
CLINICAL UPDATE: COMMUNICATION ISSUES AND ADVANCE CARE PLANNING

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OBJECTIVES: *To provide a clinical update on practical strategies to enhance the quality of communication in the palliative and end-of-life medical care settings.*

DATA SOURCES: *Published articles, textbooks, reports, and clinical experience.*

CONCLUSION: *The components of effective and compassionate care throughout the advanced illness trajectory require thoughtful and strategic communication with patients, families, and members of the health care team. Unfortunately, few health care professionals are formally trained in communication skills.*

IMPLICATIONS FOR NURSING PRACTICE: *Nurses who possess self-awareness and are skilled in effective communication practices are integral to the provision of high-quality palliative care for patients and families coping with advanced malignancies.*

KEY WORDS: *Communication skills, palliative care, self-awareness, advance care planning discussion*

SINCE the publication of the original article in 2005, the literature on communication issues among family members, medical professionals, and patients with life-limiting illnesses has grown and evolved. None-

theless, it remains true that high-quality care for patients at the end of life can be promoted when health care providers: 1) ensure desired physical comfort and emotional support; 2) promote shared decision-making; 3) treat the dying person with respect; 4) provide information and emotional support to family members; and 5) coordinate care across settings.¹ To implement these components of effective and compassionate care, health care professionals must be able to successfully communicate with patients, family members, and other health care team members. Unfortunately, few professionals are formally trained in communication skills.² The professional literature is replete with examples of clinicians' communication difficulties, including studies that show how suboptimal communication practices can

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negatively affect patient care and the patient and family's ability to cope with the demands of advanced illness.³⁻⁶

The challenges to effectual communication among health care professionals, families, and patients throughout the advanced illness disease trajectory are many and can include: medical professionals' fears about causing psychological harm⁷ or diminishing patient and family hope when communicating bad news,⁸⁻¹⁰ medicine's denial of death and dying, overuse of medical jargon by providers,¹¹⁻¹³ professionals' fear of being blamed for poor outcomes,⁸ and providers' own difficult personal and professional experiences with dying and death, which impacts their willingness to confront such issues with patients and families.⁵ Family members and patients also bring their own issues to clinical encounters that can negatively affect the quality of communication, including their previous experiences with and expectations about the health care system,¹³ medicine in general, illness, death, and the patient or caregiver role. Depending on patient and family background, communication may be further challenged by beliefs that the provider is an expert and should not be questioned or challenged. They may fear offending the provider by asking too many questions or be reticent to take up extra time when others are waiting.¹⁴ Clearly, this can be a challenging communication context for nurses who work with those coping with advanced malignancies. This article seeks to provide practical strategies to enhance communication quality in the palliative and end-of-life care settings. Topics include specific communication skills that can be incorporated into one's practice with patients and families who are confronted with end-of-life issues, the centrality of the professional-patient relationship in effective communication, the importance of provider introspection and self-awareness as relationship-building tools, and tactics to initiate and sustain advance care planning discussions with patients and families.

COMMUNICATION SKILLS IN PALLIATIVE CARE

Palliative care is an interdisciplinary approach to medical treatment with the goals of improving quality of life and relieving suffering for patients with chronic and advanced illnesses. As a patient-centered approach, palliative care teams seek to holistically address patient and family

concerns and needs, from biomedical to spiritual matters.¹⁵ Pain and symptom control are central to palliative care, but research that represents the voices of patients indicates that emotional and spiritual support are also integral components of effective palliative care.^{9,16-18} To meaningfully address the critical physical, emotional, practical, and spiritual domains of palliative care,¹⁹ health care professionals need to communicate clearly and supportively with patients, families, and other health care providers. Communication can be considered the primary medium of care delivery,²⁰ and is a process between two or more people born out of a relationship. Relationship problems, including a lack of trust and a diminished sense of rapport, can inherently impact the quality and content of communication.^{4,5,13,21}

It has been suggested that the manner in which information is presented to patients and families is equally or possibly more important than the content of what is said.²² One recent study revealed that the therapeutic alliance was a predictor of patients' quality of life at the end of life.²³ Therefore, it is important for nurses to engage in the efforts necessary to promote strong working relationships with patients and families. This can be accomplished by employing basic interpersonal skills, including good attending behavior, open-ended questions, and active listening skills.⁴ Equally important is the provision of a setting that provides the context for optimal communication to support patients' sense that they are being listened to and cared about. This includes an appropriate environment (eg, private, comfortable), allocation of enough time to process information and emotions, and inclusion of the patient's identified support system.²⁴ This becomes even more important when patients and families must process bad, sad, or disappointing news, and the professional's full attention on the exchange is necessary.

