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Communication in life-limiting illness: A practical guide for physicians

Challenging but essential patient-physician conversations about advance care planning, goals of care, and final days of life can help dying patients receive the best care possible.

ABSTRACT: Communicating with patients and families affected by life-limiting illness is challenging. Evidence supports using thoughtful and deliberate communication approaches that balance hope and reality in a caring and honest way. Clinical resources for everyday practice are available and include information about advance care planning, goals-of-care discussions, and support for patients and families in the final days of life. Physician-patient conversations will vary with the cultural, personal, and disease diversity encountered across clinical practice. What matters most is that these conversations occur and are not avoided.

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Communication, an essential part of all clinical practice, involves particular challenges and rewards when patients are facing life-limiting illness. These interactions are not usually restricted to the doctor-patient relationship but occur in the context of family relationships and diverse cultural and spiritual perspectives.[1] There is well-established evidence that effective communication can result in positive clinical outcomes. Patients with advanced cancer who had end-of-life discussions with their physician were less likely to receive chemotherapy in the last 2 weeks of life, had lower rates of ventilation, resuscitation, and intensive care use, and overall improved quality of life.[2,3] Importantly, such discussions were not associated with higher rates of depression or anxiety in patients.[3] Early discussion of end-of-life wishes and values of hospitalized older adults led to improvements in anxiety and depression scores of bereaved family members following the patient's death when compared with the scores of relatives who did not have such discussions.[4] Furthermore, lack of discussion related to end-of-life care has been shown to result in higher health care costs in the final week of life and a worse quality of death associated with such expenditures.[5]

Communication clearly has value for the care of the patient and family as well as for the stewardship of medical resources. All clinicians must develop an informed approach to communication with patients with life-limiting illness and consider this skill as essential as taking a history, performing a procedure, or prescribing a drug. Three of the most challenging conversations involve advance care planning (ACP), goals of care, and the final days of life.

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Advance care planning

Advance care planning began as the process of documenting patient treatment preferences and designating a substitute decision-maker to act should the patient become incapable. While these are still integral components of advance care planning, a broader understanding of ACP has emerged as a process of engaging in conversations related to wishes, values, goals, fears, and hopes of the patient and family.[6] The intent is to begin such discourse well before acute illness occurs so that care appropriate to the individual's preferences can be discerned throughout the illness trajectory.

Many clinicians have expressed concern that initiating conversations too early in the illness trajectory might lead to increased patient distress and a sense of impending discontinuation of life-prolonging therapies.[7] In opposition to this view, a study found that avoiding end-of-life conversations in an effort to maintain hope was actually viewed as unacceptable by patients[8] and substitute decision-makers.[9] Patients and caregivers have identified physician discomfort with such conversations as being a barrier to having them,[6] and patients generally expect their physician to initiate ACP discussions.[10]

First implemented in the care of patients with incurable malignant disease, advance care planning is applicable to all patients regardless of diagnosis or prognosis. While the general goals of ACP discussions remain similar across diagnoses, the specificity of conversation will vary with the disease and its severity. Training programs for ACP discussions recognize that for healthy individuals, ACP may be limited to designating a substitute decision-maker and a general discussion of life values.[11] It can be challenging to make decisions for possible medical situations ahead of the actual event. For example, a patient may consider artificial nutrition acceptable as an intervention to facilitate recovery from acute illness but not for indefinite use, especially if the patient is in a dependent, noncommunicative state. The most effective information for future decision making outlines what brings value and meaning to living for the patient rather than what might be wanted in a range of hypothetical clinical scenarios. If specific complications and interventions become more likely as the disease progresses, then the advance care plan can be changed to give appropriate directions.

