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Care towards the end of life in older populations and its implementation facilitators and barriers: a scoping review

Running title: end of life care implementation

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Care towards the end of life in older populations and its implementation facilitators and barriers: a scoping review

Abstract

Purpose: To inform health system improvements for care of elderly populations approaching the end of life (EOL) by identifying important elements of care and implementation barriers and facilitators.

Design: A scoping review was carried out to identify key themes in EOL care. Articles were identified from MEDLINE, the Cochrane Library, organizational websites and internet searches. Eligible publications included reviews, reports and policy documents published between 2005 and 2016. Initially, eligible documents included reviews or reports concerning effective or important models or components of EOL in older populations and evidence was thematically synthesised. Later, other documents were identified to contextualize implementation issues.

Results: Thematic synthesis using 35 reports identified key features in EOL care: (i) enabling policies and environments; (ii) care pathways and models; (iii) assessment and prognostication; (iv) advance care planning and advance directives; (v) palliative and hospice care; (vi) integrated and multidisciplinary care; (vii) effective communication; (viii) staff training and experience; (ix) emotional and spiritual support; (x) personalized care; and (xi) resources. Barriers in implementing EOL care include fragmented services, poor communication, difficult prognostication, difficulty in accepting prognosis, and the curative focus in medical care.

Conclusions: Quality EOL care for older populations requires many core components but the local context and implementation issues may ultimately determine if these elements can be incorporated into the system to improve care. Changes at the macro-level (system/national), meso-level (organizational) and micro-level (individual) will be required to successfully implement service changes to provide holistic and person-centered EOL care for elderly populations.

Keywords: Health services research, end of life care, older populations, scoping review, implementation issues

Introduction

End of life (EOL) care is the process of caring for the medical, social, emotional and spiritual needs of people who are approaching their end of life. EOL care will likely include a range of both medical and social services, such as disease-specific interventions or palliative/hospice care ¹. Good EOL care involves a shift away from curative care to a palliative approach to allow people to die with dignity, without excessive pain or distress and in a setting of their choice ².

The World Palliative Care Alliance (WPCA) and World Health Organization (WHO) advocate a number of strategies to improve palliative care at the EOL: policy to enable palliative care; inter-professional collaboration; sufficient resources to meet needs; and engagement of the public and professionals in discussions and education about palliative care at the EOL ². According to the WHO, palliative care for people facing life threatening illness can improve patient and family's quality of life (QOL) by preventing and relieving suffering and through early identification, assessment and treatment of pain and other physical, psychological or spiritual problems ³. In other words, palliative care is a need-based concept. On the other hand, EOL care is a time-based concept, which may include palliative care as an important component as well as various preparations for the last stages of life.

It is challenging to identify the relevant population of 'elderly EOL patients' per se, because of unpredictable prognosis. Therefore, for the purpose of this paper, we refer to care models that are appropriate to both EOL patients and to older patients who may be nearing the last phase of their life; henceforth the term 'EOL patients' will be used for simplicity.

Historically, palliative care was largely centered on the care of patients with cancer, but in recent years the focus has broadened significantly to encompass all individuals with terminal conditions or elderly who are approaching the end of their lives. In fact, the majority of people worldwide needing palliative care suffer from non-malignant conditions². The growth of research in EOL care practices in older, largely non-cancer patient populations, is a result of the demographic changes observed in many developed countries.

There is a growing body of literature relating to EOL care in elderly populations, but few existing reviews focus on practical aspects of implementing core EOL care components. Therefore, our aim was to identify core elements of EOL care for older populations and to present common implementation issues (i.e., barriers and facilitators) as a resource for planning and implementing health system improvements.

Methods

To generate a rapid summary of key EOL care components across the broad evidence-base, the scoping review method was first applied and we followed recommended stages for this approach⁴. Once saturation of key themes was achieved, targeted searches were conducted to supplement evidence relating to implementation issues (Figure 1).

Literature search and article selection

Publications were initially identified from the Cochrane Library and MEDLINE. The MEDLINE search was conducted in June 2015 (Appendix Table 1) using the following keywords: (terminal care OR end of life OR advance directives OR advance care planning) AND (integrated delivery of health care OR total quality management OR quality of health care OR quality improvement OR organizational models). A pragmatic publication date cut point of 10 years was adopted to identify more recent studies and documents; hence, literature publication dates spanned from 2005 to June 2015. Further literature search (for review articles, guidelines, policy documents, governmental / healthcare provider reviews or policy

statements) was then conducted using internet search engines and governmental/ organizational websites to fill gaps in elements of EOL care or care settings. Searching was supplemented by examining bibliographies of already included papers.

Inclusion criteria were developed based on increasing familiarity with the identified studies, a standard approach in scoping reviews. Literature reviews and reports were included if they reported or discussed care at the EOL in older populations, were published since 2005 and written in English. Potential documents were excluded if they focused on (i) assisted suicide or euthanasia, (ii) specific medical treatments or therapies (e.g. dialysis or medical treatment for stroke at the EOL), or (iii) EOL care in younger populations (aged less than 60 years old). Citation screening and application of eligibility criteria were performed independently by two reviewers, with discrepancy resolved by discussion. A third reviewer was invited for consensus adjudication if discrepancy persisted.

Thematic synthesis

Studies were included until saturation of themes (core elements of EOL care) was reached. One researcher systematically read each included article and extracted data on main themes. Data were charted and coded according to emerging themes to highlight and connect common EOL care components and implementation issues. The articles grouped by these common themes were then reexamined (by referring back to the original publication), and these themes are narratively presented here. The heterogeneous nature of evidence included in this scoping review (systematic reviews, summary reviews, individual trials and policy documents) made formal quality assessment impractical; thus, relevant articles were instead selected until saturation of themes was achieved.

Supplemental literature searching

Supplemental searches using Cochrane, Medline and internet search engines were conducted up to April 2017 to expand evidence relating to implementation issues in EOL care practices for older populations.

Results

Of the 107 reviews identified in the MEDLINE search, 22 were relevant. Three relevant publications were identified from a search of the Cochrane Library, and 10 other reports were identified through internet searches and from institutional websites. Initially, 35 reports and reviews were included in this rapid scoping review to identify important components and issues in EOL care. Evidence for implementation issues for each identified theme was supplemented in later searches, and additional articles are cited to support the summaries of each care component.

The majority of included publications were reviews or reports focusing on EOL or palliative care in ageing populations from a multinational perspective, with evidence from the UK and the US dominating this field. Reports collated summaries and findings for implementing service changes and identified barriers and facilitators to quality EOL care. Details extracted from each of the 35 included reports are presented in Appendix Table 2.