Providing one's undivided attention through nonverbal channels, such as directly facing the patient, being at eye level, and avoiding distractions sends the message that what the patient is conveying is important and that the nurse is truly listening.²⁵ Professionals must often multitask during patient visits to maximize efficiency because of the time constraints present in medical settings. One may review a medical chart at the beginning of the visit while the patient is talking or transcribe information into a computerized

record as the patient discusses symptoms. The nurse may indeed be listening, but the patient may not perceive it that way. Nurses can develop strategies to minimize the negative impact of such activities, such as reviewing the medical chart before sitting down with the patient, and explaining to the patient the necessity of recording information during the visit (eg, expressing to the patient, "As we talk, I will be entering information into your record so I am sure to accurately record your concerns"). Conveying a sense of non-hurried presence may be more important than the actual time spent with the patient or family member.⁸ There are times when it is necessary to focus one's full physical and mental attention on the patient and avoid such distractions (eg, when the patient is discussing difficult emotional reactions and/or processing challenging news). Avoiding interruption and giving patients undivided attention, even for a few moments, communicates that the health care professional is fully present and ready to listen.

Other nonverbal strategies that promote rapport include maintaining an open posture and appropriate eye contact.²⁵ A closed posture (eg, arms folded across the chest or legs tightly crossed) can inadvertently suggest defensiveness and the desire to be cut off from what is being said. It is helpful to slightly lean forward toward the patient to demonstrate interest, engagement, and presence. Nurses may be unaware of their nonverbal behavior during patient interactions. Paying attention to one's body language during patient encounters can help to cultivate self-awareness. If one notices that his or her nonverbal behavior does not convey openness or interest, it may be helpful to reflect on such questions as, "Am I feeling uncomfortable or defensive?," "What is preventing me from connecting with this patient or family?," "Does this patient or family remind me of someone I have known or know?," or "Do I have specific fears about addressing this issue with the patient or family?" Being mindful of these issues can promote self-awareness about how nonverbal behavior can be influenced by contextual as well as personal factors.

Appropriate eye contact is another important component of nonverbal communication. Looking patients in the eyes while talking and listening signals emotional connection, psychological presence, and that the provider is truly listening to, connected with, and concerned about the patient.

As previously discussed, multitasking can be distracting and can also inhibit the health care professional's ability to make eye contact. The importance of direct eye contact is valued in the dominant Western culture, but may not be appropriate when interacting with patients and families from diverse backgrounds. Providers should assess the appropriateness of direct eye contact in cross-cultural encounters. For example, when discussing serious subjects, certain Native American tribes will avoid making eye contact.²⁶ Among other cultural groups, averting one's gaze when speaking with those in authority is a demonstration of respect.^{27,28} In cross-cultural interactions in which providers are not sure of the cultural roles about various nonverbal behaviors, observing how the patient and family interact with one another and other members of the medical staff can provide direction regarding nonverbal nuances.²⁸

Nonverbal communication skills set the stage for relationship building, and active listening strategies, such as the use of open-ended questions, paraphrasing, reflection of feelings, and summarizations²⁵ further help the nurse to develop rapport, build trust, and develop empathy. Given that conversations in advanced illness can be stressful and fraught with strong emotion, patients can misunderstand or mishear what is being communicated by professionals. To develop patient-centered care plans, professionals need to develop the skills to really hear what the patient and family are communicating. For example, a patient-centered communication style, which elicits and validates patient concerns using a warm and inviting voice tone, is associated with more in-depth patient-provider interaction.²¹ Time constraints can be a systemic barrier to the use of active listening, when at all possible, patients should be allowed to ask for and share information at their own pace and in their own way. Although necessary for assessment, providers may over-rely on closed-ended questions. Open-ended questions, although more time-consuming, allow patients to express what is most important to them. This can allow clinicians to gain valuable insight into the patients' unique experience of their illnesses. It is equally important to encourage patients and families to ask questions and take the time to answer them sensitively and honestly.

