
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The phases of dying during End of Life care

Whilst not described in every study, the phases of dying during EoL care was frequently acknowledged as impacting on the provision and delivery of EoL care (Barclay et al., 2014; Handley et al., 2014; Kinley et al., 2014). The phases of dying during EoL care were described as the different stages or trajectories that residents went through when nearing death. Specifically, the literature described how care home staff sometimes found it difficult to discriminate between residents who were near death and residents who were not. This impacted on EoL care provision by preventing care home staff from planning and 'readying' themselves for the end stages of residents' lives (Handley et al., 2014; Barclay et al., 2014; Kinley et al., 2014). This was particularly prevalent for residents on unclear or complex death trajectories (Barclay et al., 2014; Handley et al., 2014; Kinley et al., 2014).

Handley et al. (2014), Barclay et al. (2014) and Kinley et al. (2014) each used similar research methods to examine the phases of dying; however the scale of each study varied considerably. Barclay et al. (2014) conducted a mixed methods study. Residents, care home staff and healthcare professionals were interviewed and residents' case notes were reviewed. The study described trajectories to death, specifically how different illness types and death trajectories could influence healthcare staffs' ability to carry out appropriate EoL care. It was observed that certain illnesses could lead to hospital admissions more commonly than others with more clear trajectories. However, these findings are limited because, despite consent being obtained from 121 residents, the study focused mainly on only 23 participants who died during the 12 months of data collection. Additionally, the

study stated that care home staff and healthcare professionals were interviewed, but does not detail how many.

Despite their study being small in scale, the results from Barclay et al. (2014) supported similar findings by Handley et al. (2014) and Kinley et al. (2014). Handley et al. (2014) reported how different death trajectories, particularly when unclear or unexpected could impact on care home staffs' decisions, particularly regarding admissions to hospital at the EoL stage of care. The methodology of Handley et al's study was similar to that used by Barclay et al. (2014). Handley et al. (2014) used a mixed method design utilising interviews and case note reviews. 63 residents, 30 care home staff and 19 NHS healthcare staff from different disciplines were interviewed. Handley et al., who only included care homes without on-site nursing provision, suggested that registered and non-registered care home staff may react differently when making decisions at the end of life stages. However, Kinley et al. (2014) and Barclay et al. (2014) found similar results in care homes with and without on-site nursing.

Kinley et al. (2014) also reported similar findings, describing stages of death which ranged from 'dwelling', which represents slow expected death, to 'sudden', which represents unexpected death. They also noted that these different death trajectories could influence staffs' decision-making ability. Kinley et al's study examined the case notes of residents who had died within 38 care homes over a three year period, which equated to 2,444 residents, a considerably larger sample than either Barclay et al. (2014) or Handley et al. (2014). They used the case notes to extract specific data, including demographics; diagnoses; use of acute services; place and type of death and use of end-of-life care tools (e.g. advance care plans (ACPs) and EoL documentation).

Each of the three studies had a slightly different way of describing the phases of EoL care. Handley et al. (2014) referred to them as death trajectories ranging from 'clear' to 'unclear'. Barclay et al. (2014) used terms ranging from 'anticipated' to 'unpredictable', while Kinley et al. (2014) described the stages of death ranging from 'dwelling' to 'sudden'. Despite the different terminology, the overarching concept is consistent throughout, which is that the phases of dying experienced during EoL care seem to follow similar patterns ranging from steady decline to a complex and unpredictable trajectory.

All three of the studies also described how lack of awareness of the phases of dying during EoL care can often result in care home staff making 'reactive' or 'in the moment' decisions (Barclay et al., 2014; Handley et al., 2014; Kinley et al., 2014). For example, Barclay et al. (2014) described how, particularly with 'uncertain' or 'unclear' dying trajectories, staff tended to panic when the resident unexpectedly deteriorated and admitted the resident to hospital, where they died inappropriately. However, Barclay et al also reported how interprofessional team-working can help provide support in these moments. This interprofessional team-work will be discussed in a later theme.

Summary of main findings:

- Different phases/trajectories of death during EoL care were acknowledged in the literature.
- The phases /trajectories of death were recognised as impacting on EoL care.
- Healthcare staffs' understanding and knowledge of these phases was shown influence decision making when providing EoL care.
- Sudden and unexpected death trajectories often caused healthcare staff to panic and admit the resident to hospital.