Definitions for quality EOL care among studies differ, but studies generally focus on similar themes. The thematic analysis identified components for quality EOL care for older populations at the macro-level (policy/health system/national context), meso-level (organizational), and micro-level (individual), and the 11 components are discussed below (See Table 1). Each EOL care component may be implemented with differing success, depending on local barriers and facilitating factors. A summary of evidence on implementation factors is presented in Table 2.

Macro-level factors

1. Enabling policies and supportive environments

The presence or absence of enabling policies and supportive environments is seldom specifically researched but many of the included studies and reports identified that good EOL care can only exist within an enabling environment where sufficient institutional policies are in place to permit changes to

occur. Policies should enable quality EOL care to be delivered by ensuring funding and training, while care outcomes should be aligned with important features of EOL care.

The perennial ‘cure culture’ in medical care is a significant barrier to implementing EOL care⁵. Many systems currently do not reward clinicians for ‘just conversations’ or for supportive care, with the focus being on treatment targets or payment by results. A shift in policy, guidelines, or emphasis on patient QOL at the EOL will help change this focus. Strong leadership in hospitals and an EOL care steering committee have been identified as possible facilitators⁶. In the UK, national EOL care strategy and services have been established and are in place to enable good EOL care, including central and charity funding for hospice care, hospices that provide much of the EOL care, specialist palliative trainees that are distinct from generalists, and specific training in medical schools.⁷

Meso-level factors

2. Care pathways and models of care

It is suggested that integrated care pathways for EOL may promote access to services and proactive pain management, engage patients and families in decision-making and clarify goals among patients, families and the care team, provide a framework to tackle complex issues, and provide a mechanism to measure outcomes^{5, 8}. Clinical pathways may span the last few days of life or longer and may include anticipatory prescribing, withdrawal of unnecessary treatments, conversion of oral to parenteral medications and procedures to follow at death⁸. After recognition of the dying process, strong clinical leadership with financial commitment is needed to employ designated facilitators or to provide training for clinicians to apply the pathway to EOL care⁵. EOL care pathways are diffusing across the globe,⁹ despite little empirical evidence of their benefits^{10, 11} and a rapid evidence review commissioned in the UK identified no strong evidence for potential benefits or risks in applying ‘pathways’ to manage EOL care^{12, 13}. The Liverpool Care Pathway was widely adopted across the UK until 2014 and received increasing criticism over (i) the lack of experienced clinicians and reviews of patient status, (ii) prescription practices for

symptom control and sedation, and (iii) perceptions of withholding medication and hydration, with negative consequences¹⁴. A 2016 Cochrane review on EOL care pathways identified only one study of low quality¹⁵; thus, the evidence appears insufficient to specifically recommend the use of care pathways.

Despite the criticisms mentioned above, barriers in using EOL care pathways include time and resources for training and implementation as well as poor understanding about the pathway, which can cause providers to treat the pathway as a simple checklist. Acceptance among the healthcare team is also a problem, with some clinicians expressing concerns about pathways^{8,9}.

3. Assessment and prognostication

Unpredictable patient prognosis or trajectory means clinicians cannot easily identify when the EOL is approaching^{6,16}. The challenges of accurate prognostication are frequently cited in literature as a significant barrier to planning care¹⁶⁻¹⁹. Moreover, there is ambiguity over the definition of EOL¹⁸. The question “would you be surprised if this person were to die in the next 6-12 months?” may be a helpful tool for clinicians to identify those approaching the EOL⁶. In addition to objective prognosis tools, using senior, more experienced or palliative care doctors for conducting prognosis is also beneficial^{6,16}. Despite ongoing challenges and uncertainty in determining EOL prognosis, the Gold Standards Framework ‘Prognosis Indicator’ was identified by the UK General Medical Council as a useful tool^{20,21}.

4. Advance care planning and advance directives

Advance care planning (ACP) protocols help clinicians and patients work through and document their wishes, and structured family conferences may be useful in facilitating ACP²². ACP improve the completion of Advance Directives (ADs), improve patient and family outcomes, decrease life-sustaining treatments, increase palliative/hospice care, and increase the concordance between patient wishes and the care received^{16,23-25}. In nursing homes, ACP appears to offer general benefit, but the body of evidence is not of high quality, and many patients are too ill or cognitively impaired to benefit from ACP at the last stage of their lives²⁶.

There are significant barriers that prevent ACP being widely adopted: competing work demands ²⁷; lack of protocols, training and appropriate methods of providing information to patients ²²; poor knowledge among patients about ACP ²⁸; lack of understanding about the values and implications of using ACP among health professionals ²²; the emotional and interactive nature of the ACP process and general reluctance to discuss death and unpredictable circumstances ^{22,27}; and problems in sharing decisions within and between health care organizations ²⁷. General practitioners (GPs) also report that patients' fear of upsetting their families, denial of illness or reluctance to think of future health problems, and GPs' fear of destroying hope or damaging patient-GP relationships are also barriers to ACP ²⁸. Many nurses feel that they are well-positioned to undertake ACP discussions but require more training, and that the ACP process and terminology may need to be simplified ²⁹.

While increasing facilitators for ACP will not cancel out barriers, ACP is most likely to succeed when elements are workable in the complex and time-pressured clinical work flows ²⁷. A simplified decision-making tool may help ACP to be widely adopted; however, since clinicians are likely to take the path of least resistance, policy or incentives may be necessary to encourage usage ²⁷. Factors associated with greater use of ACPs include: longer time and home setting for discussions; reimbursement for GPs; emphasis on GPs' responsibility to initiate discussion; and having accumulated skills in the area to foresee future health problems ²⁸.

ADs, as a legal document, often result from the ACP process and are helpful to document care preferences and prevent unwanted or unnecessary treatment; but as with ACP, discussions may be avoided by families, patients and care professionals, and clinicians may feel they lack training for AD completion ²². Interventions can improve communication about ADs and include standard forms for making a living will, but there is currently no evidence for which intervention or approach is best ³⁰. A systematic review of educational interventions to improve AD completion did not find conclusive results as only a few studies were identified, and there was no clear evidence of benefits; however, written-and-oral-combined education to increase AD use may be more effective than written information alone ³¹.

Families may also have opposing or unrealistic views of prognosis and many override an AD³²; however, involving the family in the beginning of the AD process may prevent this. Moreover, ACP use would be increased with hospital policy requiring use of ADs and with legislation to support the use of ADs and to protect the GPs who comply with the AD wishes²⁸.

