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Article:

Khonsari, S., Johnston, B. orcid.org/0000-0003-4051-3436, Patterson, H. et al. (1 more author) (2024) Mechanisms of end-of-life communication contributing to optimal care at the end of life: a review of reviews. BMJ Supportive & Palliative Care, 14 (e2). e1622-e1634. ISSN 2045-435X

https://doi.org/10.1136/spcare-2024-004904

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This article has been accepted for publication in BMJSPCARE following peer review.
The definitive copyedited, typeset version is available online at
10.1136/spcare-2024-004904

Manuscript revised: 190324

BMJ Supportive & Palliative Care

Word Count: 6,000 words (Excludes: title page, abstract, tables, figures, acknowledgements, contributions and references)

Current word count: 5450

Abstract: 250 words

Tables/Figures: ≤ 8

References: ≤ 80

Title (should be short and informative; include at least 3 key phrases and 3 additional keywords with study design)

Mechanisms of end of life communication contributing to optimal care at the end of life: A review of reviews

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ABSTRACT (245 words)

Background: End-of-life communication is an essential component of high-quality care, but its potential mechanisms for improving care are not well understood.

Objectives: to summarise the potential mechanisms by which end-of-life communication may contribute to enhanced end-of-life care in any setting.

Design: An overview of systematic reviews, with a narrative synthesis of results. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines was followed. Study quality was assessed using the AMSTAR (A MeaSurement Tool to Assess Reviews) tool.

Data sources: CINAHL, MEDLINE, Cochrane, SSCI, and PsycINFO databases, were searched from inception to January 2024 . Manual searches were also conducted.

Eligibility criteria for selecting studies: Systematic reviews (published in English) related to end-of-life communication, where the target population were adult patients in their last year of life, relatives, caregivers, and/or healthcare professionals involved in communicating with dying patients.

Results: We reviewed 35 eligible studies. The reviews suggest potential mechanisms of effective end-of-life communication including collaborative decision-making, tailoring communication to individuals, using effective communication strategies, and incorporating communication skills into practice. The reviews also highlighted barriers related to patients, professionals, and organisations.

Conclusion: This review highlights a nuanced understanding of potential mechanisms of end-of-life communication, emphasising the need for tailored training, policy enhancements, and interprofessional collaboration. It calls on healthcare professionals to reflect on their practices, advocating for co-designing a person-centred communication model that addresses patient preferences at the end of life. Importantly, in culturally diverse contexts, there is a need for a communication paradigm that embraces diversity to provide truly empathetic and effective end-of-life care. This concise roadmap may foster compassionate, dignified, and effective end-of-life communication.

Registration number: Protocol registered with Prospero (CRD42022271433, 29/03/2022).

Keywords (min 5): end of life; communication; mechanisms; review; death; dying

COMPETING INTERESTS

None declared.

Please include the key messages of your article after your abstract using the following headings. This section should be no more than 3-5 sentences and should be distinct from the abstract; be succinct, specific and accurate.

What is already known on this topic – *summarise the state of scientific knowledge on this subject before you did your study and why this study needed to be done*

- Effective end-of-life communication enhances care quality and supports patients and families.
- Understanding the mechanisms of effective communication is crucial to inform healthcare professionals' practice and improve the quality of end-of-life care.

What this study adds – *summarise what we now know as a result of this study that we did not know before*

- This study offers valuable insights into the complexities of end-of-life communication and highlights potential mechanisms for effective communication at the end of life.
- The identification of persistent barriers emphasises the need to address and mitigate these obstacles to ensure effective communication.

How this study might affect research, practice or policy – *summarise the implications of this study*

- Understanding and implementing mechanisms of end-of-life communication can lead to more patient-centred care, as healthcare professionals can tailor their communication to individual needs and preferences.

A broad range of barriers may impact the end-of-life communication. However, the study findings can inform co-designing of communication models, ensuring that healthcare settings prioritise communication as an integral component of end-of-life care provision

.**FUNDING**

This work was part funded by a Scottish Government grant 2021/2022 and NHS Greater Glasgow and Clyde endowment grant.

COMPETING INTERESTS

None declared.

INTRODUCTION

The world's ageing population is leading to an increase in deaths globally (1). In the United Kingdom (UK), one in four people will be aged 65 or older by 2050, resulting in a growing demand for palliative care (2). Effective communication between healthcare professionals, patients and their families is essential for providing high-quality end-of-life care (3-5). Good end-of-life communication can promote a compassionate and dignified approach to care, improving overall quality of care and supporting patients and their families (3, 6, 7). However, communicating effectively can be challenging, and healthcare professionals may lack the necessary skills and confidence to deliver bad news and guide end-of-life decisions (8, 9). Notably, a significant number of complaints against healthcare professionals are related to communication issues, highlighting the extent to which patients feel their unique needs are being disregarded by healthcare providers (10-12). Without effective communication, patients' needs may go unaddressed, leading to delays in appropriate actions and reduced quality of life (13). A recent study analysing 692 patient and relative complaints revealed that communication problems occurred throughout the entire patient journey, from diagnosis to death (12). Patients reported not receiving adequate information, feeling unheard, and experiencing disrespect and impersonal treatment (12). This emphasises the critical role of communication, and underscores the need to prioritise it in order to achieve person-centred care.