End of life preplanning processes

Preplanning processes were identified as playing a key role in the provision of EoL care, particularly in aiding staff to adhere to residents' wishes. For example, advance care plans (ACPs) were often used by a range of healthcare staff to communicate residents' preferences, notably preference for place of death, to other healthcare staff and external services, such as GPs and other out of hours services (Livingston et al., 2012; Stone et al., 2013; Froggatt et al., 2009; Goddard et al., 2013; Mathie et al., 2012; Kupeli et al., 2016b; Ong et al., 2011).

Preplanning tools such as ACPs also appeared to focus outcomes and prepare care home staff for the different phases of dying during EoL care by providing information necessary for appropriate, personalised and planned EoL care. However, it was equally conveyed throughout the literature that engaging in EoL preplanning care discussions with residents and relatives was commonly avoided by care home staff (Handley et al., 2014; Froggatt et al., 2009; Wye et al., 2014; Ong et al., 2011).

Froggatt et al. (2009) found that the use of ACPs can further help reduce reactive decisions during EoL care. Froggatt et al. (2009) conducted a mixed method study which specifically described and explored the use of ACPs. Froggatt et al used questionnaires (n=213) and interviews (n=15) to collected data from care home managers. Thematic analysis of this paper uncovered how ACPs can help staff focus on structured pre-planned processes or instructions to help inform their EoL care decisions.

Froggatt et al's findings were supported by Ong et al. (2011) who conducted a study of eight care homes to explore reasons for admitting residents to hospitals at the end of their lives. The study found that out of 340 patients admitted to hospital from care homes, 40% died within 24 hours, suggesting a high level of less appropriate admissions. The study suggested that poor communication between care home staff and patients and relatives led to a lack of preplanning documentation, which contributed to decisions on admissions at the EoL.

The consequences of not having ACPs in place was further supported by Kupeli et al., who explored the provision of EoL care in care homes for residents who have dementia. The study interviewed a range of care home staff (n=8) and healthcare staff working within the National Health Service (NHS) (n=6). Results indicated that study participants viewed ACPs as a method to reducing inappropriate hospital admissions from the care home and reducing unnecessary treatments (Kupeli et al., 2016a). However, Kupeli et al. (2016a) discussed that these positive views and understandings of ACPs may not be representative of the views of care homes staff throughout the whole care home sector across the country. Furthermore, these findings may not represent the routine practice for the wider care home demographic as the study only explored the care of patients with dementia.

Livingston et al. (2012) exemplified Kupeli et al.'s (2016a) statement that positive practices may not be applied throughout the whole care home sector. Livingston et al. (2012) conducted a qualitative study that interviewed 58 care home staff in a 120 bed care home which provided both residential and nursing care. The interviews continued until data saturation was reached. The study aimed to examine the barriers to and facilitators of good EoL care for residents with dementia. Results found that care staff, nurses and doctors did not see themselves as a team, but rather focused on their separate responsibilities. As a

result, they communicated poorly with each other, residents and their families about approaching death. The study also reported that staff members were unaware of the benefits that ACPs could provide at the end of life for residents and their families. It was also reported that staff were worried about being blamed for the residents' potential death, therefore tended to ignore preplanning information and send the patient for admission to hospital based on fear of the consequences of not doing so.

Similar findings were evidenced by Stone et al. (2013), who carried out a qualitative descriptive study, interviewing 28 participants. The participants ranged from residents, family members and staff members from three nursing homes. The study described how care home staff would commonly avoid discussions about death and pre-planning, despite residents themselves often being open to such discussions. They contended that it was staffs' lack of understanding of ACP and pre-planning documentation that led to their lack of engagement, alongside their perceptions that residents did not want to discuss ACP. The findings of Stone et al. (2013) are backed up by larger research projects such as Froggatt et al. (2009), Mitchell and McGreevy, (2016) and Handley et al. (2014). Froggatt et al. (2009) suggested that illness type and trajectory may be part of the reason why EoL care discussions did not take place. They discussed how residents with communication and cognition problems often found it hard to engage in EoL care discussions, and how care home staff themselves found it difficult to engage with residents in this category.

