

Advance Care Planning and End-Of-Life Communications: Practical Tips for Oncology Advanced Practitioners

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Abstract

Advance care planning discussions ensure patients' values and goals of care, including the freedom to choose their place of death, are respected. The benefits of advance care planning and early end-of-life care discussions are often delayed, as these discussions are not initiated early in patients' cancer trajectories. As a result, patients' wishes often remain unknown until the last phase of their life. Evidence suggests that many patients inappropriately receive aggressive treatment near the end of life, which leads to higher resource utilization, decreased quality of life, and increased cost. The purpose of this article is to provide practical tips to the oncology advanced practitioner on initiating advance care planning and end-of-life care discussions with patients and their families or caregivers.

The 2014 Institute of Medicine report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, identified an urgent need for improvement in health care at the end of life. To improve care at the end of life, providers and patients must engage sooner in conversations to explore patients' understanding of their disease status, treatment preferences, and goals of care through shared decision-making (Lum, Sudore, & Bekelman, 2015; Sinuff et al., 2015).

Advance care planning (ACP) is a patient-centered, voluntary, and ongoing process of communication

among patients, family members, caregivers, and health-care professionals to understand, review, and plan for future health-care decisions. Advance care planning promotes shared decision-making in accordance with patients' values and preferences for medical care. It includes the selection of a surrogate decision maker before a medical crisis or the loss of a patient's decision-making capacity through advance directive (AD) documents (Sinuff et al., 2015; Sumanilog et al., 2017). An AD comprises a medical power of attorney (surrogate decision maker), living will (articulates the patient's wishes for cardiopulmonary resuscitation,

mechanical ventilation, tube feedings, and dialysis at the end of life), and out-of-hospital do not resuscitate (OOH DNR) documents (Carr & Luth, 2016). The goal of ACP is to help patients receive medical care that is aligned with their preferences (Lum & Sudore, 2016).

BENEFITS OF AND BARRIERS TO ACP AND END-OF-LIFE DISCUSSIONS

The benefits of having ACP discussions include increased patient autonomy, reduced unwanted and unnecessary treatments, and reduced length and number of hospitalizations (Klingler, in der Schmitzen, & Marckmann, 2015). In addition, lower rates of ventilation, resuscitation, and intensive care unit admission have been reported, as well as increased use of palliative care with early hospice enrollment and decreased cost of care at the end of life (Bestvina & Polite, 2017). There is also less decisional conflict among surrogate decision makers (Chiarchiaro, Buddadhumaruk, Arnold, & White, 2015), and the place of death can be based on the patient's preference towards the end of life (Khan, Gomes, & Higginson, 2014).

Barriers to ACP include a lack of time, discomfort with difficult discussions, and fear of affecting patients' hope and emotional coping (Chander et al., 2017; Odejide et al., 2016). Granek, Krzyzanoska, Tozer, and Mazzotta (2013) explored oncologists' views on end-of-life communications and revealed various physician-related barriers to ACP and end-of-life communications, including personal discomfort with death and dying, reluctance to communicate painful information, perception of other physicians' failure, focusing too much on a cure or treatment, along with a lack of experience with communicating end-of-life news and lack of mentorship in modeling communication strategies about end of life.

PROVIDER COMMUNICATION

The ability to communicate well is important for quality patient care and has been associated with higher patient satisfaction, better patient outcomes, less patient anxiety, better adherence to treatments, and better care at the end of life (Granek et al., 2013). Studies focused on enhancing communication skills have demonstrated an increase in discussions between patients and providers (Holland

et al., 2017). Wittenberg and colleagues (2020) conducted a 2-day educational program called COMFORT Communication for Oncology Nurses, a train-the-trainer program funded by the National Cancer Institute to improve patient-centered communication in cancer care. The curriculum consisted of seven modules addressing palliative care communication. The course was presented to 269 nurses from 34 states and Washington, D.C. These nurses further taught an additional 9,720 oncology providers (physicians, nurses, social workers, and chaplains) and initiated palliative care communication training at their respective institutions. A post-course survey at 12 months revealed that the course participants had implemented institution-wide system changes and communication skill-building programs, and on average, each nurse had trained 37 other health-care providers.

APPROACHES AND INTERVENTIONS TO PREPARE PATIENTS AND FAMILIES

Literature shows various interventions for patients and families to assist in ACP discussions, including use of values and goals questions through a vignette technique, educational pamphlets, website training, and video education on CPR with or without narratives. Table 1 includes resources for patients on preparing for ACP discussions. Another intervention consisted of preparing the staff and providers through face-to-face education, a vignette technique, and support through the electronic medical records/communication support program (Epstein, Shuk, O'Reilly, Gary, & Volandes, 2015; Hoverman et al., 2017; Michael et al., 2016; Stein et al., 2013; Sudore et al., 2017; Volandes et al., 2013).

Walczak and colleagues (2017) conducted a randomized controlled trial of a nurse-facilitated communication support program for advanced cancer patients to assist them in discussing prognosis and end-of-life care. They found a positive result in patients' readiness to address questions to their physicians regarding their disease status.

