

Communication in palliative care: talking about the end of life, before the end of life

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ABSTRACT

Increasing evidence demonstrates the benefits of early end-of-life care discussions with patients with life-threatening illness and their families. However, these conversations often do not occur. This review explores some of the many barriers faced by clinicians in relation to end-of-life care discussions, including prognostic uncertainty, fear of causing distress, navigating patient readiness and feeling unprepared for these conversations. The value of core clinical communication skills, potential strategies for improvement and areas for future research are also discussed. It is essential that clinicians offer patients facing life-threatening illness, and those close to them, the opportunity to discuss end-of-life issues in line with their information and decision-making preferences. With a growing and ageing global population, supporting both generalist and specialist providers of palliative care in this task is key. With careful preparation, fears of undertaking these discussions should not be a barrier to initiating them.

INTRODUCTION

Palliative care aims to improve the quality of life of patients with life-threatening illness and their families.¹ Although palliative care is applicable and valuable throughout the disease trajectory,^{2–5} some of the most challenging discussions in palliative care are regarding end-of-life issues. This can include talking about prognosis, preferences and priorities (eg, life-prolonging and/or palliative treatments, place of care, place of death), as well as hopes and fears regarding dying and death—a process often formally referred to as anticipatory or advance care planning (ACP). In the context of a growing and ageing global population, the demands for palliative care services cannot be met by specialists alone.^{6–8} Therefore, the responsibility of communicating about end-of-life care with individuals with life-threatening illness, and those close to them, will increasingly fall to generalist, as well as specialist, providers of palliative care.

The importance of communication in healthcare has long been recognised within medical education as a foundation of good care,^{9–10} and reports continue to highlight the need for open and honest discussions with patients, and those close to them, at critical times.^{11–12} Despite this, 60%–90% of patients with life-threatening illness report never having discussed end-of-life care issues with their clinician.^{13–15} This review aims to summarise the evidence regarding the importance of timely end-of-life care discussions, explore barriers faced by clinicians and highlight key findings and recommendations for practice.

WHY ARE END-OF-LIFE CARE DISCUSSIONS SO IMPORTANT?

The benefits

There is strong evidence of the benefits of end-of-life care communication with patients with life-threatening illness and their families. Discussing a greater number of end-of-life care topics increases the likelihood of concordance between patient-reported goals of care and the goals documented within their medical records, and increases patient satisfaction with care.¹⁶ Indeed, in a recent US study of patients with chronic obstructive pulmonary disease (COPD), those who reported having end-of-life care discussions were twice as likely to rate the quality of their care as the 'best imaginable'.¹³ Furthermore, end-of-life care discussions also influence subsequent treatment decisions: a recent prospective study of over 1000 US patients with cancer found that end-of-life care discussions prior to the last 30 days of life were significantly associated with fewer aggressive medical interventions.¹⁷ Although aggressive medical interventions may be appropriate for, and preferred by, some individuals, patients' quality of life and relatives' bereavement adjustment are reported as significantly better when patients receive fewer aggressive medical treatments towards the end of life.¹⁴ Findings across each of these studies are consistent with a recent systematic review of the impact of ACP on end-of-life care, which, across over 100 studies, found evidence of a positive impact in the form of reduced hospitalisations, increased use of hospice and palliative care services, decreased use of life-sustaining treatments and better compliance with patients' wishes.¹⁸

Sooner, rather than later

In addition to the benefits of having discussions about end-of-life care issues, research has also demonstrated the importance of initiating such conversations sooner, rather than later. In a recent Canadian study,¹⁹ physicians, residents and nurses reported that one of the top five barriers to 'goals of care discussions' was patients' lack of capacity. In line with this report, a recent review of the medical records of outpatients with cancer in the USA demonstrated that while 79% of patients were deemed to have capacity when admitted to hospital, 40% of these individuals lost capacity before an end-of-life care discussion could take place.²⁰ Patients who lost capacity, and therefore had surrogate decision-makers, were significantly more likely to receive more aggressive life-sustaining treatments than those who took part in their own end-of-life care discussions. The impact of early discussions can also extend to those close to patients prior to death, and into bereavement. In a recent US