Research consistently reveals that the majority of patients want open and honest information

about their diagnosis and prognosis,²⁹⁻³² but information needs vary across individuals and cultures and within the same patient's illness trajectory. For example, Parker and colleagues³² review of the literature in this area concluded that English-speaking patients wanted less information with fewer details as the disease progressed, while caregivers' need for information increased during the same time frame. Therefore, professionals should assess patient and family information needs and review them over time. For example, a professional may ask, "How much do you want to know about your (or your family member's) illness now and what the future may hold?", "How specific do you want this information to be?", "Could you tell me more about what information you need at this point?"² With a cancer diagnosis, bad news may be delivered over and over again as the patient's health status changes. Warning patients that a difficult message is about to be delivered may help to psychologically prepare the patient and family.^{2,13}

Although patients and families often want honest information about the illness, they also want to maintain hope. Sensitive, empathic, and authentic communication can support and sustain patient and family hope when the prognosis is poor by reframing it in a broader context, which can include hope for symptom control, nurturing relationships, cultivating spirituality and inner peace, maintaining dignity, and reflecting on meaningful events.²² Hope, a multidimensional and complicated construct, does not have to be linked only to survival. Facilitating discussions that support patients and families in their grief while exploring realistic goals can include asking questions such as, "When you think about the future, what concerns you the most?", and "When you think about the future, what is most important to you?"³³

Not only are discussions about the future important in supporting patients and families, assessing their understanding throughout the illness trajectory is equally integral. Effective questions to ask to learn about how patients perceive their illness and treatment options are: "What is your understanding of where things stand now with your illness?"³⁴ "What have other providers been telling you about your illness lately?"² As patients' and families' perceptions and levels of trust may be colored by their past experiences, asking about their previous encounters with the medical system and health care providers can provide insight into

fears, concerns, and expectations they have now and for the future.¹³ Such questions, followed by silence and appropriate nonverbal skills, can be a powerful strategy to assess what the patient and family currently knows and understands, thereby providing an opportunity to correct any misinformation, answer any questions, and gain insight into what is important to the patient during this time. These questions can also prompt nurses to connect with other health care team members to get additional information, provide a needed update, or clarify misunderstandings.

During any patient encounter, the use of paraphrasing can demonstrate empathy and promote rapport and trust. Paraphrasing involves repeating back to the patient the content of the communication, using some of the patient's own words.²⁵ One does not want to "parrot" what the patient expresses, but by repeating back the essence of the patient's communication, any misunderstandings can be clarified. When paraphrases are used, understanding is enhanced. Empathic listening in and of itself can be therapeutic to palliative care patients and their families.³⁴ Below is an example of paraphrasing:

Nurse: "I'd like to hear about what you understand about your illness at this time" (pauses).

Patient: "I'm really not sure. I know that the last test I had showed that the cancer is starting to spread and the doctors are worried about that. Dr. Jones said something about the chemotherapy that I'm on, that maybe it isn't working like it is supposed to. But I'm not sure about that either. When she told me and my wife about the spreading of the cancer, I was shocked. I really thought this treatment was going to work. I just don't know what to do next."

Nurse: "It sounds like you have a lot of unanswered questions about your cancer and the treatment. You know that the cancer has spread and that Dr. Jones has some concerns about the effectiveness of the chemotherapy. This was a shock because you had faith this treatment was going to work. What are some specific questions you have at this time about your illness or treatment?"

In this example, the provider began with an open-ended question and let the patient discuss his perspective in his own way. Instead of trying

to immediately answer the questions that the patient expressed, empathy was demonstrated through the use of paraphrasing. The nurse ended with another open-ended question that invited the patient to discuss his most salient questions and concerns. Although this exchange may have taken more of the professional's time, the increase in understanding and potential for enhanced trust is a worthy investment.

Nurses who work with patients with advanced malignancies routinely encounter patients' and families' strong emotions. Displays of despondency, anger, fear, or other negative emotions can be hard to manage. If patients' intense emotions go unacknowledged, they may experience health care professionals as distanced or uncaring. Like paraphrasing, reflecting back a person's feelings can foster empathy and rapport through acknowledging and validating a patient's emotion. Reflecting feelings does not "fix" the underlying problem, nor does it offer solutions for coping.³⁴ However, it is a way that the provider can communicate compassion and understanding in a nonjudgmental fashion. Strong displays of emotion are often tempered and people de-escalate when a provider validates patients' or family members' feelings:

Family member: (Angrily) "You people said this surgery would get the cancer! He was supposed to go home next week. He can't stay here any longer and he hates it here! You're telling me he has more treatment, more torture to go through?! I can't believe this."