STRATEGIES FOR EFFECTIVE ACP AND END-OF-LIFE COMMUNICATION

The key concepts of advance care planning include (1) assessing patient and family readiness

Table 1. Patient Resources for Preparing for Advance Care Planning

Resource	Description	Link
PREPARE	An ACP website with videos that focus on preparing patients for communication and decision-making. This website creates a tailored summary of patients' values and preferences that can be used to initiate the conversation with the clinician.	https://www.prepareforyourcare.org
ACP Decisions	Presents ACP videos describing how overall goals of care, CPR, and mechanical ventilation can influence patients' and surrogates' preferences for end-of-life care.	http://www.acpdecisions.org
The Conversation Project	Provides a written toolkit with values-based questions to help individuals start ACP conversations.	http://theconversationproject.org
The GO WISH card game	A set of cards that describes potential quality-of-life values and may facilitate conversations among older adults with cognitive impairment.	http://www.gowish.org

Note. ACP = advance care planning.

for these important discussions and identifying the barriers, (2) identifying a surrogate decision maker (medical power of attorney), (3) exploring patient and family understanding of the disease status and treatment options, (4) discussing the values, goals of care, and options for end-of-life care, (5) documenting patient preferences in the medical record, and (6) revisiting the discussions at every change in treatment plan and/or change in clinical status, including at every hospitalization (Lum & Sudore, 2015).

Bernacki and Block (2014) conducted a narrative review of evidence about ACP and end-of-life communication and provided a systematic approach for clinicians (Table 2).

Effective communication includes both verbal and nonverbal strategies (Table 3). Nonverbal communication skills are the first step in building a relationship with patients and families, followed by verbal communication to develop a common understanding and encourage a positive dialogue (Wasylynuk & Davison, 2016a, 2016b).

DISCUSSION AND IMPLICATION FOR PRACTICE

The 2014 Institute of Medicine report emphasized that the lack of ACP and end-of-life discussions is due to patients/family and clinicians waiting for each other to initiate these discussions. Oncology clinicians include physicians and advanced practitioners (nurse practitioners and physician assistants). Advanced practitioners are integral members of the oncology team and contribute

greatly to oncology care by providing a diversity of services to cancer patients, from a new patient visit to follow-up care for symptoms and toxicity management, diagnosing various acute conditions, prescribing, first assists in surgery and procedures, as well as genetic counseling (Bruinooge et al., 2018).

Although there have been no published articles to date that have compared outcomes of ACP discussions if led by a physician compared with an advanced practitioner (Bestvina & Polite, 2017), the results of a study conducted by Goswami, Mistrick, and Barber (2020) demonstrated that ACP discussions by the advanced practitioner were associated with an increased AD completion and also a change in the code status of advanced cancer patients. There was a significant difference in ACP rates of admitted patients (15% vs. 100%, $p < .001$), total ADs completed (5% vs. 65%, $p < .001$), either AD or code status changes (20% vs. 85%, $p < .001$), and medical power of attorney (5% vs. 65%, $p < .001$). In the outpatient setting, ACP rates differed (0% vs. 100%, $p < .001$), as well as number of total ADs completed (0% vs. 40%, $p < .001$) and OOH DNR orders (0% vs. 10%, $p < .192$). There was also an additional positive outcome as shown by an increase in hospice enrollment of admitted patients (15% [3/20] vs. 40% [8/20]). As a result, at preintervention only one patient out of eight died in an inpatient hospice, and at postintervention it was noted that two of four patients died at home in the home hospice and the other two died during hospitalization with comfort care in place.

Table 2. Strategies to Systemize ACP and End-of-Life Communication

Intervention	Description
Train clinicians	<ul style="list-style-type: none"> • Communication skills training
Identify patients at risk	<ul style="list-style-type: none"> • Patients with progressive disease • Patients with no next of kin or who live alone
Trigger communication in the outpatient setting before a crisis	<ul style="list-style-type: none"> • Develop as criteria with appropriate timing <ul style="list-style-type: none"> » Disease progression » Treatment change » Toxicity from treatment » Increased symptom burden • Schedule separate visit
Educate patients and families	<ul style="list-style-type: none"> • Initiate discussion before decisions are required • Provide appropriate information about prognosis based on information preferences • Focus on goals and values about care • Encourage discussion of non-medical goals • Encourage families and patients to reflect on and clarify their wishes through discussion on an ongoing basis
Use checklist conversation guide	<ul style="list-style-type: none"> • Understanding: What is your understanding about your illness? • Information preferences: How much information would you like from me about your illness? • Prognosis: Share prognosis tailored to information preferences • Goals: What are your most important goals if your health situation worsens? • Fears/worries: What are your biggest fears and worries about the future with your health? • Function: What abilities are so critical to your life that you can't imagine living without them? • Trade-offs: If you become sicker, how much are you willing to go through for the possibility of gaining more time? • Family: How much does your family know about your priorities and wishes?
Improve communication of critical information in the EMR	<ul style="list-style-type: none"> • Designate a site in EMR for a "single source of truth" for recording and retrieving of patients' values, goals and preferences of care as well as other key information • Health-care proxy • Medical order for life-sustaining treatments • Code status
Measure and report performance	<ul style="list-style-type: none"> • Develop appropriate performance standards

Note. EMR = electronic medical record. Information from Bernacki & Block (2014).