Mechanisms of communication refer to the underlying processes, strategies, and factors that shape how healthcare professionals interact with patients and their families (14). These mechanisms encompass a wide range of positive elements including clarity, empathy, trust, and collaborative decision-making. In essence, mechanisms of communication encapsulate the 'how' and 'why' of successful end-of-life conversations. Understanding these mechanisms is essential to the development of training programmes for healthcare professionals, and can ultimately enhance the quality of end-of-life care (3, 15-17).

This review is part of an ongoing project in Scotland, which aims to identify the key concerns of dying patients and their families, and to make recommendations to enhance end-of-life communication and care experiences. Initial scoping indicated that several systematic reviews on the topic of end-of-life communication had already been conducted; however, these reviews cover various aspects of the phenomena, making it challenging for healthcare professionals and decision-makers to find and interpret the evidence. A need was established therefore, for an overview of systematic reviews (18). These are similar to traditional systematic reviews except that the units of analysis are systematic reviews rather than individual studies (19).

The specific aim of this overview was to synthesise the mechanisms of effective end-of-life communication. Our objectives were:

- To identify and summarise what is known in existing systematic reviews about the potential mechanisms by which communication may contribute to optimal end-of-life care; and
- To describe the overall quality of existing systematic reviews.

In addressing these objectives, it is hoped that this review can support healthcare professionals to reflect on their experience and develop strategies to enhance their interactions with patients and their families.

METHODS

METHODS

The methodology of this review was informed by the Joanna Briggs Institute's methodological guidance for conducting an overview of systematic reviews (20) and was reported according to the Preferred Reporting Items for Overviews of Reviews (PRIOR) statement (21) (see online supplementary). Given the volume of reviews that have previously explored the delivery of end-of-life care, an overview review of reviews was selected as the most appropriate methodology to synthesise this evidence base.

Research question

What is known about the potential mechanisms by which end-of-life communication may contribute to enhanced end-of-life care in any setting?

Eligibility criteria

Table 1 provides the inclusion and exclusion criteria for this review.

Table 1. Inclusion and exclusion criteria

	Inclusion	**Exclusion**
Type of sources	• Original review articles published in peer-reviewed journals with a clearly formulated question using systematic and explicit methods to identify, select and critically appraise relevant research. • Systematic reviews published in English language.	• Non-systematic scoping reviews, • Reviews with search strategies limited to one database, • Reviews where formal evidence appraisal was not undertaken, or data from individual studies, • Studies not focused on end-of-life communications, • Grey literature, opinion papers, letters, theses, dissertations, and abstracts in proceedings. • Systematic reviews published in other languages, with no English translation available
Types of participants	• Studies involving adults (age >18 years) in their last year of life, family carers of people who were in their last year of life or had died, regardless of their underlying disease, and health care professionals involved in	• Studies involving children and/or young people (end-of-life decision-making process in adults is likely to be qualitatively

	communicating with people who are dying.	different.)
Concept	- For the purposes of this review, the concept or intervention of interest, was defined as the mechanisms of communication OR conversation OR discussion OR information/education shared between health care staff and people who are dying and their families.	- No restrictions
Context	- Studies conducted in any setting (i.e., hospitals, community services, primary care, day care and hospice, residential aged care) that provides palliative and end-of-life care were included.	- No restrictions
Outcome	- The characteristics and mechanisms of communication about prognosis and end-of-life care between healthcare professionals and people approaching the end of life, and their families.	- No restrictions

Definition of terms

Table 2 provides the operational definitions of the terms in the context of our study.

Table 2. Operational definitions of the terms in the context of the study

	Operational definition
Palliative and end-of-life care	- The World Health Organisation (WHO) defines palliative care as an approach to improving the quality of life of people with a life-limiting illness and those close to them through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (22). According to the Scottish Partnership for Palliative Care (SPPC) (23), end of life care is a core part of palliative care which should follow from the diagnosis of someone entering the process of dying, whether or not they are already in receipt of palliative care. It tends to be provided by health and social care professionals to people living in any setting, in the community, in care homes and in hospitals and alongside other forms of specialist care, such as geriatric care (22, 23). - This review defines palliative and end-of-life care as taking place in a broad range of settings, comprising both generalist and specialist care provided in the home, in inpatient units, and in hospices. This