Handley et al. (2014) also explored how care home staff engaged in EoL discussions with residents. They found that all staff who were interviewed recognised the importance of initiating pre-planning discussions, particularly regarding preferred place of death. However, despite this understanding of the overall benefit of pre-planning discussions, they reported

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that care home staff in two homes expressed hesitancy and uncertainty about how to start discussions with residents about death. Specifically, they were unsure when the right time to start discussions was, and how to involve family members in these discussions.

This lack of EoL care discussions was also acknowledged by Wye et al. (2014), who conducted a qualitative realist evaluation which aimed to evaluate EoL services in English care homes. Methods of data collection included 15 observations of services, interviews with family carers (n=43) and healthcare professionals (n=105) and analysis of documentation. Their results supported findings that suggest that EoL care discussions are often neglected in practice. Wye et al noted how time restrictions and poor staffing levels forced care home staff to rush and miss out or avoid vital aspects of EoL care, such as discussions with residents and family regarding pre-planning and death.

Despite the infrequency of EoL care discussions, Goddard et al. (2013) found that care home staff and community nurses did recognise the importance of establishing EoL care preferences and encouraging advance care planning discussions. However the study acknowledged it was small in scale and only explored practice in two care homes, which limited the generalizability of its findings.

Mathie et al. (2012) carried out a qualitative study which interviewed 63 care home residents recruited from 6 UK care homes. The study highlighted the importance of ongoing discussions with care home residents and their relatives, revealing that these discussions can produce opportunities to talk about dying and preplanning. Furthermore, the study revealed that facilitating these discussions earlier rather than later may be important, particularly for residents with dementia (Mathie et al., 2012).

Summary of main findings:

- Evidence suggests that good practice is not always applied throughout the care home sector in the UK.

- It is important to facilitate ongoing discussions with care home residents and their families throughout their time in the care home.

- Engaging in EoL care discussions with residents and family members to gather information for preplanning processes was acknowledged as lacking in care homes.

- The most commonly used preplanning tool appeared to be ACPs.

- ACPs were an effective tool in disseminating vital preferences of residents amongst interprofessional healthcare staff and external services.

- ACPs improved decision-making by helping staff prepare and plan for unexpected or sudden death trajectories experienced during EoL care.

Understandings of end of life care

Varying understandings of, and perspectives about EoL care among staff were evidenced, which seemed to be determined by profession and care setting and context (Handley et al., 2014; Mitchell and McGreevy, 2016; Lawrence et al., 2011; Goddard et al., 2013). However, some studies found evidence of a general ethos towards EoL care amongst care home staff that differed from that of professionals working in other settings. That ethos involved a more holistic approach to care than was found elsewhere.

Lawrence et al. (2011) conducted a qualitative study using interviews to explore how EoL care was experienced from the perspectives of bereaved family carers (n=27) and care professionals (n=23). Participants were recruited from care homes, general hospitals and

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the community. The wide range of participants uncovered how understandings of EoL care varied amongst these different professional groups in different care settings. For example, it was found that in care home settings staff understood EoL care as holistic care which involved forming bonds with residents and they emphasised communication with both the dying resident and their families. However, this understanding was largely absent amongst general hospital staff who had a much more detached, task focused understanding of EoL care provision. Additionally, the study revealed that bereaved relatives particularly valued this 'close relationship' with care home staff and they tended to see it as a key determinant of good quality EoL care.

Differences in attitude were also found between care home and community staff. Goddard et al. (2013) conducted a qualitative study which used interviews to explore the views of care home staff (n=80) and community nurses (n=10) on providing EoL care in care homes. The study described how care home staff and community nurses had both similar and differing views of EoL care. For example, both participant groups understood that a caring approach is required and that emotional support should be provided to relatives both before and after the bereavement. However, differences in understanding of EoL care were also apparent. For example, care home staff believed that EoL care should commence early on and tended to favour the use of ACPs early on too. In contrast, community nurses believed that EoL care should only commence when the resident is notably diagnosed as being at the end of life or terminal phase.

Appreciation of participants' understandings of EoL care was complicated by the fact that many studies did not distinguish between palliative care and EoL care (Lawrence et al., 2011; Mitchell and McGreevy, 2016; Barclay et al., 2014). Palliative care is a non-curative

intervention designed to provide patients with comfort and support, irrespective of their time left to live (WHO, 2011; NICE, 2011). EoL care is a subset of palliative care and is confined to the last days/weeks of life (Fisher et al., 2000; NCPC, 2006). However, the commencement of the EoL care stage within the process of palliative care is unclear, thus left open to individual interpretation (Mitchell and McGreevy, 2016; Lawrence et al., 2011; Goddard et al., 2013).