Patients can be scheduled for ACP discussions as an independent visit, which can result in shared decision-making, enhanced patient understanding of their rights, and ultimately allow for care options that reflect their values and goals. Advance care planning discussions can be billed as a separate visit, and patients can be scheduled for such discussions (Centers for Medicare and Medicaid Services, 2018; Sonenberg & Sepulveda-Pacsi, 2018). Advanced practitioners can adopt strategies and tips on ACP and end-of-life communications to develop confidence in initiating these discussions.

SUMMARY

Advance care planning and end-of-life discussions are important for patients, families, and health-care providers. Adopting communication

strategies can help overcome the barriers to effective communication on these difficult discussions. There is a need to explore patients' values and goals of care. Advance care planning with goals-of-care discussions should not be delayed until the patient is hospitalized.

There are various interventions to prepare patients and families for ACP and end-of-life communications, strategies to overcome barriers for oncology health-care providers, and practical tips to initiate these difficult conversations. These conversations ultimately enhance cancer patients' understanding of their illness, treatment options, goals of care, and finally prepare them for their end-of-life care based on their preferences. Advanced practitioners are an integral part of the oncology team and also serve as patient advocates. Hence, they can learn skills

Table 3. Nonverbal and Verbal Communication Strategies*Nonverbal strategies*

- Create an appropriate environment to help the patient feel safe and comfortable.
 - » Ensure privacy.
 - » Prevent interruptions (silence call notifications, electronic devices, television, etc.).
 - » Ensure adequate time.
 - » Remove physical barriers (e.g., tables, chairs) between you and the patient.
- Maintain a relaxed and non-hurried, open posture, paying undivided attention and conveying a sense of respect for personal space.
 - » Sit down and face the patient at eye level. Place your hands on your lap or on the arms of the chair.
 - » Do not fidget or multitask.
- Make appropriate eye contact. This denotes emotional connection and helps patients engage. Watch for cues indicating a patient is uncomfortable with eye contact (e.g., gazing away).
- Observe the patient's level of comfort.
 - » Address any discomfort, such as pain or anxiety.
- Use appropriate touch: Gently touch arms, hands, or shoulders, as it demonstrates empathy.
 - » Watch for cues that a patient is uncomfortable with touch.
 - » If a patient starts crying, move closer to them, offer a tissue, and if they are comfortable with touch and closeness, gently touch them.
- Practice active listening.
 - » Lean in towards the patient.
 - » Nod.
 - » Say "hm" or "uh-huh."
- Listen without interrupting. This allows the patient to respond at their pace.
 - » Be comfortable with silence.

Verbal strategies

- Speak slowly and clearly using simple, everyday language. This helps the patient to understand and digest what is being said.
 - » Use short words and sentences.
 - » Use a friendly and comforting tone.
 - » Use the patient's preferred language (with language translator).
- Speak honestly and in a straightforward manner. Patients value open and honest communication.
- Avoid medical jargon, as it may cause confusion.
- Avoid saying "if" or "but," as it may cause fear and confusion.
- Pause often. This helps the patient to reflect on what is being said, ask questions, or make comments.
- Use open-ended questions. This elicits responses that are often descriptive and elaborative, allowing better understanding and providing opportunities from which to draw further questions.
- Respond to emotions by verbalizing empathy. This conveys respect and compassion.
 - » "I can't imagine how difficult that must have been for you and your family."
 - » "I admire your willpower to fight this."
- Explore the meaning of ambiguous words and phrases.
 - » In response to "I don't want to be a vegetable," ask, "What does being a vegetable mean to you?"
 - » In response to "I want to die with dignity," ask, "What does dying with dignity look like to you?"
- Use screening questions. This allows the patient to add additional information before the next question.
 - » "Is there something else you are afraid of?"
- Paraphrase what you have heard. This shows that you were listening and provides the patient an opportunity to clarify any misunderstanding and/or provide further information.
- Check for understanding. This ensures that the patient understands what has been said.
 - » "Now that you've heard about the responsibilities of a surrogate decision maker, who would you like to trust in this role to make decisions for you if you are unable to yourself?"
 - » "I understand that you do not want to be like a vegetable. Do you mean a do not resuscitate order?"
- Summarize the conversation to ensure a mutual understanding of what has been discussed.
 - » "Now that you understand your disease status, am I correct in understanding that your goal for treatment is...?"
 - » "As you mentioned, your goal is to be comfortable and to be able to go home. Would you like me to get our palliative team on board to help you with managing your pain and symptoms?"
 - » "Would you like to discuss this with anyone else in your family before you make final decisions and advance directives?"

Note. Adopted from Kalowes (2015); Moore & Reynolds (2013); Wasylnuk & Davidson (2016a, 2016b).

such as nonverbal and verbal communication strategies to build their confidence in initiating ACP and end-of-life discussion with cancer patients and their families. ●

Disclosure

The author has no conflicts of interest to disclose.

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