	ensures the full spectrum of care settings relevant to the provision of palliative and end-of-life care are captured.
Optimal end-of-life care	• Optimal end-of-life care is characterised by personalised and equitable care which is accessible to all regardless of their identity, geographical location, or circumstances. It is delivered by well-prepared, empathetic, skilled, and knowledgeable healthcare professionals. It focuses on maximising comfort and well-being through informed and timely conversations, by conducting regular care reviews, and by addressing physical, psychological, emotional, and spiritual needs while considering the individual's priorities, preferences, and wishes (22, 23). • It is important to acknowledge that the perception of optimal end-of-life care may vary between different guidelines and stakeholders, including health care professionals, patients, and their families. Therefore, this review incorporates the perspectives of these various groups.
Mechanisms of communication	• Mechanisms of communication are defined here as the specific processes, strategies, and techniques employed during communication interactions that contribute to effective and meaningful exchanges between health care professionals, people nearing the end of life, and their families. • These mechanisms encompass the various elements and actions involved in communication practices that can enhance end-of-life care and improve outcomes for individuals in their final stages of life.

Searching and identifying relevant articles

CINAHL, MEDLINE, Cochrane, SSCI (Social Sciences Citation Index), and PsycINFO were searched from inception to January 2024 for English-language systematic reviews related to end-of-life communication. Reference lists of included studies were also searched, and related articles or those which cited the included reviews were also checked for eligibility. This search strategy was developed with the assistance of an experienced librarian (PC) at the University of Glasgow (see Appendix 1 for search terms used). The initial searches were conducted in November 2021; and subsequently extended, to capture additional studies published up to 31st May 2023. PROSPERO, Cochrane library, and clinicaltrials.gov were all searched for in-process citations of registered reviews.

Screening and study selection

Two investigators (SK and BJ) removed duplicates and screened titles and abstracts. The first author (SK) and another member of the research team (HP) independently screened the full texts according to the predefined inclusion and exclusion criteria. Disagreements were resolved by consensus after discussion, with mediation available from a third reviewer.

Quality appraisal

Each review was appraised and rated by two investigators (SK and HP) independently using the AMSTAR-2 (A MeaSurement Tool to Assess systematic Reviews) (24). AMSTAR is based on the Cochrane Handbook for Systematic Reviews of Interventions, but has been adapted to ensure the correct methodology is followed in systematic reviews (24, 25). It is a concise checklist of necessary items for conducting high-quality reviews. AMSTAR-2 is an updated version of AMSTAR utilising a domain-based rating system, categorising items into seven critical domains and nine non-critical domains. AMSTAR-2 evaluates overall review quality of the reviews classified as high, moderate, low, or critically low, based on the presence of critical or non-critical flaws. It also introduces a stricter approach by requiring appraisers to provide only "yes" or "no" responses for each domain, eliminating the options for "not applicable" and "cannot answer” (25). Quality scores were not used to exclude reviews, but rather to illustrate the quality of the synthesised evidence.

Data extraction and synthesis

Data extraction tools were piloted alongside the initial search strategies. The final standardised data extraction tool was designed to capture the following information: author, year, country, design, aims, number of articles included and type of studies, setting, key findings and themes relevant to end-of-life communication (see Appendix 2). Two investigators (SK and HP) independently extracted data from the selected articles. All records were managed using EndNote and the selection process is documented in a PRISMA flow diagram (figure 1). Disagreements were resolved by consensus amongst authors.

In addition to aggregating and summarising the results of systematic reviews, extracted data were synthesised using a narrative approach. Extracted data were analysed thematically, following the principles outlined by Braun and Clarke (26) and using qualitative analysis software NVIVO 12. Codes were combined into categories, which were merged into major themes based on the research question, aim, and specific objectives. The analysis was guided by an iterative process of discussion and resolution of coding discrepancies between the team.

Other considerations: Protocol and registration

The protocol was pre-registered on PROSPERO (ID: CRD42022271433) in March 2022.

RESULTS

Figure 1 details the screening process. The database searches identified 1513 reports, of which 40 underwent full-text review and 29 were deemed eligible for inclusion. A further three systematic reviews were identified from hand searching, resulting in 32 eligible reviews included in this overview.

Description of the included systematic reviews

The main characteristics of the included reviews are summarised in the supplementary material (Appendix 2). The reviews were published between 2007 and 2024 and were undertaken in Singapore (27); Belgium (28); Canada (29); Switzerland (30); Denmark (31); Germany (32, 33);

Netherlands (16, 34); Italy (3, 35); China (36-38); Australia (5, 8, 39, 40); the United States of America (15, 41-47); and the United Kingdom (48-56). The reviews included studies published between 1982 and 2022. Out of 32 systematic reviews, the majority (n=26) included qualitative or mixed-methods studies; and only six (15, 29, 32, 40, 42, 44) included quantitative studies only. The quantitative reviews focussed on clinical end-of-life communication interventions (15, 29, 32, 40, 42, 44), but the majority were focused on healthcare professionals', patients', caregivers', and families' perspectives and experiences of end-of-life communication. Studies also covered a range of settings, including the home, hospital, hospice, primary care, and nursing homes.