5. Palliative care and hospice

The transition to palliative care may begin well before the EOL and many agencies and governments now recognize the value of palliative care for patients who cannot benefit from curative treatment^{1, 2, 33}.

However, many clinicians and nurses see hospice care or palliation as a 'label' or distinction, and are therefore reluctant to recommend this as they feel that termination of curative treatment is a sign of giving up hope^{6, 34, 35}. It has therefore been suggested that hospice should be presented as a concept, rather than a place, and include provision of medical, emotional and spiritual care to patients and families in various locations¹⁷.

Many clinicians hold the mistaken belief that referral to palliative services will shorten life because life sustaining treatments are withdrawn¹⁶, and nurses cite a knowledge deficit about the efficacy of hospice care³⁴. In fact, a retrospective study found that survival was approximately one month longer for patients who received hospice, compared to standard, care³⁶. However, for palliative care to take effect, physicians must take an active role in recommending care and provide more than basic information about the services³⁵. Earlier referrals may help shift the focus of palliative care away from "the end."³⁵

On the whole, palliative care models are heterogeneous, with different elements being applied in various settings³⁷. Specialist palliative consultations can improve symptom control, QOL, emotional burden and caregiver and patient satisfaction by focusing on: (i) prognosis and goals of care; (ii) documentation using Advance Directives (ADs); (iii) discussion about foregoing specific treatments and/ or diagnostic interventions; (iv) family and patient support; (v) discharge planning; and (vi) symptom management³⁷.

In many cultures, death is a taboo subject ^{6, 16, 22, 38}. The curative focus of medicine and medicalization of death results in many clinicians viewing death as a failure rather than an inevitable part of life course ^{6, 16, 38}. A commonly reported challenge for accepting palliative/hospice care is patients' and families' denial of death ^{17, 35} or unrealistic expectations of care ¹⁷. Discussions with families soon after terminal diagnosis may help with acceptance and lead to earlier entry into hospice/palliative care ¹⁷. A good understanding of the disease pathology and the ability for patients and families to participate in decision-making can facilitate this ³⁹. Hospital nurses are in a good position to initiate discussion about EOL care and facilitate communication between the health and social care teams, and thus open patients and families to the concept of palliative care ⁴⁰. However, nurses are often excluded from care planning discussions ³².

In nursing/care homes, there is a reported culture of striving to keep people alive, fear of talking about dying, lack of responsibility for recognizing dying, resistance to change and a general lack of palliative knowledge and skills among staff, and poor collaboration with other health professionals. Implementing care policy standards can improve palliative/EOL care and increase staff knowledge and confidence, reduce unnecessary medications and improve patient outcomes such as pain, agitation and respiratory secretions ⁴¹.

In the hospice setting, a barrier to quality care is a shortage of nurses and the fatigue experienced by these nurses that comes with working with dying patients ³⁵. Hospices are identified as rich sources of experience that can mobilize and train generalists in the community and care homes, and may act as organizational hubs in the community to recruit volunteers ⁶.

6. Integrated and multidisciplinary care

Fragmented EOL services are a significant challenge^{18, 19}. Since multiple services may be needed for symptom management, psychosocial care or EOL care, planning and coordination of services is crucial ²⁵. Effective palliative care models often include elements of shared, coordinated or multi-disciplinary care and typically include a lead clinician in the team ³⁷, or use a physician and a nurse as minimum core

members, one of whom is specialized in EOL care²⁵. In the UK, multidisciplinary teams are identified as necessary while round-the-clock access to coordinated care is identified as one of the core components of quality and safe EOL care^{42 1 13}. Clinical networks also aid the formal linking of services, but few studies have examined these, and evidence for effectiveness is scarce. Nevertheless, formally established networks may provide more benefit than informal links between services³⁷.

Care provided by a comprehensive team that spans inpatient and outpatient settings appears to improve QOL, symptom management, satisfaction with care and likelihood of dying at home, although there may be no impact on admission rates or length of stay²⁵.

In general, case managers are found to play a central role in maintaining open communication between care staff or clinicians and patients or families¹⁷, improving outcomes (e.g. satisfaction with care and QOL) and reducing service utilization. Effective models of palliative care tend to include case management; however, only a few studies examined the impact of case management alone, and a high degree of variability exists in the outcome assessment^{37 43}.

7. Resources

The lack of experienced EOL care workers is a significant and commonly reported problem at hospitals, which are often unsuitable settings for dying due to the lack of physical and private space for patients and for family discussions^{16, 32, 39}. Non-specialists also have insufficient time to deliver effective EOL care, especially in busy wards where dying patients are not prioritized or appropriately supported^{32, 39}.

Home care is preferred by some patients, while others consider dying at home too overwhelming¹⁷. In nursing homes, there is also often insufficient time to care for dying patients and a shortage of hospice or experienced nurses in palliative and EOL care⁴⁴. For those who wish to die in place, services must be available at the dying place of choice to prevent re-admission to hospital. Facilitators for non-hospital care and dying in place include coordinated services, electronic record management, rapid response

service to directly treat patients, systems that permit rapid discharge, and specialist community palliative care teams ^{6,37}.

Micro-level factors

8. Effective communication

Poor communication within teams can delay critical care decision-making ¹⁶ and was identified as the most significant barrier to EOL care quality in the community setting ¹⁷. Poor flow of information between providers and settings is also a problem for care at the EOL ¹⁹, although dynamic care registers may help by prioritizing patients with the greatest need ⁶. Poor communication from community GPs may result from a lack of knowledge about services and procedures for EOL care ⁶. For example, it was observed that clinicians often suggest hospice admission but then provide inadequate information to patients about what hospice care is or how to access it ¹⁷.

Barriers to communication between healthcare professionals and patients include prognostic uncertainty, fear of causing distress, professionals feeling unprepared for EOL discussions, and uncertain or fluctuating patient readiness for conversations ⁴⁵. Nevertheless, more frequent communication between healthcare providers and patients can result in fewer aggressive interventions and reduced hospitalization ⁴⁶. Communication may be improved with the use of a model or training about when to say what and how, so that staff can identify triggers for initiating the big conversations ¹⁶. However, many of the studies providing evidence relating to EOL communication interventions or communication tools are of low quality and highly variable, making it difficult to identify specific strategies to improve communication for better patient outcomes ⁴⁵⁻⁴⁷. Communication between clinicians and families is critical to the way families perceive the overall quality of death ¹⁶ and families of patients in the intensive care unit (ICU) cite communication as their key need ⁴⁸. Healthcare professionals acting as case managers may play a central role in maintaining open communication between patients/families and clinicians ¹⁷.