Nurse: "This is difficult news for you to..." (patient interrupts)

Family member: "Difficult?! You have no idea. I can't bear the thought of him in this hospital anymore. This is too much to deal with. I have to take care of my kids, too. My sister is going to be devastated when she hears this. What am I going to do?"

Nurse: "I can see you are overwhelmed with this right now. You have so much on your plate to deal with. What can I do right now to assist you with some of your immediate concerns?"

In this example, the nurse could have become defensive, which may have further angered the family member. Instead, the daughter's feelings were validated and the opportunity for the nurse to connect with her became a real possibility.

Finally, the technique of summarization can be helpful to ensure that the health care professional has picked up on the important themes of a meeting. Larson²⁵ refers to summarizations as "big paraphrases." This technique involves recounting the broader themes that were covered during an appointment and can be used throughout a discussion to make sure that central ideas are remembered and understood. In the following example, a nurse uses summarization to capture the content of an interaction with a patient regarding a discharge plan:

Patient: "At this point, that is what is on my mind."

Nurse: "Let me take a minute to make sure I understand your concerns and current situation. You are worried about meal preparation and being able to get into the bathtub so that you can bathe at least every other day. Your son is available for some help, but he can't come to your home every day to help you because of what he has going on with his own work and family. You really want to stay in your home as long as possible, so a home health aide seems like a good idea to you. I'll check into the available options and let you know what I find out. Is there anything that I missed?"

Patient: "No, that sounds good. Thank you."

The nurse reiterated the main points covered during the appointment and developed a plan that addressed the patient's identified issues. When summarization is used, patients are reassured that the provider truly understands the most important concerns or issues expressed during the encounter.

When using active listening techniques and providing information to patients and families, nurses should be cognizant of the language they use. The use of medical jargon and technical language can result in ambiguities in communication.^{6,11-13} Medical professionals routinely use such language, disregarding that patients and families may not easily grasp what they are saying. Jargon can impede patients' and families' abilities to grasp medical realities, be used as a tool to obfuscate difficult truths, and can distance the health care professional from the patient.^{11,12} For example, Reisfield and Wilson¹² point out that health care professionals may use terms intended to mean one thing but may mean the

opposite to a layperson. For example, a clinician may inform a patient that a biopsy is “positive,” indicating that a disease state is present, but a layperson may think the word “positive” is indicative of a favorable outcome (ie, an absence of disease). Table 1 provides a list of common clinical terms that may have antonymous meanings.¹² In addition to language that can be misconstrued, clinicians may also use euphemisms that can function to soften the truth but ultimately confuse patients. In cancer treatment, euphemisms include the terms “growth,” “spot,” or “mass.” Common jargon that patients may misunderstand include “malignancy,” “carcinoma,” and “metastases.”¹²

To address the communication challenges associated with jargon and the task of relaying complicated medical information to patients and families, Schaep¹³ suggests that practitioners use a “bilingual approach” – medical jargon is accompanied by an explanation of the words or phrases in lay terms. Such a strategy can provide important educational opportunities for patients and families; by utilizing this communication tactic, patient and family understanding of complex terms are clarified in the current interaction and can lay the foundation to utilize the new terms in seeking additional information at a later time. Another communication technique to enhance patient and family understanding of medical terms and processes is the selective and culturally relevant use of metaphors and analogies where familiar situations and words are used to explain the unfamiliar. In fact, one recent study suggests that such use of metaphors and analogies was associated with more favorable patient perceptions of oncologists’ communication.³⁵

As previously discussed, effective communication is tailored to the needs of the individual

patient and family and assessment of communication preferences over time is necessary.^{24,31} What are the patient’s and family’s cultural and educational backgrounds? Does the patient or family member need time to absorb news before he or she is ready to ask questions and discuss options? Does it help to have loved ones present or does the patient prefer to have discussions with health care professionals alone? Continued assessment of the patient’s communication preferences can provide a context for meaningful exchanges among health care professionals, patients, and family members.