Quality of reviews

Only one review was deemed high quality; the rest were either low or critically low due to not meeting one or more of the seven domains considered critical. Common reasons for poor quality included missing exclusion justification, absence of a registered protocol, and failure to report the sources of funding for the individual studies included in the review (Appendix 3).

End-of-life communication mechanisms

The thematic analysis resulted in six potential mechanisms through which end-of-life communication may contribute to the enhanced end-of-life care:

1. Facilitating collaborative decision-making
2. Tailoring communication to individuals
3. Employing evidence-based communication strategies
4. Organisational support for effective communication
5. Identifying and overcoming barriers to effective communication

Theme 1: Facilitating collaborative decision-making

All included reviews focussed on the importance of collaborative decision-making and its various dimensions.

Respect autonomy, wishes and preferences

Several reviews emphasised that shared decision-making between healthcare professionals, patients and families is an essential part of end-of-life communication (3,10,15,18,23-25,34,35). This approach empowers patients and families (15, 38) and reduces negative emotional effects for surrogate decision-makers (55). Healthcare professionals should be trained to listen to patients and families, clarify their values, and provide written plans to accompany verbal discussion (15, 39). Continual updates and availability of healthcare professionals for discussions may help resolve discrepancies and improve decision-making (3,8,18,48). A certain amount of planning for these discussions, including deciding who should be present, who should deliver the information, and the appropriate setting, may also be beneficial (37, 39). Clear documentation and a written advance directive improve the quality of dying and decrease fear at end of life (3). People who are dying should also have the option to be copied into all correspondence related to their care, to increase transparency and enhance trust in the healthcare system (34).

Family involvement and identifying roles

The importance of family involvement was also discussed. Involving patients and their families in decision-making is crucial in palliative and end-of-life care, with family members playing a significant role in making decisions (27, 47, 48). Family involvement can be facilitated by providing access to information, holding family meetings, building rapport, allowing patients and families to ask questions, and seeking emotional support (29, 30, 34).

According to Quinn et al. (57), there are eight informal roles for family members: primary caregiver, primary decision maker, family spokesperson, out-of-towner, patients’ wishes expert, protector, vulnerable member, and healthcare expert. Each of these roles may create a potentially complicated dynamic within the family system and between the family and healthcare domains (43, 57). Identifying family members' roles and allowing the patient to choose a preferred decision-maker are also important (3, 27, 39, 47, 48). Failure to recognise these roles can delay access to end-of-life care and reduce satisfaction (27).

Reaching consensus on decisions made, regular updates and future planning

Doctors and other healthcare professionals should present both curative and palliative options as an evolving plan (55), demonstrate risks and benefits of each option (46), and give families adequate time and control over treatment withdrawal (55). An information-seeking approach which involves seeking to understand each other's perspectives and concerns, increases the likelihood of coming to an agreement (41). When patients cannot express their preferences due to cognitive decline, involving relatives in the decision-making process and orienting them to patient wishes can facilitate better care and minimise anxiety for family carers (3, 15, 39). Regular updates can help families accept the need to transition to palliative care and avoid unnecessary treatments (3, 15).

Theme 2: Tailoring communication to individuals

The importance of tailored communication was highlighted in multiple reviews. End-of-life communication should be tailored to each patient's individual situation, including their current condition, level of understanding, desire for information, cultural and religious background, and life experiences (3, 10, 11, 13, 15, 23, 25, 27, 30-35, 38, 47, 48).

Cultural background

Acknowledging the patient's cultural preferences, values, and beliefs, and actively involving their family members in the decision-making process are essential to achieving cultural competency (38, 43). Cultural differences in the concept of autonomy and information seeking may hinder effective communication in some cultures, where patients may seek information and emotional support from close relatives or friends instead of healthcare professionals (27, 36, 38). To address this, a spokesperson should be identified for each family to ensure effective communication takes place at their level of understanding (8, 37, 55).

Timing and initiating

Effective end-of-life communication between healthcare professionals, patients, and families can be challenging, with patients often waiting for healthcare professionals to initiate conversations. Conversely, healthcare professionals may be waiting for cues from patients, leading to the "elephant in the room" phenomenon (31, 48). Healthcare professionals can plant the seeds of future (more challenging) conversations when patients' symptoms are well managed and allow them to have some control over the discussion (3, 31).