9. Staff experience and training

Clinicians report a lack of skills and confidence in discussing EOL preferences and treatment options, while community clinicians lack experience in EOL care as they experience only a few cases per year⁶. In some cases, hospital staff may not have experience in EOL care, causing delay in referrals to specialist EOL teams¹⁶. Additionally, general nurses may lack experience and knowledge about care at the EOL, including identification of imminent death, which in turn causes stress because nurses may not fully understand care goals or understand physicians' reluctance to prescribe high dose analgesia³⁹. Also, nursing home staff report insufficient training, time, and resources for proper EOL care, which causes moral stress on a daily basis, as they perceive their care as sub-optimal⁴⁴. Barriers for case managers to increase their skills for evidence-based EOL care standards include lack of time, limited access to literature, and limited computer skills¹⁷.

One of the UK's recently published six ambitions for EOL and palliative care includes that all staff are prepared to care, and to achieve this, all healthcare professionals need to be competent and have up-to-date knowledge⁴⁹. Education initiatives in hospitals may be delivered by palliative care teams or hospice staff, who had experience in dealing with death³⁸. Mandatory training on both EOL services and communication skills has been recommended⁶ and interventions focusing on improving communication skills, knowledge and attitudes among health care professionals were found to significantly improve symptom control²⁵.

10. Emotional and spiritual support

The EOL places a huge emotional burden on patients and families^{27, 37, 38} and creates worry about pain, emotional symptoms and spiritual distress⁴⁴. Some treatments or procedures may be unnecessary or aggressive for EOL patients¹⁷ and greater emphasis is needed for high-touch care³⁵. Spiritual support is an important domain for EOL care^{19, 50} and both in the UK and US, spiritual wellbeing and the need for staff that can provide emotional and spiritual support have been recognized as important for good care^{1, 42}.

The importance of integrating psychological and spiritual care in palliative care is also highlighted by the WHO ⁵¹. Having a sense of contribution, meaning or purpose for the life remaining is also beneficial for patients ⁵⁰. Emotional support, in the form of compassion, physical touch, maintaining hope and a positive attitude, is also important for good EOL care ⁵². Educational interventions for patients and informal caregivers focusing on management of symptoms and coping skills were found to improve caregiver QOL and patient symptom control ²⁵.

11. Personalized care

Individualized care and respect for individual choice are important aspects of EOL care ^{1, 19, 50} and patients should be involved and supported in decision-making ^{5, 50, 52}. Clear communication about illness and death, as well as discussion about preferences, can prevent decision-making being left to crisis situations ⁵⁰. On the other hand, patients may choose to defer decision-making to family ⁴⁴; hence, it is also important to consider the family dynamic and not only plan around the patient ²². Making provision for choice can allow individuals to live as fully as possible until the end of their days and involving the family in multidisciplinary decision-making enables sound memories to establish and satisfaction with care that can help the bereaved live on ⁵³. Good practice guidelines from the UK outline two models for decision-making in EOL care and treatment: one model for patients with capacity to make decisions describes collaborative approaches between the doctor and patient, while the other approach for adults that lack decision-making capacity involves advanced decisions, legal proxy decision-makers and family members. In these cases, the doctor makes decisions according to these factors and in conjunction with other members of the healthcare team ²⁰.

The roles and balance between the individual and family in decision-making are likely to differ in different settings, cultures and depending on the patients' health status and cognitive ability. Families may put pressure on patients to accept more aggressive treatments and not to give up hope, and as a result, individuals can struggle with the stress of making difficult decisions ³⁵. Health professionals are therefore

responsible for striking a balance to best meet patient needs and family expectations. Clear and open communications, in addition to ACPs and ADs, may help. The US Institute of Medicine specifically recommends a personalized and family-centered model for EOL care which recognizes the importance of an individualized approach in the wider family context ¹.

Discussion

Although the evidence from different countries is diverse, common themes emerge around important elements and service gaps in EOL care, and barriers or facilitators in implementation, that are likely to influence the quality of care. Principal issues concern inadequate policy and guidelines for supporting key aspects of EOL care, or systems which lack important elements, such as integrated services or ACP. In terms of individual staff, key problems include experience and training, and the care culture among clinicians and care professionals. Poor communication was often noted as one of the most significant barriers to quality care at the EOL ^{17,48}. The perennial issue of the uncomfortable nature of death and clinician and patient or family reluctance to tackle the topic was also highlighted by many reviews.

Implementing changes at all levels of the system may take several years and a series of successive steps. This was recognised in the UK, with the introduction of the End-of-life care strategy in 2008, to improve care quality. It was recognised that the aims may take over a decade to achieve ^{6,54}. The UK recently outlined six ambitions for palliative and EOL care going forward, which include (i) each person being treated as an individual; (ii) fair access to care; (iii) maximization of comfort and wellbeing; (iv) coordinated care; (v) all staff being prepared to care; and (vi) each community being prepared to help and support ⁴⁹.

The provision of quality EOL care appears to involve many different components, including care pathways, ACP, ADs, coordinated services, case managers, effective communication, education about EOL care, an individualized approach and emotional or spiritual support. The complex nature of interventions to improve care is heightened by the diverse nature of services, policies, health status of

patients, levels of family involvement, cultural attitudes and staff experience or training. It therefore appears impractical to identify the ‘best’ model or policy for EOL care but rather, each factor must be contextualized and assessed at a local level and improvements implemented with the particular setting in mind.

The role of the family was emphasized in many articles and raises important ethical issues in respect of personal vs. relational autonomy as well as the role of family in decision-making for the patient. In the event of illness, health professionals must decide whether, when and to what degree a patient can take charge of the care of their choices and how the family should be involved in the process. The role of family in decision-making is likely to vary across cultures and individuals, but local policy and taking account of cultural factors would enable health professionals to strike this difficult balance.

Other elements of EOL care may vary depending on the context, resources and preferences, and it is likely that a tailored approach will be needed in different settings. For example, in many countries the majority of people prefer to die at home, though, in reality, this is seldom achieved^{55 16 56}. International practices should be adopted with care and through careful monitoring of local preferences. This may be particularly relevant in non-Western cultures such as Hong Kong, where only one-third of nursing home residents would accept community EOL care⁵⁷, and as high as 52.4% general adults preferred to die at hospitals⁵⁸, highlighting that a universal policy may not be suitable for all health systems and populations.