Patients who perceive health care professionals as compassionate, emotionally supportive, empathetic, and caring are more likely to trust and be comfortable with such providers,¹⁷ facilitating open and genuine dialogue. A nurse who behaviorally demonstrates these qualities develops rapport with patients, and they feel cared about and comfortable sharing thoughts and feelings. In developing rapport, the nurse conveys warmth and listens to patients in such a way that they feel heard and understood. Patients are respected as complete human beings, with unique histories, full lives, and distinctive value systems. To effectively convey empathy and compassion, nurses need to be genuine; such qualities can be difficult to “fake.” A genuine nurse is authentic yet appropriate in his or her interactions with patients and families. Authenticity requires self-awareness and self-understanding as to what the nurse brings to the encounter with the patient. Continued assessment of a patient’s understanding of the illness and treatment options, communication preferences, and physical, emotional, practical, and existential concerns can assist nurses in delivering patient-centered care. Self-assessment of one’s own emotional and behavioral reactions to patients and families is

TABLE 1.
Antonymous Meanings

Term	Clinical Meaning	Lay Meaning
Disease progression	Deterioration	Improvement
Disease regression	Improvement	Deterioration
Advanced	Unfavorable prognosis	Favorable prognosis
Positive (eg, biopsy)	Presence of disease	Absence of disease
Negative (eg, biopsy)	Absence of disease	Presence of disease

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also crucial in cultivating effective communication in palliative care and avoiding burnout.

INTROSPECTION AND SELF-AWARENESS

Conversations in advanced illness can be emotionally charged and difficult for providers and patients alike. A cancer diagnosis and the medical decisions that must be made can evoke a psychological crisis for patients and families.⁵ Depending on such variables as personality composition, coping style, previous experiences, and future expectancies, patients may react to bad news and the resulting stress with anger, anxiety, fear, acceptance, hopefulness, denial, shock, or any combination of the above. These emotional reactions influence one's ability to process information and effectively communicate. Providers also react to their patients' emotional states and displays depending on their personality, preferred methods of coping, and previous life experiences. Social and contextual features, such as behavioral expectations for "good patients," may impact the communication quality among nurses, patients, and families. Self-awareness of one's emotional reactions is imperative. Patients and families can provoke a wide range of reactions from providers, and if one is not aware of how a certain patient impacts professional behaviors, patient care may be compromised. For example, an uncomfortable provider may engage in distracting nonverbal behaviors that are manifestations of his or her emotional state and inability to make eye contact (eg, wringing the hands, fidgeting, etc). Patients can easily detect these nonverbal cues, and may choose to avoid difficult topics to be a "good patient" and to shield the nurse's feelings. This can impact what the patient is willing to reveal and compromise open dialogue.

Another important factor for nurses to consider is their experiences of grief and loss. Nurses often develop close bonds with their patients over the course of treatment, and are routinely faced with the deaths of their patients. How they cope with such losses can impact their level of engagement with living patients.^{36,37} Grief experienced as a result of a patient's death can be described as disenfranchised, not publicly acknowledged, or supported. Nurses are often expected to go on "as usual" after the death of the patient, regardless of the closeness of the nurse-patient bond.³⁷ In the oncology setting, professionals are routinely faced

with difficult patient losses, which are impacted by relational factors (eg, closeness to the patient/family, the death of younger patients, long-term patient relationships, unexpected deaths), contextual factors (eg, unprepared families and patients, unrealistic expectations, excessive treatments, chaotic family systems), and contemporary medicine's culture of cure.³⁸ Grief is indeed a normal response among nurses, and needs to be acknowledged and processed to move through.³⁹ Research suggests that grief responses among palliative care nurses are repressed because of "intrapsychic disenfranchisement" (ie, detachment from one's feelings) and societal norms about grief reactions among professionals ("business as usual"). This disconnect, personally and socially, can lead to distressing signs and symptoms among professionals.³⁷ These signs and symptoms can be indicative of burnout or compassion fatigue, an emotional exhaustion resulting from caring for and identifying with patients who are suffering. In recent years, the literature on burnout has evolved,⁴⁰ and compassion fatigue has emerged as a concept that some argue may be a more descriptive and accurate representation of the phenomenon.⁴¹

Nurses who work with patients who suffer from advanced malignancies experience grief and other strong emotions that result from dedication to and care for their patients. This is normal and expected. It is emotions that are denied or unexamined that can become problematic. Under these circumstances, such feelings can "leak" into encounters one has with patients, and behavior is influenced by factors that are unknown to the professional.³⁶ This is known as countertransference, "the conscious or unconscious phenomenon that occurs when the clinician reacts to a (patient) based on the clinician's own past experiences, preferences, preconceptions, fantasies, and fears."⁴² Countertransference, however, can also increase empathy and compassion, and does not necessarily have to negatively impact patient care.⁴² One key to appropriately utilizing countertransference is self-awareness, the acknowledgement and exploration of one's emotional reactions that result from various patient encounters.