Timing is crucial, and conversations should be initiated at diagnosis or shortly after with early involvement from the palliative care team (3, 13, 23, 31, 48). According to Cripe et al. (46), early, intermediate, and final conversations are reasonably distinct; early conversations focus on treatment and expectations, intermediate conversations involve discussions about changes in disease and functional status, while the final conversation occurs at the point of transition to end-of-life care. Each stage requires adequate time to understand possible changes in care plans, and ongoing discussions should be tailored to meet individual needs and held at key turning points including physical decline or exacerbations (3, 15, 38, 46, 52).

Understanding and willingness to discuss dying

People may not be prepared to talk about dying. Patients’ understanding and willingness to discuss end-of-life issues need to be sensitively assessed by healthcare professionals through both questions and non-verbal cues (53, 55). Patients' attitudes towards such conversations and desiring more information associated with various factors, including younger age, higher education, longer life expectancy, trust in HCPs or healthcare systems, and strong faith (30, 31, 39, 44, 54).

Some may welcome these conversations, but many do not realise the life-limiting nature of their disease. Others do not wish to openly acknowledge their poor prognosis and engage in discussions about end-of-life issues (48-50). Therefore, it is crucial to ask patients about their preferences in advance and to remain flexible in case their preferences change (50, 53).

Theme 3: Employing evidence-based communication strategies

Using effective communication techniques tailored to patients and their families at the end of life is important in improving communication outcomes (14, 18, 25, 27-29, 32, 34, 35, 37).

Multi-disciplinary approach with clear documentation

Collaboration across various disciplines, including chaplaincy, social work, psychiatry, psychology, and palliative care, is crucial in addressing psychological and social issues during end-of-life care planning (41, 48, 49, 51, 53, 55). A multi-disciplinary team approach may help spread the burden of communication and create a culture which enables better end-of-life conversations (15). Assigning a key healthcare professional to each patient may improve communication and collaboration between specialist and non-specialist healthcare teams, ensuring effective documentation and circulation of information (34).

Deliberate language

Effective strategies for improving end-of-life communication include repetition, pacing, and staging to accommodate the relatives' information preferences (55). Healthcare professionals can encourage questions, summarise information, and use communication aids such as visual analogue scales to overcome difficulties related to intangible topics such as pain (39, 50, 53, 55). Pacing and staging involve breaking information into small units without jargon across multiple conversations, allowing adequate time for comprehension within each conversation (39, 55). Silences in conversations or using minimal vocal cues like "Mm" can encourage patients and families to engage in difficult conversations (52). Additionally, the importance of written plans can provide clarity and guidance in end-of-life discussions (3, 15, 39).

Simple, honest language is seen to be essential for promoting understanding of the patient's prognosis and engaging in collaborative decision-making (3, 40, 53, 55). The absence of honest communication can result in false hope and ambiguity (34), and may ultimately damage the perceptions of healthcare professionals by patients and their families (53, 55). Adopting a dual approach of continuing to provide acute care while acknowledging the likelihood of death and picking up cues that the patient would like to discuss their terminal condition is recommended (16, 28, 40, 48, 55). Practicing "Rainy day" thinking across teams is recommended; this can be described as ‘hoping for the best but preparing for the worst’ (48, 54).

Open and empathetic communication

Effective end-of-life conversations necessitate open and empathetic communication. This includes providing assurances that the patient will not be left alone, addressing any suffering, recognising nonverbal indicators of compassion, and offering supportive statements (37). Such conversations result in greater satisfaction among patients and families (29). Sensitively held discussions with multiple opportunities to talk and inquiring about emotions are crucial (25, 31). Physical connections, such as holding hands or sitting next to the patient, are also important in indicating caring (34). It is also essential to recognise emotional states, in order to deliver effective end-of-life care (29, 47).

Implementing evidence-base communication interventions

Several reviews noted the potentially positive effects of communication interventions. These interventions, if used earlier in a patient's care trajectory can reduce hospital days and care expenses, prevent conflicts between healthcare professionals and patients/families, and improve knowledge, attitudes, comfort, self-awareness, and preparedness for end-of-life care (18, 28, 29, 37, 43). These interventions target various stakeholders: healthcare professionals, patients, family/caregivers, and multiple other groups. Structured communication tools, evidence-based prognostic tools, and clinical event-triggered family meetings can improve communication around prognosis and empower patients and families to ask questions (25, 28, 29, 35). Psychoeducational interventions involving conversations around patient concerns, values, and care preferences with trained facilitators show promise in improving concordance between patients and caregivers (18, 43). System-based interventions, such as clarifying roles and responsibilities within the team for end-of-life communication, can also have positive outcomes (31, 45).

Theme 4: Organisational support for effective communication

Many of the included reviews highlighted the need for training and organisational support to facilitate better communication, as well as the negative effects of not doing so (3, 5, 8, 13-15, 18, 25, 28-30, 32, 36, 40, 43). Several of the included reviews highlighted that end-of-life communication is influenced by the unique circumstances and environment in which it occurs (27, 41, 53, 54, 56). Therefore, it is important to fully explore the factors that affect end-of-life communication, including organisational culture and available infrastructure.