It is important for the physician to initiate an advance care planning discussion by introducing the topic and normalizing the conversation as one necessary to have with all patients. It is also important to determine what the patient understands about his or her individual health currently, as this will affect how the conversation unfolds and establish whether the patient has discussed this understanding or hopes for future care with anyone. In some cases, the initial doctor-patient ACP conversation will be the first time a patient has considered the need for a substitute decision-maker, and it is most helpful for the substitute decision-maker to be present for subsequent conversations. Even when the initial ACP discussion addresses only a few introductory questions, it provides an opportunity to offer further resources for the patient to review before a follow-up meeting. ACP conversations ideally occur early in the illness trajectory in the outpatient setting, but may be initiated in a hospital or care facility. Sample questions for initiating and continuing ACP discussions[12,13] are outlined in **Table 1**.

Avoiding end-of-life conversations in an effort to maintain hope was actually viewed as unacceptable by patients and substitute decision-makers.

In British Columbia, the *My Voice* workbook provides a framework for approaching ACP discussions.[14] The workbook begins by asking the patient to think about beliefs, values, and wishes for future health care and then proceeds to help the patient document these in the form of a representation agreement, an advance directive, and an enduring power-of-attorney agreement. It is important to record ACP conversations in the patient chart and to obtain a copy of any documents completed by the patient for future reference. Many patients, and occasionally some legal professionals and physicians, are not aware of the difference between appointing someone

Table 1. Questions for advance care planning conversations with patients.[12,13]

Introduce the topic	"One thing I like to do with all my patients is to discuss advance care planning. Do you know what this means?" "Is this something you would feel comfortable discussing today?" "Is there someone you would like to be present with you for these conversations?" "What do you understand about your illness or what's happening to you?"
Assess prior knowledge	"Do you have an advance care plan? Do you know what I mean by this?" "Have you done any of the following: written a living will, appointed a health care representative, completed an advance directive?"
Identify substitute decision-maker (if no plan prior to review)	"If decisions about your care needed to be made in the future and you were unable to speak for yourself, whom would you want me to ask about your care?"
Explore prior conversations	"Have you talked to your substitute decision-maker, family, or other health care providers about your wishes or preferences for health care that may come up (e.g., resuscitation)? May I ask what you discussed?" "Could a loved one correctly describe how you would like to be treated in the case of a terminal illness?"
Understand values	"What is important to you as you think about this topic?" "Where do you fall on a scale with the following endpoints?" 1 = Let me die without medical intervention, except for control of pain and symptoms. 5 = Do not give up on me no matter what; try any proven or unproven intervention possible.
Determine end-of-life care preferences	"If you could choose, would you prefer to die at home, in hospice, in residential care, or in hospital?"

in a power-of-attorney agreement to make financial decisions and naming a substitute decision-maker in a representation agreement to make medical decisions. It is important to clarify this distinction.

In addition to the *My Voice* workbook designed for use in British Columbia, other resources and interactive tools for patients are available through the Speak Up program.[12]An additional resource for patients is the Engage with Grace tool, which poses five questions to encourage further conversation.[13]

Goals of care

For patients with advanced illness, whether their primary diagnosis is progressive organ dysfunction, motor neuron disease, cancer, or some other life-limiting disorder, there comes a time in the illness trajectory when a discussion of goals of care becomes essential to providing patient-focused care. Goals of care is a vague term that should not be considered synonymous with code status, although this is anecdotally often the case. While advance care planning is intended to be done well ahead of any need for medical decision making, goals-of-care discussions occur during the course of illness. Many goals-of-care discussions will include considering whether it is time to shift from a disease-modifying therapy to a palliative care approach that minimizes or rationalizes medical interventions to focus on therapies likely to increase patient comfort and improve quality of life.

There are significant barriers to goals-of-care discussions, including patient and family factors, physician discomfort in initiating the conversation, and systemic pressures and dynamics. This last barrier can involve ambiguity or uncertainty regarding who is the most responsible clinician.[10,15] Evidence can guide when and how these discussions occur. With respect to timing, it can help to answer the so-called surprise question: "Would you be surprised if this patient died in the next 6 to 12 months?" A response of "no" indicates the time is likely right for a goals-of-care discussion.[16] In general, patients with a progressive disease, decreasing function, or an acute episode necessitating hospital admission or changes in treatment are those who would benefit from a focused goals-of-care discussion.