The rapid review and non-exhaustive search criteria used here are methodological limitations in our work and it is possible that publications in certain topics or in other languages have been missed. However, studies were included until saturation of themes was reached. There is no universal methodology for conducting scoping reviews but they aim to present an overview of a potentially large and heterogeneous body of literature⁵⁹. Given the diversity in existing EOL care literature, a scoping review methodology was selected as a pragmatic method to summarize important components of care and implementation issues. Despite the diversity of the papers, many common themes were identified, leading to confidence in

the general applicability of our summaries. As noted in another review in this topic ³⁷, publications tend to focus on setting-specific care (ICU, community, hospices) or single elements of care (CGAs, case management, communication) rather than whole models. It is therefore challenging to know how each of these elements will interact in other settings ³⁷, and few previous reviews of evidence consider the broad and system-level context when summarizing themes. This review somewhat addressed this gap in literature and examined a broad range of evidence to identify key concepts and issues in EOL care. An additional limitation is the lack quality assessment criteria, which may decrease confidence in findings. However, standard quality assessments may have limited application when the evidence-base is heterogeneous, as in this review.

Conclusion

Providing quality EOL care takes time and effort, and needs enabling policies, high-quality clinical leadership, well-designed hands-on training, compassionate care and enthusiasm for providing quality care for dying patients ⁶⁰. EOL care may be improved by incorporating the important elements identified in this review. Service planning and implementing changes to EOL care systems will be facilitated through (i) understanding the levels at which changes are required (macro-, meso- and micro-level), and (ii) understanding common barriers and facilitators, and (iii) taking account of local contexts at different levels of the system. We recommend that before changes are implemented, investigations of local barriers and facilitators are undertaken so potential issues can be avoided. Service planners must first identify both short- and long-term priorities before establishing policy, funding and systems for the long-term planned changes.

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Table and figure legends:

Table 1: Summary of end of life care components

Table 2: End of Life (EOL) care implementation barriers and facilitators

Figure 1: Overview of review methods and identified themes in EOL care.

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Table 1: Summary of end of life care components

Macro-level (policy/ contextual) factors

1. *Enabling policies and supportive environments*

- Policies should enable quality EOL care to be delivered by ensuring funding, training and care outcomes that are aligned with important features of EOL care.

Meso-level (organizational) factors

2. *Care pathways and models of care*

- Care pathways and models can guide care staff and ensure consistent and individualized care by providing frameworks for service access, guidelines for pain management, decision-making aids and providing feedback for improving patient outcomes.
- Clinical pathway use depends on identification of the EOL and on strong clinical leadership, with financial commitment, to implement care that best meets patient needs.

3. *Assessment and prognostication*

- Assessing health trajectories to predict when to initiate care discussions and when to implement EOL care plans are important for good EOL care.
- Inaccurate prognostication is a persistent barrier to planning care.
- Training, frameworks and experience are likely to improve prognostication, but uncertainty will likely remain an ongoing challenge because of unpredictable trajectories.

4. *Advance care planning (ACP) and Advance Directives (AD)*

- ACP is a series of steps that trigger thinking and discussions about future care. Care plans should be made through patient and care provider consultations and take account of local services, preferences and cultural considerations.
- ADs document care preferences for the EOL, but legislation may be required to support clinicians who choose to follow ADs.
- Planning is often delayed because of reluctance to discuss dying, but care can be improved when discussions are initiated earlier.

5. *Palliative care/ Hospice*

- Palliative services may not be generally accepted by patients, families or healthcare staff.
- Shifting away from medicalized treatment to high-touch care can improve EOL experiences.
- Facilities are needed to enable palliative care in chosen locations and training is needed to support healthcare staff in delivering quality palliative care.

6. *Integrated and multi-disciplinary services*

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- Integrated care teams, with case managers, can improve the quality of EOL care and enable consistent care to be provided while helping patients to navigate the health care system and avoid unnecessary treatment.
 - Clinical networks that link different services enable patients to benefit from different care services while maintaining care continuity.

7. *Resources*

- Healthcare staff often have insufficient time to initiate discussions, plan care and tackle barriers to quality EOL care.
- Facilities and services to enable death in the location of choice may not be in place.
- Committed funding and leadership in EOL care are needed to ensure patients have choice in services and access to the necessary care.

Micro-level (individual) factors

8. *Effective communication*

- Good interaction is needed between patients, families and care providers.
- Poor communication results in poor satisfaction with care and delayed decision-making.
- Earlier information from care providers, including what to expect at the EOL, can help patients to feel in control and plan care.

9. *Staff experience and training*

- Experience in EOL care is concentrated among a small number of specialists, but growing EOL care demands will necessitate widespread training in EOL care.
- Healthcare staff consistently report a lack of knowledge and skills about existing services, how to provide EOL care and how to communicate difficult issues with patients.

10. *Emotional and spiritual support*

- Emotional strain for patients and families can be alleviated with compassionate care, physical touch and by maintaining hope.
- Spiritual support or providing patients with meaning and purpose is an important component of EOL care.

11. *Personalised care*

- Provision must be made to permit and encourage individuals to participate in decision-making.
 - The family context is an important aspect of tailoring care around individual needs.
-