Mitchell and McGreevy (2016), using questionnaires completed by 56 care home managers, found that their overall knowledge of palliative care was variable. It was good in some areas such as therapeutic pain relieving strategies, but poor in others such as understanding the underlying philosophy of palliative care. However, the study only explored understandings of palliative care thus did not explore how staff discriminate EoL care from palliative care. Nonetheless, as stated above EoL care is a subset of palliative care therefore staff's wider understandings of palliative care can still provide useful insights into the delivery of EoL care. Moreover, exclusions of other care staff in this study meant that variations in understanding between professional groups could not be explored.

Handley et al. (2014) supports the findings of Lawrence et al. (2011) and Mitchell and McGreevy, (2016) in regard to varying levels of understanding of palliative and EoL care. Moreover, understandings of EoL care have been shown to vary depending on the different death trajectories discussed earlier. It was reported that towards the end stages of life, care home staff often presented differing understandings and responses. For example, when a resident's death trajectory was sudden or unexpected, care home staff tended to want to prolong life and admit the resident to a hospital (Handley et al., 2014; Barclay et al., 2014).

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These variations in understanding seemed to be particularly prevalent in care homes without on-site nursing provision (Handley et al., 2014).

Summary of main findings:

- Understanding of EoL care can influence how healthcare staff provide care.
- Understanding of EoL care seems to vary in care homes according to profession, care setting and context.
- A lack of discrimination between EoL and palliative care may influence healthcare staffs' understanding of when to commence EoL care.

Interprofessional End of life care provision

Interprofessional EoL care provision manifested itself as a range of professional groups working together to provide EoL care to residents and their families in care homes. Specifically, it was frequently conveyed that general practitioners (GPs) and district nurses (DNs) worked together with care home staff, residents and families to share and discuss decisions about the management and planning of EoL care. For example, GPs often needed input from DNs, family, care home staff and residents to ascertain key information; e.g. preference for place of death (Kinley et al., 2014; Handley et al., 2014; Barclay et al., 2014; Wye et al., 2014; Froggatt et al., 2009; Livingston et al., 2012; Kupeli et al., 2016b). Despite this interprofessional approach, uncertainty was expressed by healthcare staff in relation to who should be involved in EoL care provision and at what stages (Handley et al., 2014; Kupeli et al., 2016b).

Kinley et al's large study found that interprofessional working played an important role in EoL care provision. For example, they note that GPs and DNs often relied on each other for information and support. However, the exclusive reliance of this study on case note examination meant that it was unable to capture the in-depth experiences of interprofessional care provision. However, Kinley et al's findings were supported by both Barclay et al. (2014) and Handley et al. (2014), who used interviews alongside the examination of case notes.

For example, Barclay et al reported how GP support was essential in enabling interprofessional collaboration and teamwork. Specifically, care home staff stated that they felt supported by the presence of a GP. This finding was echoed by Handley et al. (2014) and Kinley et al. (2014), who also found that collaborative working helped coordinate decisions and prevent reactive approaches to care by helping care home staff feel supported and part of a team.

Nonetheless, Handley et al. (2014) described how staff members involved in the provision of EoL care were often unclear about who was responsible for providing particular aspects of that care. For example, uncertainty was expressed about who should initiate and be involved in EoL discussions. Handley et al found that this uncertainty often resulted in resident not being formally diagnosed as nearing the EoL. Uncertainty about who should be involved in EoL care and lack of formal diagnoses for residents nearing the EoL tended to be particularly impactful in a crisis, heavily influencing decisions about whether to admit residents to hospital (Handley et al., 2014).

This finding was supported by Froggatt et al. (2009) who observed that care home staff were unclear about who should engage in EoL discussions and when. They recommended a

more discriminating approach should be taken in regard to who is responsible for which elements of EoL care discussions. Barclay et al. (2014) and Kinley et al. (2014) noted that clear interprofessional working arrangements were essential in preventing unnecessary admissions to acute services.