Novack et al³⁶ define self-awareness as, "insight into how one's life experiences and emotional make-up affect one's interactions with patients, families, and other professionals." Self-awareness begins with paying attention to one's inner life, emotional reactions, and concomitant behaviors.

Novack et al³⁶ suggest that professionals reflect on the following issues to promote self-awareness: core beliefs/personal philosophy, family of origin influences, gender and sociocultural influences, feelings about boundary setting in medical care, attitudes toward conflict and anger, dealing with “difficult” patients, and attitudes toward death and dying.³⁶ Questions for reflection are presented in Table 2.

As nurses develop insight into how their emotional reactions impact their behavior in patient care situations, steps can be taken toward behavioral change, and resisting the tendency to become over- or under-involved with evocative patients and families. It is not the health care professional’s responsibility to “fix” challenging patients or difficult family dynamics, but it is important to monitor one’s own inner reactions and manifest behavior, such that patient-centered care is optimized. As a strategy to regulate one’s behavior and make positive changes as part of cultivating self-awareness, Meier et al⁴³ suggest these steps: 1) name the experienced feeling; 2) accept the normalcy of the feeling; 3) reflect on the emotion(s) and its possible consequences; and 4) consult a trusted colleague for support and guidance. Through taking the time to be mindful of and process one’s emotions, emotional states can be identified and the process toward positive behavioral changes can begin. Objectifying feelings in a nonjudgmental manner can promote conscious control over emotional states, allowing professionals to make rational behavioral choices. Accepting that strong emotional reactions are normal when providing palliative care helps to reduce guilt about one’s feelings and give health care professionals permission to explore how the emotional reaction influences patient care. Finally, processing difficult emotions and their resulting behaviors with trusted colleagues can help to provide needed emotional support and the avoidance of burnout and compassion fatigue.

Introspection and self-awareness are critical components of delivering compassionate and patient-centered end-of-life and palliative care, but are only a part of what nurses can do take care of themselves so they can effectively care for others. One recent study⁴⁴ examined the effect of a training designed to enhance communication in palliative care and increase personal introspection related to relationships, meaning making, and coping. The authors found that emotional exhaus-

TABLE 2.
Questions for Reflection to Promote Self-Awareness

Family of origin issues
What roles did I have in my family?
How might I be replicating these roles in my work?
What lessons did I learn from my family about the nature of relationships, caregiving, and acceptable responses to illness?
What kind of patients might I associate with family members or loved ones?
Gender/sociocultural issues
What messages have I integrated about sex roles?
How might my attitudes contribute to instances of communication with the opposite sex?
Do I respond to and communicate differently with male and female patients and colleagues?
With what culture do I identify?
How does my cultural background influence my values?
How do I emotionally, cognitively, and behaviorally respond during cross-cultural encounters?
How has the medical culture influenced how I respond to patients and families?
Feelings and emotional responses in patient care
How do I maintain professional boundaries yet be empathetic with patients and families?
If I experience a strong emotional reaction to a patient or family, what is that emotion?
Where does it come from? How does it impact my professional behavior?
What sort of patients elicit an angry response in me?
What sort of work situations make me angry and why?
How do I generally handle anger and conflict? What might I do differently that is more productive?
“Difficult” patients
What type of patients and families do I consider difficult?
What sorts of biases may underlie my tendency to label certain patients as difficult?
What emotions do I experience when I work with “difficult” patients?
Caring for dying patients
How have my personal experiences with loss and grief impacted my abilities to work with patients who are dying?
How do my own attitudes and fears of death and vulnerability affect my patient care?
If I were dying, what type of medical care would I want?