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qualitative study, family members stated that timely end-of-life care discussions enabled them to make the most of the time they had with the patient, and make use of hospice and palliative care services sooner.²¹ In addition, having such conversations before the patient becomes too unwell can be crucial in allowing relatives to prepare for death while also maintaining hope.²² It has been recommended that critical events such as diagnosis, perceptions of a change in condition (eg, patient with COPD experiencing more frequent exacerbations), presentation of unrealistic expectations (eg, patient with heart failure seeing treatments as curative), discussions about treatment complications or decisions (eg, poor response to anticancer treatment) or referral to palliative care may all act as prompts to start end-of-life discussions.²³ This is not a prescriptive or exhaustive list, but may highlight useful prompts for healthcare practitioners to provide opportunities for discussion.

WHY DO CLINICIANS FIND THESE DISCUSSIONS SO DIFFICULT?

Despite strong arguments for opening and expediting end-of-life care discussions, for many people living with a life-threatening illness, these conversations still do not occur: fewer than 40% of patients with cancer,¹⁴ 15% of patients with COPD¹³ and 10% of patients with chronic kidney disease¹⁵ report having discussions about end-of-life care issues with their clinician. Often patients and relatives will wait for the topic to be raised by their clinician,²⁴ while clinicians rely on patients and relatives to start the conversation—aptly captured in the paper by Almack and colleagues, titled ‘After You’.^{25 26} Consequently, this can result in a perpetual cycle of non-discussion. This cycle is fuelled by multiple barriers, including (but not limited to) prognostic uncertainty, fear of the impact on patients, navigating patient readiness and feeling inadequately trained for, or unaccustomed to, such discussions.^{19 25–30}

Prognostic uncertainty

Uncertainty regarding disease trajectory and prognosis has frequently been cited by clinicians as a cause for avoiding end-of-life care discussions, particularly for non-malignant life-threatening illnesses.²⁶ As a result, these patient groups are significantly less likely to experience ACP discussions.³¹ This was recently explored in a study in Belgium,²⁷ where general practitioners described their difficulty with recognising the ‘terminal stage’ or a ‘key moment’ in the illness trajectory for people with dementia and heart failure, in order to prompt ACP discussions. Similarly, in a recent study of Dutch patients with organ failure, approximately 70% had not experienced complete discussions about end-of-life care.³² While uncertainty regarding disease trajectory and prognosis may obscure the ‘best time’ for an end-of-life discussion, it is this very uncertainty which makes provision of opportunities for early discussion so important. Patients and relatives may not choose to take up these opportunities: patients with organ failure, for example, can be particularly reluctant to contemplate death and dying.³³ However, providing opportunities for discussion, for example, when an illness-related change occurs (see above), is crucial. Although discussions were infrequent in Houben’s study of patients with organ failure,³² when they did occur they were rated well for quality (scoring 6–8 out of 10), suggesting anticipation regarding the discussion should not be a reason to avoid one.

Fear of causing distress

Another perceived barrier that inhibits discussion initiation by healthcare providers is concern about the potential impact of

end-of-life care discussions on patients and those close to them. Research has shown that many clinicians continue to avoid these discussions due to a fear of destroying hope or causing harm.^{25 26 30} Indeed, maintaining hope has been identified as extremely important to patients and relatives.³⁴ However, hope is not necessarily incompatible with knowledge of life-threatening disease or prognosis, and can mean more than simply survival.³⁵ A recent review of the literature found that patients can maintain hope while also acknowledging their terminal prognoses, whether they continue to hope: for a cure; to live longer than expected; to enjoy a good quality of life; to achieve personal goals or to have a peaceful death.³⁴ Furthermore, a recent study of Japanese family members found that 73% were able to both maintain hope and prepare for the patient’s death.²² With regard to causing harm, evidence suggests that end-of-life care discussions are not associated with poorer psychological patient outcomes,¹⁴ and that the majority of terminally ill patients and their relatives do not find talking about death, dying and bereavement stressful.³⁶