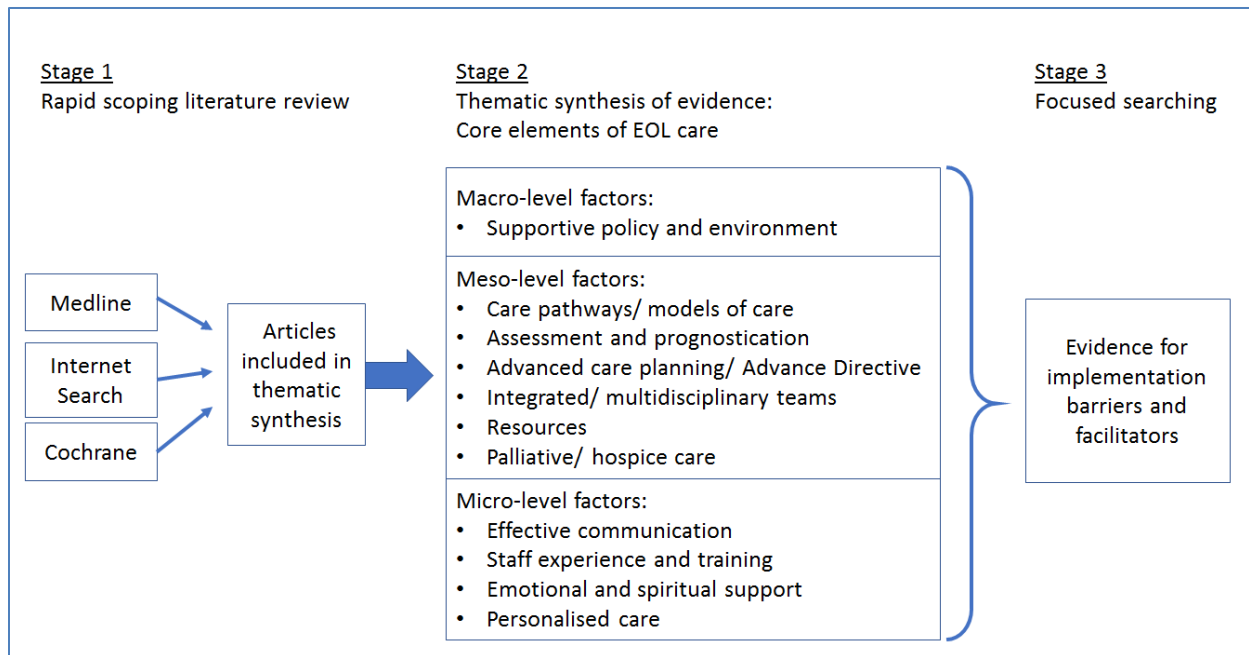
Table 2: End of Life (EOL) care implementation barriers and facilitators

Component of quality EOL care	Barriers	Facilitators
Macro-level (policy/ contextual) factors		
1. Enabling policies and supportive environments	<ul style="list-style-type: none"> Policy change barriers in nursing homes: resistance to changes, lack of collaboration, a culture of medicalization and ‘striving to keep alive’.⁴¹ 	<ul style="list-style-type: none"> Strong clinical leadership in hospitals.^{5,6} EOL care steering committee in hospitals.⁶ Financial commitment to facilitator roles and clinician training.⁵
Meso-level (organizational) factors		
2. Care pathways and models of care	<ul style="list-style-type: none"> EOL care pathway barriers: poor prognostication, non-acceptance of healthcare team, insufficient resources and time for education and training, time restraints and time needed to follow care pathways.^{5,8} 	<ul style="list-style-type: none"> System-based organizational model in nursing homes.⁴¹ Case management in complex interventions of EOL care.³⁷ Resources, time, money, training on care pathway and staff acceptance are needed to implement care pathways/models.^{8,9,61} Audit and feedback facilitate staff motivation for using care pathways and monitoring progress.⁶¹ An appointed facilitator can drive care path implementation.^{61,62}
3. Assessment and prognostication	<ul style="list-style-type: none"> Trajectories are unpredictable and estimating prognosis is difficult.^{6,17-19} More contact with patients makes prognostication harder and less accurate.¹⁶ Generalists/ inexperienced staff struggle to estimate prognosis or identify EOL.^{6,16} In nursing homes, individuals do not take responsibility for recognizing dying.⁴¹ Health professionals often cannot recognize imminent death, which may lead to dying alone.³⁹ 	<ul style="list-style-type: none"> The surprise question can be used for clinicians ‘would you be surprised if this person were to die in the next 6-12 months’.⁶ Prognostication is improved with a senior or palliative care doctor.¹⁶ Use a tool for prognostication.¹⁶

Component of quality EOL care	Barriers	Facilitators
<p>4. Advance care plans (ACP)/ Advance directives (AD)</p>	<p>Barriers to developing plans include:</p> <ul style="list-style-type: none"> • Lack of ACP knowledge (clinician and patient).²⁸ • Delays in decision-making.¹⁶ • Doctor belief that other professionals are responsible for ACP.²⁸ • Doctor doubts about the content and practical aspects of living wills.²⁸ • Staff lack of experience in using ACPs.²⁸ • Clinician fear of upsetting patients/ families by initiating discussion.²⁸ • Nurses, who may be closer to patients and families, are often excluded from planning discussions.³² • Discussions are stressful and challenging.^{22, 27, 28} • Competing work demands.²⁷ • Fear of talking about dying in nursing homes.⁴¹ <p>Barriers to implementation include:</p> <ul style="list-style-type: none"> • Conflicting patient/organization preferences.²⁷ • Non-electronic notes on plans may be lost in transitions.³⁰ 	<ul style="list-style-type: none"> • Clear institutional commitment to recognize, record, share and act on patient preferences.²⁷ • Policy requiring ACP.²⁸ • Legislation supporting AD use and protection for doctors that follow ACP.²⁸ • Shared planning between staff and patients with nurse mediation.^{32, 50, 63} • Clinicians believe their role includes ACP discussions.²⁸ • GP time, reimbursement and familiarity with patient.²⁸ • Good prognostication.¹⁶ • Clear communication about prognosis and death.⁵⁰ • Simple decision-making tool for ACP that does not require specialist involvement.²⁷ • Earlier discussions make plans more beneficial.²⁵ • Clinician training, protocols, decision-making tools and supportive policy.²⁸
<p>6. Palliative care and hospice facilities</p>	<ul style="list-style-type: none"> • Slow EOL identification.⁶ • Medicalized/ curative model of care.^{6, 16, 39, 41} • Palliative care or death is seen as failure or giving up hope.^{6, 34, 35} • Limited specialized palliative services.¹⁶ • Clinicians do not have to administer the extensive treatments they prescribe to those with poor prognosis.³² • Poor clinician communication on palliative care benefits.¹⁷ • Lack of palliative care knowledge/skills in nursing homes.⁴¹ • Lack of knowledge about efficacy and purpose of palliative care among nurses/clinicians.^{16 34} 	<ul style="list-style-type: none"> • Rapid community response team and rapid discharge planning for death at home.⁶ • Discussion soon after terminal diagnosis helps with acceptance to hospice care.¹⁷ • Home-based palliative care is facilitated by creating care goals, communication and skill enhancement for primary care team and patients/caregivers.³⁷ • Cultural shift away from viewing death as failure.⁶¹ • Mandatory, ongoing training and education on EOL care (especially for Doctors).⁶¹ • Patients/families understand disease pathology, accept prognosis and participate in decision-making.^{39 35} • Physicians take an active role in recommending hospice care and facilitating service transfer.³⁵ • Specialized palliative care teams.^{6, 16}