Wye et al. (2014) also supported the idea that interprofessional teamwork is an essential part of EoL care. Despite this, they found that important members of the team, such as GPs and DNs, who were not based in care homes, were frequently not present at crucial moments, which undermined the level of support that care home staff felt they were given (Barclay et al., 2014; Handley et al., 2014; Kinley et al., 2014; Ong et al., 2011).

Similar findings were highlighted by Kupeli et al. (2016b) who explored the attitudes of a range of healthcare staff (n=14). These professionals ranged from commissioners to home managers. The study revealed a fragmented approach to care. Specifically, poor relationships between care home staff and external healthcare professionals was evidenced. Care home staff who participated in the study commonly highlighted that they felt undervalued by external healthcare professionals (Kupeli et al., 2016b). Handley et al. (2014) also discussed that care home staff often felt their expertise and knowledge was undervalued.

Furthermore, interaction between care home staff and specialist palliative care services appeared to be limited. Lawrence et al. (2011) observed limited access to palliative care services and acknowledged this as a common phenomenon throughout the care home sector. However, where available, it was found that input from specialist palliative care services provided valuable instruction and support, helping to instil staff with the confidence

to carry out and manage EoL care themselves. These findings were echoed by Handley et al. (2014) who added that care homes without on-site nursing provision tended to rely more heavily on external palliative care services for support carrying out EoL care. However, Ong et al. (2011) found that access and communication between palliative care services was equally poor in both nursing and residential care homes.

Summary of main findings:

- Interprofessional collaboration is an essential part to providing EoL care, however poor relationships between care home staff and external services were highlighted as impacting on interprofessional collaboration.
- Support from a range of professionals, notably GPs and DNs, helped care home staff feel part of a team and better able to make decisions.
- It was noted that staff expressed uncertainty as to who should be involved in EoL care and at what stages, which was found to be particularly impactful in a crisis.
- A lack of interaction between specialist palliative care services and care homes was highlighted.

Discussion

A number of areas of concern were identified in the literature in relation to the phases of dying during EoL care; EoL preplanning processes; understandings of EoL care; and interprofessional EoL care provision. However, it is important not to exaggerate either the extent of the problems currently pertaining in care homes, or the exceptionality of EoL care in care homes as compared to other healthcare contexts.

It should be remembered that many of the findings referred to variations in care, which means that excellent care is already being delivered in some locations. That is not just important for those who are currently receiving a high standard of care, but it also means that there are exemplars that can be used to support the rolling out of good practice across the sector.

Even in an area such as pre-planning for the end of life, where there is considerable evidence that staff engagement in the activity is far less than it should be, there is also evidence that staff members appreciate the benefits of pre-planning, and only avoid engaging in it because they lack the confidence and knowledge to do so. This is important because it means that the problem is not caused by staff resistance to new practice, which implies that if the appropriate support is provided, then the successful implementation and sustainability of pre-planning more widely across the sector is achievable.

It should also be noted that many of the problems identified here are not unique to care homes. Thus, for example, care home staff members are not alone in finding difficulty in caring effectively for residents who have complex end-of-life trajectories. The lack of prognostic clarity that is associated with chronic life-limiting diseases, such as non-malignant respiratory disease, that are characterised by intermittent acute-on-chronic episodes, entails a significant challenge to EoL care for healthcare professionals regardless of care setting or professional background (Crawford et al., 2013;   ).

Similarly, the failure of healthcare professionals to engage in advance care planning is a wider problem that has also been evidenced in acute care settings. Thus, for example, Heyland et al. (2013) found that in just 30% of cases did acute hospital documentation accord with the expressed preferences of elderly patients at high risk of dying. Part of the

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problem is a general reluctance by healthcare professionals to engage in difficult

conversations with those in their care (████████████).

Generalist healthcare practitioners' lack of understanding of EoL care, and consequent gaps

in their confidence and competence, is an issue that, while improving, has long plagued

palliative care. This issue has been identified both in relation to medicine (Shanawani et al.,

2008) and nursing (Wallace et al., 2009). Part of the confusion relates to variable

understandings of what is meant by EoL care, and how it relates to palliative care (Shipman

et al., 2008). Once again, the problems faced by care home practitioners are shared across

the field of generalist palliative care.