Goals of care may be established between a clinician and patient at the bedside, on admission to hospital, iteratively over multiple outpatient visits, or at a more structured family meeting after hospital admission. Family meetings are common and are thought to improve communication, bereavement outcomes, length of stay, and resource utilization.[17]

In a goals-of-care discussion physicians will often explain the medical context of the treatments being offered, what the risks and benefits are, and guide patients and families to explore patient expectations in terms of prognosis and level of function.

The following outlines one approach to a goals-of-care discussion.

1. Find out how much information the patient and family wish to have. Give the patient and family permission to ask questions and explore their understanding of the patient's disease and future.

- "Please ask for clarification or more detail if you like, or let me know if you're hearing more detail than you feel you need."
- "Before we talk in detail, it would help me to know what you understand about your illness."
- "Can you tell me your understanding of your medical situation right now?"
- "What do you expect your health will look like in the future?"

2. Summarize the medical situation. Know the patient's medical history well enough to summarize it without reading off the chart and refer back to the chart only for details when needed (e.g., size of lesions, lab values, medication doses).

- Maintain eye contact with the patient and any family present to get a sense of understanding.
- Use simple language and define medical terms if used. For example, "Your creatinine is high, meaning that your kidneys aren't working well."
- Check understanding along the way. For example, "Does that make sense?"

3. Ask questions regarding values and preferences. Find out what is important to the patient at this time (e.g., place of care; burden of treatment that is acceptable; important upcoming milestones; tasks, hobbies, pastimes, and occupational, family, or social engagements that are important to maintain).[10]

- "If your health situation worsens, what are your most important goals?"
- "What are your biggest fears and worries about the future with your health?"
- "What abilities are so critical to your life that you can't imagine living without them?"
- "If you become sicker, how much are you willing to go through for the possibility of gaining more time?"

4. Incorporate values and preferences information into recommendations for a treatment plan and present possible options. This may include shifting the focus of care to symptom management rather than active treatment of the underlying disease. Use discretion when discussing plans that are not true options (e.g., patient might want to go home, but given your diagnosis and the patient's function this is not an option).

5. Discuss options and your recommendation. This may occur either after sitting in silence during the meeting or after allowing hours or days to pass so that the patient and family can digest the information and confirm a plan.

6. Check understanding. Summarize information heard from the patient and family and clarify what changes, if any, will be made directly after the meeting or when you will confirm a care plan.

Keep in mind that the process is a dynamic one and the order of steps outlined above can vary. Whatever the order, the steps in a goals-of-care discussion should focus on the patient rather than clinical values: the patient's quality of life, important upcoming milestones, and perception of wellness are more important than vital signs, laboratory values, or findings on imaging. Undoubtedly, the questions described above involve assessment that is not a standard part of medical history taking; physicians are not accustomed to asking about a patient's values, and these may take several conversations to elicit fully.

When a goals-of-care discussion is successful, a collaborative plan emerges, grounded in the clinician's medical knowledge and guided by the patient's priorities. Some conversations can evoke significant emotion and lead to conflict. A patient and family may request futile interventions, refuse to discuss unwanted outcomes, or become angry and blaming. In these situations, tools may be needed to help clinicians break bad news, display empathy, and conduct effective family meetings. Physicians should remind themselves to use open body language and appropriate eye contact,[18] respond to emotional cues,[19] and check understanding of patients and family members.[20] Many physicians are familiar with the SPIKES model,[20] which was designed to help deliver bad news to cancer patients and can be used in a variety of health contexts.[21] Another evidence-based approach used by experienced clinicians is the VALUE model,[22] which is more appropriate for goals-of-care discussions because it focuses on gathering information from the patient and family rather than on relaying information:

- **V**alue and appreciate what the family said.
- **A**cknowledge emotions.
- **L**isten.
- **U**nderstand: ask questions that allow one to know the patient as a person.
- **E**licit questions from the family.