Component of quality EOL care	Barriers	Facilitators
5. Integrated and multidisciplinary services	<ul style="list-style-type: none"> Lack of multidisciplinary collaboration with nursing homes.⁴¹ Lack of coordination or care registers leads to inappropriate hospital admissions at EOL and loss of medication or care preference details.^{6, 30} 	<ul style="list-style-type: none"> Hospices may act as organizational hubs within the community and recruit volunteers.⁶ Standard forms to communicate medication and care preferences.³⁰ Interdisciplinary teams.⁶⁴ A focus on communication, coordination and rapid needs-based assessments.³⁷ Formal clinical networks may aid integration of services.³⁷ Dynamic EOL care electronic registers.⁶
7. Resources	<ul style="list-style-type: none"> Lack of physical space in hospitals to have family visits/discussions.^{16, 32} Insufficient physical space in hospitals to die privately.³⁹ Insufficient time and resources to care for patients in nursing homes⁴⁴. Care home improvements are limited by time and available staff.⁶³ Staff have insufficient time to deliver effective EOL care in intensive care units.³² Taking time with a dying patient is not prioritized or supported in busy settings.³⁹ Shortage of hospice nurses and nurses experience fatigue in dealing with dying patients.³⁵ 	<ul style="list-style-type: none"> Trained volunteers can provide care in the community and effective palliative care.^{37, 65}
Micro-level (individual) factors		
8. Effective communication	<ul style="list-style-type: none"> Inadequate communication is the most significant barrier to good EOL care.¹⁷ Death is taboo and difficult to discuss.^{6, 22} Clinicians lack skills and confidence to tackle EOL discussions.⁶ 	<ul style="list-style-type: none"> EOL communication model or training.¹⁶ Case managers facilitate open communication between health care team and patient/family.¹⁷ Care pathways promote communication between patients, families and care teams.⁵ Clinicians are proactive in family communication: honest prognostic information, allow families to speak in discussions and provide private space for discussions.^{16, 48}
9. Staff experience and training	<ul style="list-style-type: none"> Barriers to training include time restraints, limited access to resources and limited computer skills.^{8, 17} Community clinicians may be unsure of procedures and 	<ul style="list-style-type: none"> Mandatory workforce training on services.⁶ Mandatory workforce training on communication skills.⁶ Iterative improvement by providing feedback.⁶

Component of quality EOL care	Barriers	Facilitators
	<ul style="list-style-type: none"> available services.⁶ • Staff lack education and experience in EOL discussions and care.^{6, 16, 18, 32, 63} • Nursing home staff resistance to change.⁴¹ • Nurses have insufficient knowledge and training about clinical decisions at EOL including clinician reluctance to prescribe high dose analgesia, lack of understanding around care goals, insufficient medication knowledge.³⁹ 	<ul style="list-style-type: none"> • Hospices are good sources of experience and can facilitate training for community or care home staff.⁶ • Specialized palliative care teams can deliver education for staff.¹⁶ • Care home staff are willing and keen to increase their knowledge for EOL care.⁶³
10. Emotional and spiritual support	<ul style="list-style-type: none"> • Patients worry about pain and control of physical and emotional symptoms.^{44, 50} • Patients may experience depression, anxiety, spiritual distress, family breakdown, financial strain and social stigma.^{44, 65} • Clinicians are not reimbursed for ‘talking’ with patients and listening to their thoughts and wishes.³⁸ 	<ul style="list-style-type: none"> • Remain as active as possible and continue to live while dying with a sense of meaning.^{16, 50} • Compassion, physical touch, maintaining hope, being positive, reassurance, interaction, honest communication, consultation services.^{17, 37, 50, 52} • Patients are prepared for death and have opportunity/support for a sense of resolution for important issues/relationships.^{38, 50} • Acknowledge emotional and social suffering.³⁸ • Mindful listening about thoughts and goals.³⁸
11. Personalized care (Patient and family involvement in decision-making)	<ul style="list-style-type: none"> • Unrealistic family expectations.³² • Conflicting family opinions.³² • Patients and caregivers lack knowledge about available services and how to access them.³⁷ • Lack of family participation in care planning.¹⁷ • Unrealistic expectations of death.¹⁷ • Family/patient denial of death.¹⁷ • Death is taboo and difficult to openly discuss.⁶ • Denial of death and difficulty in making decisions.³⁵ • Families may pressurize patients into accepting more aggressive forms of care.³⁵ 	<ul style="list-style-type: none"> • Treat individuals as unique and consider patient and family values in decision-making.^{50, 52} • Frequent discussions with patient/family.¹⁷ • A focus on pain management.¹⁷ • Compassionate care.¹⁷ • Clear, honest and direct information.³² • Patients want to be mentally alert but have sufficient pain relief and want reassurance about pain control.⁵⁰ • Death in location of choice with continuity of care.⁵⁰ • Nurse communication skills are central to how patients perceive their illness and care.³⁹ • EOL pathways can clarify care goals among patients, families and providers and enable decision-making.⁵ • ACP ensures patient or family wishes are considered before crisis decision-making is necessary.⁵⁰



Appendix Table 1: Medline search strategy for identifying initial international literature on end of life care

1	Terminal care/	22045
2	end of life.tw.	11739
3	exp advance directives/	6115
4	exp advance care planning/	7145
5	"Delivery of Health Care, Integrated"/lj, mt, og [Legislation & Jurisprudence, Methods, Organization & Administration]	5211
6	total quality management/	11968
7	**"quality of health care"/ or exp quality improvement/	37525
8	models, organizational/	15751
9	meta analysis.mp,pt.	81545
10	review.pt.	1962155
11	search.tw.	166124
12	9 or 10 or 11	2101121
13	1 or 2 or 3 or 4	32214
14	5 or 6 or 7 or 8	67384
15	12 and 13 and 14	186
16	limit 15 to english language	183
17	limit 16 to yr="2005 -Current"	107

Medline search strategy: June 2015

Appendix Table 2: Detailed findings and conclusions from international literature on end of life care