Communication skills training and observation

Effective end-of-life communication requires healthcare professionals to be trained in various skills, including initiating discussions, managing emotions, collaborating with other disciplines, and addressing individual needs (32, 41). Practical training that combines theory, evidence, skills description, and observation is crucial (27, 44, 54-56). Role-playing with structured and constructive feedback on communication skills, with periodic booster sessions can help healthcare professionals handle difficult conversations and navigate topics such as delivering bad news, discussing treatment options, and initiating end-of-life discussions (15, 32, 41, 44). Exploring organisational barriers (44, 54, 56) and providing a supervised and supportive environment for learning from bereaved relatives may also contribute to better communication (27, 44, 49).

Reflective practice and self-awareness

Healthcare professionals have reported needing psychological support for end-of-life communication due to feeling overwhelmed by emotional and social issues (55, 56). To address this, interventions should consider facilitating reflective practice and self-awareness (41, 55), and should create opportunities for multidisciplinary healthcare professionals to develop skills in following the patient's agenda (53). Reflective practice has been highlighted as a valuable clinical tool to help normalise emotional experiences, and reduce an individual’s sense of failure when working with people at the end of life (56). Therefore, healthcare services and commissioners should allocate resources towards the investment in and promotion of reflective practice within their organisations (5, 55, 56).

Awareness and familiarity with policies and protocols

Stigma around palliative care, focusing on treatment, lack of protocol, tools and training impede healthcare professional’s communication with people at the end of life (54, 56). To promote early initiation of end-of-life discussions and individualised person-centred care, policies and protocols should be implemented, alongside fostering relationships with patients and families to facilitate effective end-of-life communication (27, 54, 56).

Cooperative and supportive environment

Effective end-of-life communication can be fostered by a supportive environment that encourages facilitative behaviour and skills. Conversely, conflict among staff can lead to blocking behaviours (27, 54), such as avoiding conversations, not actively listening, and dismissing concerns (27, 56). The cautiousness of healthcare professionals in their communication - often driven by the desire to maintain a positive perception of the hospital or healthcare institution - can further impede open dialogue (27). Additionally, the lack of management support for delivering holistic care poses a challenge to effective communication in end-of-life settings (54). To address these barriers, healthcare services should not only provide practical skills training but also prioritise the creation of a cooperative environment (31). This may be achieved by improving ward structures, promoting constructive reflection between senior and junior colleagues, and fostering effective communication strategies through mentorship (56). Sharing experiences encountered in end-of-life care, especially those modelled by senior colleagues, can significantly contribute to enhancing end-of-life communication and improving overall patient care (27, 56).

Theme 6: Identifying and overcoming barriers to effective communication

Effective end-of-life communication requires identifying and overcoming barriers arising from various factors (8, 27, 41, 48, 50, 51, 53, 54, 56) that are described below.

Lack of continuity

Patients with multiple comorbid conditions often receive care from multiple healthcare professionals, resulting in a lack of continuity in end-of-life discussions due to inadequate documentation and communication (50). Additionally, limited time and resources, especially in the community setting, hinder end-of-life conversations and transitions to palliative care (5, 30, 32, 41, 50, 53, 54). To overcome these barriers, healthcare services should allocate sufficient resources, provide private and comfortable spaces, remove time limitations, and enhance documentation and communication for better care continuity (5, 53, 54).

Physician-dominated and medically-focused conversation

Patient, family, or physician focus on medical issues hinders initiating end-of-life discussions (31). Physicians often prioritise medical aspects over discussing emotional issues and end-of-life care with patients, leading to a lack of understanding and disempowerment (11, 13, 25, 34). This can be attributed to their role as information givers rather than collaborators, resulting in a controlling communication style avoiding palliative care discussions (14, 25). Nurses also have a role in end-of-life discussions, but their involvement can be unclear, as they may describe themselves as "just listening" due to physicians controlling the conversation (31). Role clarification between nurses and physicians is crucial to ensure effective end-of-life discussions (45), and healthcare professionals should prioritise patient-raised issues and avoid assumptions about their communication needs (14, 25).

Limited application of shared decision-making

The reported styles of involvement can be categorised into two approaches: presenting or recommending what has already been decided by the medical team, or framing it as a collaborative process where the family ultimately makes the final decision (34). Healthcare professionals often present recommendations without consistently providing clear information about the reason for the decision (55). Additionally, end-of-life discussions are typically considered only when healthcare professionals believe all treatment options have been exhausted and life support should be withdrawn or withheld, indicating a lack of confidence in taking responsibility for the dying patient (3, 34, 36).