Finally there is the issue of interprofessional practice, and specifically the utilisation of

specialist palliative care practitioners by healthcare teams providing EoL care. Once again,

the lack of specialist support to care homes is in line with findings in relation to the care of

dying older people in acute hospitals. Gardiner et al. (2011) observe that specialist palliative

care services remain predominantly focussed on cancer, which means that older people,

who are more likely to suffer from non-malignant diseases, are disadvantaged in their

access to these services.

Not only are the problems experienced by care homes similar to those of other sectors, in

some ways it has taken a leading role in the improvement of EoL care. Thus, the Gold

Standards Framework Accreditation system commenced with care homes in 2004, and

subsequently expanded to domiciliary care, community hospitals and primary care

(http://www.goldstandardsframework.org.uk/history), with Phase 1 of Acute Hospital

Accreditation only commencing in 2015

(http://www.goldstandardsframework.org.uk/accredited-acute-hospitals).

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Limitations

We recognise that the difference in contexts as a result of including studies which used nursing and residential care homes, which varied in size, structure and location, and that this may reduce the generalisability of the review. Additionally, it is important to note that studies introducing an intervention were excluded because these related to specific initiatives rather than standard care.

However, existing EoL care interventions may already be implemented in the care homes used in the studies. Specifically, some of the studies included care homes which were Gold Standard Framework (GSF) accredited (Barclay et al. 2014), while others included care homes which were in the process of being accredited (Kinley et al., 2014; Handley et al., 2014; Stone, Kinley and Hockley, 2013). However, in other studies it was unclear whether the care homes used the GSF as it was not mentioned (Goddard et al., 2013; Kupeli et al., 2016a; Kupeli et al., 2016b; Mathie et al., 2012; Livingston et al., 2012; Mitchell and McGreevy, 2016; Wye et al., 2014). It was also apparent within two of the studies that participants mentioned to using the GSF, however the authors of these studies did not state which of the care homes they included used the GSF and which did not (Froggatt et al., 2009; Lawrence et al., 2011). Despite this, we feel that this review provides an enhanced understanding of the reviewed literature by providing comprehensive information about contemporary EoL care provision.

Conclusion

Given that the problems identified in the literature concerning EoL care of residents in care homes are similar to those encountered in other healthcare environments, there is logic in considering how generalised solutions that have been proposed could be applied to the specifics of care homes.

Dealing with the uncertain trajectories of some chronic illnesses requires a dynamic approach to EoL care which focusses on the changing needs of the individual (Murtagh et al., 2004; ▮▮▮▮▮▮▮▮▮▮▮). It also requires the additional skill of being able to actively manage uncertainty to minimise the anxiety it causes (Murtagh et al., 2004). All this implies the need for care home staff to be trained in the knowledge and skills required.

Making pre-planning a more uniform and utilised aspect of care in care homes also requires educational and practical support to ensure that staff are both competent and confident in undertaking the conversations required, and that they accurately record and communicate the decisions made by residents (Seymour et al., 2010). It also requires systematic implementation and monitoring within organisations (Molloy et al., 2000).

Both of the above conclusions underline the crucial link between the level of staff members' knowledge about EoL care and the quality of care that they give (Sullivan et al., 2003), and the subsequent imperative that they are provided with the educational resources to gain that knowledge.

Finally, the findings indicate that there is a need for the expansion of community specialist palliative care services, and that those services should have formalised links with care homes so that their support is available when required (Candy et al., 2009).

Given the nature of the issues identified in the literature, if these strategies are adopted across the sector, excellent EoL care can become a more consistent feature of care homes than the evidence suggests is currently the case. Due to the variation revealed in this review, further research is necessary to explore the effectiveness of EoL care interventions and strategies applied across the care home sector. Additionally, given the heterogeneity of UK care homes, this review advocates that contextual depth is explored, specifically focusing on stakeholders' experiences and interpretations of EoL care interventions and strategies in different care home contexts.

Key points for policy, practice and research

- Evidence suggests that there are variations in the quality of end of life care in care homes.

- The main areas of concern that have been identified relate to the phases of dying during end of life care; end of life preplanning processes; understandings of end of life care; and interprofessional care provision.

- Interventions applied in other healthcare sectors to improve end of life care may also be effective in the care home context.

- Further research is necessary to explore the effectiveness of end of life care interventions in the specific social, economic and organisational contexts within which care homes operate.

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