Navigating patient readiness

While offering these conversations is unlikely to cause harm, this is not to say that all patients will be ready or willing to take part. Although the majority of patients do want to receive information about end-of-life care, the timing of this information is critical—when they are ready, and not before.^{35 37 38} As a result, many patients, at some time, will be reluctant to talk about end-of-life care, and it may be particularly difficult for healthcare providers to assess the appropriate time. However, patients have acknowledged the difficulty clinicians may face here, and suggest that asking about readiness directly may be an effective strategy.³⁵ Similarly, it can be advisable to enquire about the preferences of patients and relatives regarding level of information and involvement in decisions. Professionals are very poor at estimating these preferences,^{39 40} however, exploring them with patients can increase satisfaction, improve confidence among clinicians and is not associated with heightened distress for the patients.⁴¹ Preferences for the type and amount of information, as well as involvement in decisions, should therefore form part of early interactions with patients and families. This is not a case for simply checking the ‘end-of-life care conversation’ box; it is about providing and signposting clear *opportunities* for patients and relatives to discuss their preferences and concerns, including chances for them to be revisited and changed.³⁸ Presenting these opportunities and subsequent decisions as flexible and amenable to change is valued by patients with life-threatening illness and their relatives.⁴² So long as opportunities are provided, recipients of care can guide discussions according to their readiness and preferences.

Feeling unprepared

Despite the apparent benefits of providing opportunities for these conversations, many professionals continue to feel unprepared for, or unaccustomed to, discussions about end-of-life care, and unsure about the linguistic and stylistic features preferred by patients and relatives.^{26 43 44} Indeed, the literature exploring these areas can appear contradictory and difficult to follow. Research suggests that information must be honest, while maintaining hope,^{21 34 38 45} but not so much hope that it gives unrealistic expectations.^{21 34} Information should be delivered in a way that shows empathy, but not pity,⁴⁵ in a manner that is candid but not blunt.^{21 35 46} With regard to terminology, research has suggested that explicit phrasing can lead to distress for some family members, while for others more figurative or

indirect phrasing can lead to miscommunication.⁴⁷ While these are important considerations to be cognisant of in preparing for end-of-life care discussions, we argue that of equal importance are the core, non-specialist, communication qualities that continue to be cited by patients and relatives as crucial to achieving positive communication experiences. Overwhelmingly, and unsurprisingly, patients desire to be treated as individuals, according to their preferences,^{35 38 46} by clinicians that are able to show compassion.^{21 46} They want to be listened to,⁴² build relationships with their clinicians³⁸ and receive holistic care^{34 35} in an appropriate environment with opportunities for privacy.³⁵ These undoubtedly reflect the core competencies of clinical communication across all disciplines (medicine, nursing and allied health) rather than specialist skills specific to palliative care.

WHAT CAN WE DO TO IMPROVE END-OF-LIFE CARE COMMUNICATION?

Training

Due to the varied nature of perceived barriers, there is unlikely to be a 'one-size-fits-all' solution to helping clinicians open, and facilitate, conversations about end-of-life care topics. Communication skills guidelines and strategies for structuring these conversations may be one source of support, with examples including the Australian PREPARED guidelines²³ and the British SAGE & THYME model.^{48 49} Both are formed of evidence-based components, which, when used as a whole, have been found to improve clinicians' confidence with end-of-life care conversations.^{48 50} If the concern is more regarding knowledge of palliative and end-of-life care, rather than confidence in communication skills, more general education programmes have again been successful in improving clinicians' knowledge of this field.^{51–53}

Normalising: embedding end-of-life discussion into your practice

Training and education, of course, is not the answer to all concerns about end-of-life care communication. It has been suggested that normalising end-of-life discussions could also help encourage such conversations.^{54 55} One novel intervention by Allen *et al*⁵⁶ combined education and training of US internal medicine residents with alterations in clinic workflow. This included medical assistants asking all patients aged over 65 about their ACPs, and preferences for discussing them, prior to appointments, providing them with written materials and alerting the physician if a patient opted to have an ACP discussion. This increased the confidence of residents undertaking these discussions, and, of those patients who did not have an existing advance care plan; 74% opted to open a discussion that day or at a follow-up appointment. Similarly, a randomised controlled study implementing a question prompt list for consecutive patients with advanced cancer increased discussion of end-of-life issues.⁵⁷ These successes are in line with the suggestion of Walczak *et al*⁵⁸ that multifaceted interventions may be more effective than training alone. Such efforts to normalise end-of-life discussions by embedding them within routine practice, in combination with training and support for clinicians, may help them occur sooner and more frequently.