While many goals-of-care discussions clarify the types of interventions to be initiated for patients, others address the possibility of withdrawing life-sustaining therapies. The perceived moral difference

between withholding and withdrawing therapies can vary among cultures, regions, and individuals. However, in the Canadian setting, the ethical and legal equivalence of withholding and withdrawing interventions is well established.[23] It is always important to help families differentiate between the decision to withhold or withdraw therapies from euthanasia/physician-assisted suicide as these are ethically distinct acts. For example, a physician might need to explain that withdrawing or not escalating use of a therapy does not hasten the dying process but instead avoids extending life artificially and allows for a natural death.

Overall, empathetic, direct, and honest responses to questions and exploration of questions, fears, and emotions will help find common ground. Goals-of-care discussions take time and effort, but are worthwhile because they lead to improved quality of care and clearer, shorter, and more collaborative discussions and decisions as the patient's condition and needs change further.[10]

Final days of life

Supporting a patient and family members through the final days of the patient's life can be daunting, particularly if this is not a common occurrence in your clinical practice. It can be difficult to diagnose dying because of ongoing hope that the patient will get better, because of mixed information about the overall status of the patient, and because of failure to recognize signs and symptoms of imminent death.[24] Even when clinicians accurately identify the dying process and families and patients are accepting of this, addressing questions and concerns from patients and family members can be difficult. Common questions relate to issues of hunger and thirst at end of life, prognosis, signs of imminent death, the ability of unresponsive patients to sense their surroundings, and how family members can support a minimally responsive or unresponsive patient. In general, it helps to encourage family members to be present as they are able, and to observe any end-of-life spiritual traditions important to the patient. As well, you can help by going over natural changes in breathing, intake, and alertness at the end of life as outlined in **Table 2**.

A handout about imminent death for family members is a useful resource available in many institutions (e.g., "As Death Approaches"[25] from the Vancouver Island Health Authority). Such resources can remind clinicians about important topics to discuss, and allow family members to review information later when they feel less overwhelmed.

Table 2. Common family concerns and information physicians can provide in final days of life.

Level of alertness	Alertness is less at the end of life, although brief periods of lucidity/energy can occur. Patients may be able to hear and feel touch when unresponsive, and informing family members of this can help them be present with the patient.
Oral intake	Patients usually do not feel hunger or thirst and oral intake is significantly reduced. Patient indication of hunger or thirst should guide intake.
Changes in breathing	Irregular breathing with apneic pauses may indicate a prognosis of hours rather than days. Wet breath sounds can occur and are unlikely to be uncomfortable, but may be reduced with repositioning or decreasing the production of saliva and phlegm with medication (e.g., scopolamine, glycopyrrolate).
Circulation	Peripheral pulses decrease and hands and feet may become mottled and cool.
Bowel and bladder function	Patients are often incontinent and insertion of an indwelling urinary catheter may be appropriate.
Agitation and confusion	Patients often settle with reassurance from family and care providers and in response to a calm environment. Ongoing agitation may be reduced with medication (e.g., methotrimeprazine, midazolam).

Conclusions

Communicating with patients and families facing life-limiting illness involves challenges. In conversations about advance care planning, goals of care, and final days of life, clinicians are faced with the delicate task of balancing hope and reality in a caring and honest way. These discussions also require us, as clinicians and individuals, to confront our own understanding and experience of death and dying, which can be inherently discomforting. How such conversations occur will vary with the cultural, personal, and disease diversity encountered across clinical practice. Of greatest importance is that these conversations do occur and are not avoided. In talking to our patients, we will come to know them better and help them receive care in a way that most respects who they are.

Competing interests
None declared.

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