Prognostic uncertainty

Clinicians struggle with discussing uncertain prognoses and end-of-life issues, often waiting for cues from patients before initiating discussions. This can be due to various barriers including an unpredictable illness trajectory, relying on curative and technological interventions, lack of knowledge, fear of destroying hope, and multimorbidity (48, 54). Additionally, conflicts within the healthcare team regarding treatment options and prognosis can delay the provision of palliative care and leave patients and families unprepared for the dying process (36).

Attitudes to death and dying

Healthcare professionals in acute care settings often face challenges when discussing prognosis, death, and dying with patients (56). These conversations may be considered ‘taboo’ (50), resulting in delayed end-of-life discussions or the referral of patients to other healthcare providers (50, 54, 56). Healthcare professionals' self-efficacy in end-of-life care can be affected by a lack of support from senior colleagues, fear of criticism, and a sense of perceived failure (56). Such attitudes can cause anxiety in patients and families, while the perception that the role of healthcare professionals is solely to save lives rather than assist in end-of-life care hinders effective communication (13, 15, 36).

DISCUSSION AND CONCLUSION

Discussion

This overview of systematic reviews has highlighted several potential mechanisms that are essential for effective end-of-life communication, including fostering collaborative decision-making, promoting tailored discussions to individuals, employing effective communication strategies, integrating communication skills into practice, improving organisational culture and infrastructure and addressing barriers to effective communication. Understanding and incorporating these mechanisms can have direct clinical implications for healthcare professionals and may significantly improve the quality of care patients and their families receive. It may also enhance the overall experience during this challenging time. Figure 2 provides a logic model of the processes and actions involved in effective end-of-life communication.

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Most of the reviewed studies noted that initiating end-of-life conversations can be emotionally charged, underscoring the need for HCPs to receive guidance and training on conducting these sensitive discussions effectively. This review emphasises the importance of acknowledging the inherent difficulties and challenges associated with such conversations. Challenges may arise when there is a lack of clarity regarding the initiation and maintenance of these dialogues, managing family dynamics, or ensuring the alignment of care with patients' wishes and preferences.

At the end of life, decisions regarding treatment, pain management, and care goals become pivotal. According to the reviews, patients and their families have indicated a need for clear information at all stages of the disease process about the illness itself, prognosis and symptom management, and for information that will aid decision making about clinical treatment options. Facilitating collaborative decision-making as shown by this review involves actively involving patients and their families in these decisions. This process ensures that healthcare choices align with the patient's values and preferences. It necessitates open dialogue, mutual respect, and shared understanding among the healthcare team, patients, and their families.

Every patient and family is unique, with diverse backgrounds, beliefs, and needs. These differences need to be recognised and communication styles should be adjusted accordingly. However, it is not possible to make assumptions about individuals' needs based on their demographic characteristics or cultural background. This review indicated that HCPs should clarify patient and caregiver needs individually and tailor the communication accordingly, recognising that each person's needs are likely to vary at different time points through the course of an illness. In addition, information may need to be repeated on different occasions to meet patients' and families' needs. As found in several reviews included in this study (8, 27, 30, 36-38, 53, 55), by taking into account cultural, linguistic, and emotional factors, HCPs can ensure that their communication is sensitive and relevant to the person they are caring for. Although, few reviews discounted such data (28), these factors are potentially influencing end-of-life care, and could also be considered in any communication skills training or team discussions (36, 54).

Effective communication is underpinned by evidence-based techniques and strategies that research has shown to be effective in improving end-of-life conversations (48, 52, 54, 57). This review underscores that these strategies often encompass active listening, empathy, utilisation of both verbal and non-verbal cues, and employing techniques for delivering difficult news with compassion and clarity. As indicated by multiple reviews included in this study, both patients and their families have a preference for receiving information in small chunks, free from jargon. They appreciate a HCPs they can trust, one who communicates empathetically, compassionately, and truthfully, while maintaining a balance of sensitivity and hope. HCPs should also foster an environment where questions are encouraged and regularly assess the patient's or family member's understanding. Furthermore, it is evident that some level of planning can enhance these conversations. This may include discussions about who should participate, the person responsible for conveying the information, the scope and depth of information to be shared, as well as selecting the most appropriate time and setting.

Effective communication should not be a standalone skill but an integral part of clinical practice. Integrating communication skills into practice ensures that HCPs use these skills consistently. This integration may involve regular training, continuous education, and practical application in real clinical scenarios as shown by the included reviews in this study. Healthcare organisations should also invest in improving their infrastructure to support effective end-of-life communication (5).

The culture within healthcare organisations significantly influences end-of-life care, which is a recurring theme throughout the reviewed literature. A culture that prioritises patient-centred care, compassionate communication, and staff well-being fosters enhanced end-of-life care. It also supports HCPs in their efforts to communicate effectively and make the patient's needs and preferences a top priority.