Further research

As in the study of Allen *et al*⁵⁶ above, there is a growing body of research demonstrating the success of interventions in improving clinicians' knowledge^{59 60} and confidence,^{60–62} as well as in modifying their behaviours.^{63–65} However, with the

evidence that end-of-life care discussions are positively associated with patient satisfaction and quality of life, and relatives' bereavement adjustment,^{13 14 16–18} it also seems reasonable to expect training interventions to influence these outcomes. Yet, despite these observed relationships, there are far fewer studies demonstrating the impact of communication-focused interventions on patients' and relatives' experiences and outcomes.⁶⁶ One commonly cited explanation for this is inappropriate measurement tools that lack sensitivity to change.^{67 68} This is problematic, as without confidence in the measures used to assess intervention effectiveness, including responsiveness to change,⁶⁹ we cannot discern whether lack of effect is associated with inadequate training or inappropriate outcomes. A second explanation frequently encountered for a lack of change is ceiling effects—where high baseline scores make improvements difficult to obtain. Ceiling effects have been found in a number of interventions, including some aiming to improve patient perceptions of clinicians' empathy and communication skills,⁶⁸ and ratings of therapeutic alliance⁶⁵ and satisfaction.^{61 70} These high baseline scores raise questions as to whether intervention studies are targeting the most appropriate settings, or recruiting healthcare providers and/or patients in ways that introduce bias (eg, including those more willing to talk about end-of-life care at baseline). This would compromise our ability to assess an intervention's effectiveness. In future, more in-depth exploration of what makes 'good' end-of-life care communication, using techniques such as discourse analysis^{71 72} or cognitive interviewing,^{42 73} would be recommended to refine choice and design of outcomes. In addition, targeting interventions at clinicians or settings most in need of support may make subsequent findings more meaningful.

SUMMARY

Communication about end-of-life care issues, in line with patients' and relatives' readiness and preferences, is essential. This task increasingly will become the responsibility of generalists as well as specialist palliative care providers, and therefore supporting clinicians with this important responsibility should be a priority for practitioners, researchers and policy makers. Although there are potential barriers to opening end-of-life care discussions, it is important to recognise that many of the qualities most valued by patients and relatives are the core, non-specialist communication skills relevant in all fields of medicine—sensitivity and empathy, within holistic, individualised care. It is therefore important not to let the specific sensitivities of palliative care discussions, as highlighted in the literature, deter clinicians from providing these all important opportunities.

Main messages

- ▶ Despite evidence supporting benefits of timely communication about end-of-life care, for many patients, these discussions do not occur.
- ▶ Clinicians face multiple barriers to these discussions, including prognostic uncertainty, fearing a negative psychological impact, navigating patient readiness and feeling inadequately trained.
- ▶ However, clinicians have the responsibility (and the core skills required) to offer opportunities for discussion throughout the trajectory of life-threatening illness, in order to empower patients and improve the care experience.

Sources of support have been developed, and work within this field is ongoing. However, a better understanding of how we define and measure good communication in end-of-life care is essential for future progress.

Current research questions

- ▶ How can we best support clinicians to offer opportunities for end-of-life care discussions?
- ▶ Why do interventions show such variable impact on patient and family reported outcomes?
- ▶ How do we measure 'good' communication in this context?

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Self assessment questions

Please answer true (T) or false (F) to the below.

1. In one study, of patients entering hospital with capacity, over one-third lost capacity before an end-of-life care discussions occurred.
2. Patients with non-malignant conditions are more likely to report having discussions about end-of-life care.
3. Evidence demonstrates significant psychological harm caused by end-of-life care conversations.
4. Patients with life-threatening illness can simultaneously maintain hope and acknowledge their terminal prognosis.
5. Many of the communication skills valued by patients and relatives in end-of-life care discussions are non-specialist skills.

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Answers

1. (T); 2. (F); 3. (F); 4. (T); 5. (T)