Author, year & title	Notes on report scope
Addicott 2009 † ¹ Delivering better care at end of life. The next steps.	Report from the Sir Roger Bannister Health Summit (2009). The summit aimed to keep EOL care at the centre of policy/practice and to ensure efforts to implement the EOL strategy were given focus and direction. The report sets out ten critical actions which those attending the summit felt were vital next steps in taking this work forward.
Al-Qurainy 2009† ² Dying in an acute hospital setting: the challenges and solutions	Literature review article. Challenges and solutions are discussed for death in an acute setting. The 12 main principles of a good death from 'Age Concern' are presented. A 5 step model for encouraging better communication with the dying is presented.
Carlson 2007† ³ Death in the nursing home: resident, family, and staff perspectives	Literature review on EOL care in the nursing home setting from resident, family and staff perspectives
Chan 2013* ⁴ End-of-life care pathways for improving outcomes in caring for the dying (review)	Systematic literature review of EOL care pathways (no studies met inclusion criteria).
Davies 2008† ⁵ Supporting quality improvement in care homes for older people: the contribution of primary care nurses	Examination of evidence on care needs and on how primary care and nursing care work in care home settings.
De Vleminck 2013† ⁶ Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review	Systematic review of studies on GPs opinions about GP characteristics, perceived patient characteristics and health care system characteristics in advanced care planning.
Durbin 2010† ⁷ Systematic review of educational interventions for improving advance directive completion	Systematic review including 12 randomised and 4 non-randomised studies assessing advance directives completed in adult clinic outpatients and hospitalized older people.
Dy 2008† ² A systematic Review of Satisfaction with Care at the End of Life	Systematic review including 21 qualitative studies, 4 systematic reviews and 8 additional intervention studies assessing satisfaction with care at EoL
Espinosa 2008† ⁸ Barriers to intensive care unit nurses providing terminal care: an integrated literature review	Integrated literature review of 22 studies relating to provision of terminal care in intensive care units.
Eues 2007† ⁹ End-of-life care: improving quality of life at the end of life	Focus on case managers in the community
Garcia-Perez 2009† ¹⁰ A systematic review of specialised palliative care for terminal patients: which model is better?	Systematic review of specialized palliative care models for terminal patients (provided by trained professionals)
Gomes 2013 * ¹¹	Systematic review of studies of home-based palliative care in adults with advanced illness

Author, year & title	Notes on report scope
Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregiver	
Howell 2005† ¹² Reaching Common Ground: a Patient-Family-Based Conceptual Framework of Quality EOL Care	Meta-synthesis of study data for understanding attributes of quality EOL care from the patient and family perspective
Kellehear 2013† ¹³ Compassionate communities: end-of-life care as everyone's responsibility	Policy and practice development in British EOL care
Kinley 2013† ¹⁴ The effect of policy on end-of-life care practice within nursing care homes: a systematic review	Systematic review on EOL care policy in nursing homes for the Gold Standards Framework in Care Homes (GSFCH), care pathways or other interventions to support care.
LaMantia 2010† ¹⁵ Interventions to improve transitional care between nursing homes and hospitals: a systematic review	Systematic review of interventions to improve communication about medication lists and advance directives for patients in transition between nursing homes and hospital
Leclerc 2014† ¹⁶ The effectiveness of interdisciplinary teams in end-of-life palliative care: a systematic review of comparative studies	Systematic review of 4 studies assessing interdisciplinary teams in palliative care
Lockett 2014† ¹⁷ Elements of effective palliative care models: a rapid review	A rapid review of evidence based models of palliative care to inform policy reform in Australia. Identified models of palliative care which were supported by evidence and policy documents and reports with applicability to Australia's health care system and federal/state funding structure from Organization for Economic Co-operation and Development (OECD) countries. The report focused on generalist and primary care providers of palliative services as well as specialist.
Luhrs 2007† ¹⁸ End-of-life care pathways	Summary of recent research about integrated care pathways (ICP) for EoL
Lund 2015† ¹⁹ Barriers to advance care planning at the end of life: An explanatory systematic review of implementation studies	Explanatory systematic review including 13 studies on barriers to advanced care planning.
Malespina 2007† ²⁰ Improving care of the dying: what do the experts say?	Article reviewing key points that experts at NIH conference said characterize the challenges associated with improving EOL care.
McConnell 2013† ²¹ Systematic realist review of key factors affecting the successful implementation and sustainability of the Liverpool care pathway for the dying patient	Factors influencing successful implementation of the Liverpool Care Pathway (LCP).
McCourt 2013† ²² General nurses' experiences of end-of-life care in the acute hospital	EOL care from general nurses in an acute hospital setting. Systematic review including 9 studies.

Author, year & title	Notes on report scope
setting: a literature review	
National Institutes of Health 2005† ²³ End-of-life care. National Institutes of Health statement on the state of the science.	Commentary on current research in EOL care, US focus.
OHTAC 2014‡ ²⁴ Health care for people approaching the end of life: an evidentiary framework	Ontario Health Technology Advisory Committee produced an evidence framework to focus on quality care in both inpatient and outpatient setting and focused on some key research questions, each assessed through an evidence-based analysis of effectiveness and advisory panel to aid contextualization of evidence.
Phillips 2011‡ ²⁵ End of life care pathways in an acute and hospice care: an integrative review	Literature review of 26 studies assessing EOL care pathways in the acute or hospice settings.
Rolland 2007† ²⁶ Nurses' attitudes about end-of-life referrals	Commentary on nurse attitudes in referring patients to EOL care services.
Roscoe 2006† ²⁷ Improving access to hospice and palliative care for patients near the end of life: present status and future direction	Narrative article covering issues around barriers for access to EOL hospice care
Shepperd 2011* ²⁸ Hospital at home: home-based end of life care	Systematic review including 4 studies examining care at home vs. hospital or hospice care.
Thomas 2014‡ ²⁹ Examining end of life case management: Systematic review	Systematic review including 17 studies on case management.
Treece 2007† ³⁰ Communication in the intensive care unit about the end of life	Overview/ opinion about communication issues about the EOL in the setting of intensive care
Waldrop 2012‡ ³¹ Communication and advanced care planning in palliative and end-of-life care	Focused literature review on advanced care planning in the US.
Wasserman 2008† ³² Respectful death: a model for end-of-life care	Opinion and summary description about the respectful death model.
Watts 2013† ³³ End-of-life care pathways and nursing: a literature review	Literature review on EOL care pathways in nursing
Wee 2013† ³⁴ Models of delivering palliative and end-of-life care in the UK	Narrative opinion about EOL care in the UK

* Cochrane literature search (n=3), † Medline search (n=22), ‡ Web search/hand-search (n=10).

Abbreviations: ACP, advanced care planning; AD, advanced directive; DNAR, do not attempt resuscitation; EOL, end-of-life; GP, general practitioner; GSFCH, Gold Standards Framework in Care Homes; ICU, intensive care unit; LCP, Liverpool care pathway; PCPD, patient care planning discussions; QOL, quality of life; UK, United Kingdom; US, United States.

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