This review highlights the critical importance of addressing significant challenges in effective end-of-life communication. Barriers to effective communication in end-of-life care include HCPs' discomfort with the topic, uncertainty, fear of causing distress, or lack of time. Identifying and overcoming these barriers is essential. It involves acknowledging these obstacles and finding solutions, fostering cohesive healthcare teams and promoting conflict resolution strategies, and implementing strategies to ensure that communication remains open, compassionate, and effective (45). In addition, the reviewed studies recommend board level commitment with associated policies and protocols related to end-of-life care and a national level cultural shift to initiate conversation about death and dying (54). The availability and implementation of relevant policies and processes can facilitate early initiation of end-of-life communication and promote dynamic advance care planning (3, 46, 48, 52, 54).

Limitations

The review is constrained by the quality and the methodological weaknesses of the systematic reviews included. We limited our search to studies published in English; therefore, it is possible that we missed studies published in other languages.

Many of the studies lacked details about the justification for their inclusion/exclusion criteria used, which raises further questions about the reliability of their systematic approach and results. The setting in which many of the studies were conducted may also influence their results. The majority were conducted in high income countries and mainly within acute hospitals and health care settings that may affect the generalisability of findings in terms of political, religious, and cultural differences.

Finally, the pursuit of identified mechanisms for effective end-of-life communication can unintentionally place pressure and burden for the dying patient and their relatives, leading to a sense of failure in providing a meaningful end-of-life experience (17). Therefore, it is recommended that these mechanisms should not be followed rigidly as scripts, but instead be adjusted based on the specific situation at hand (37). Despite the risks and precautions involved, understanding effective communication mechanisms in end-of-life situations was even more crucial during the COVID-19 pandemic, as it presented new opportunities to reflect, discuss, and improve the quality of end-of-life care and dying.

Conclusion

Collaborative decision-making, considering individuals' cultural differences, knowledge of patient's preferences, using effective communication interventions and strategies as well as highlighting and addressing patient, professional and organisational-related barriers contribute to enhanced end-of-life care and communication. Implementing the principles of effective end-of-life communication requires a collaborative and patient-centred approach that emphasises ongoing communication, multidisciplinary and collaborative care, and a supportive organisational culture. By putting these principles into practice, we can ensure that patients receive care that is aligned with their goals and preferences, and that their families feel supported and informed within the uncertainty of experiencing a trajectory of advanced illness.

Practice Implications

The clinical implications of this review underscore the importance of HCPs in optimising positive and effective end-of-life communication experiences for patients and families. Initiating early and ongoing end-of-life communication is essential for guiding patients and their families in discussing and reflecting on their end-of-life care wishes and preferences. Delaying these conversations can hinder patients' ability to express their preferences and impede families' understanding and active involvement in decision-making. Effective communication, shared decision-making and documenting preferences are crucial for ensuring care consistency and establishing partnerships with patients and families.

Although it may be challenging and require a significant investment of time and resources, HCPs should prioritise promoting patients' and families' understanding of the future and what to expect before death through structured and timely conversations. To facilitate effective communication, it is crucial to invest in HCP training and communication interventions. Overcoming barriers to effective communication necessitates a coordinated, multi-disciplinary approach that takes into account factors such as organisational culture, training access, and societal reluctance to discuss death and dying.

In expanding our findings, it is crucial to note that the digital dimension of end-of-life communication is often overlooked in the included studies, especially in today's technology era. Despite identifying six key mechanisms for effective communication, the aspect of managing digital legacies is seldom addressed. In the age of technology, discussions around digital assets are as vital as those concerning physical assets. This oversight presents a gap in patient-centred care. Our review emphasises the need to integrate conversations about digital legacies into end-of-life care, requiring increased awareness and, potentially, additional training for HCPs. Recognising and addressing this dimension ensures a more holistic approach, fostering compassionate and effective end-of-life communication.

Understanding the mechanisms of end-of-life communication can inform initiatives to enhance the quality of end-of-life care. There are a number of important next steps in the process of improving end-of-life care and communication. This would include further work to explore views of care at end of life from the perspective of key stakeholders (i.e. patients, their families, and HCPs) to validate the present review findings. Specifically, new strategies, such as patients and families feedback tools should be examined in future research to enhance the quality of end-of-life communication and person-centred end-of-life care. Furthermore, the findings of this review can contribute to informing the co-design of a person-centred end-of-life communication model targeted toward meeting the needs of patients, while also ensuring that HCPs are empowered and supported to deliver responsive care.

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Authors contribution statement

Contributors BJ was responsible for the overall conception and design of this study. SK helped with design, performed the searches and evaluated studies for inclusion. SK extracted data from selected studies. BJ and SK assessed the quality of selected studies. BJ, CM, SK and HP reviewed the work. BJ and SK drafted the paper. BK, SK, CM and HP revised the manuscript critically for important intellectual content BK, SK, CM and HP approved of the version of the manuscript to be published.