Data from ref. 36.

tion was significantly related to lack of time for family and meaningful non-work-related activities. Furthermore, a sense of personal well-being was related to professional fulfillment, and professional fulfillment in turn was correlated with empathy and the ability to unconditionally accept patients and families. Another intervention developed for palliative care professionals, which emphasized contemplative practices, such as mindfulness, meditation, and yoga (called *Being*

with Dying), resulted in positive outcomes for the clinicians who participated, including how they work with those who are dying and how they conduct themselves personally and professionally.⁴⁵ Both of these interventions encouraged and supported introspection and self-awareness, but also promoted other modes of self-care which may also enhance nurses' capacities to effectively communicate. Kearney and colleagues⁴⁰ provide a helpful and lengthy list of suggestions for self-care strategies and ways to mitigate burnout among those who work with patients at the end of life.

ADVANCE CARE PLANNING

Since the Patient Self-Determination Act was passed in 1990, which highlighted the importance of advance directives, advance care planning (ACP) has evolved from a "legal document-driven effort" to one that focuses on the process of clarifying values, goals of care, and hopes in the context of the patient's social system.⁴⁶ Inclusion of the patient's family and significant others is critical to a meaningful ACP process to develop a shared understanding of preferences and values salient to end-of-life decision-making. Nurses can be instrumental in assessing the patient and family's readiness to engage in the process. One study revealed several barriers to ACP, including patients' perception that the process was irrelevant to them, personal barriers including anxiety over the process or "being too busy," lack of understanding of treatment choices and the actual forms, and perceiving the health care professional as pressed for time.⁴⁷ Nurses can address many of these barriers through education, support, encouragement, and use of effective communication techniques that can promote timely ACP discussions.

Too often, issues related to end-of-life care are not discussed until a crisis occurs, and the opportunity for meaningful discussions regarding values, preferences, and life goals has been forfeited. One study revealed that more than half of end-of-life care discussion occurred during acute hospital stays instead of in the context of stable outpatient care.⁴⁸ ACP completed before an emergency and in collaboration with family and significant others has the potential to reduce family conflict and burden when decisions must be made on behalf of a loved one.⁴⁹ Such discussions

should occur throughout the illness trajectory, especially when there has been a change in the patient's condition and/or circumstances. During routine visits, providers may miss opportunities to engage in the ACP process with willing patients and families who provide verbal cues that they are open to the discussion. For example, during clinic visits, patients may bring up contingencies of their future care, and due to time constraints, task orientation associated with the visit, or simple lack of awareness, providers can miss these chances to engage in the ACP process.⁵⁰ By improving patient-centered communication practices, clinicians may be able to enhance their ability to fully participate in ACP discussions.

Areas important for ACP discussion include patient understanding of the illness, treatment and life goals, values, personal experiences with illness and death, previous experiences with the health care system, family/social system support of patient goals and values, and advance directives.^{13,51-53} It is important for providers to understand how patients' view their illness because how patients perceive their disease and its treatment, and how families and medical teams understand it, may be quite different.⁵¹ Developing a shared and informed understanding of the patient's medical issues can make discussions about treatment preferences more meaningful and relevant to the patient's specific situation, and decrease the likelihood of disagreement about options.

Patients have personal life goals that are connected to their value systems. These life goals and values are central to the ACP process. What does the patient want to accomplish in life? Is there any unfinished business that needs to be addressed? Patients' aspirations and hopes should be central to their treatment plans. For example, a patient may choose an aggressive mode of curative care for a period of time to attend an important family event or welcome a new addition to the family. Medical decisions made by patients and families are influenced by their values and life experiences. What is important to this patient and family? What is the role of religion or spirituality in this family system? What cultural traditions are central to this patient and family? How might these interact with the ACP and medical care delivery? Through exploration and understanding of these issues, providers can treat patients holistically, as unique individuals with a past, present, and future. Based on what has been and is now important to a patient, what decisions would be consistent with his or her

life narrative? Values assessments can help providers and family members develop an understanding of patient preferences that may direct decision making in circumstances that might not have been anticipated. Numerous tools exist to structure such conversations among patients and surrogates including “Making Medical Decisions,”⁵⁴ “Five Wishes,”⁵⁵ and “Your Life, Your Choices.”⁵⁶ These tools can help in encouraging discussion, but end-of-life care checklists rarely capture the complexities present in end-of-life decision-making and should not be used as a substitute for discussion among patients, family members, and providers.⁴⁶

Meaningful ACP is a two-pronged approach that involves both informal discussion and completion of formal advance directives,⁵⁷ which are legal documents that list specific treatment preferences (living will or health care directive) and specify who should make decisions on behalf of a decisionally incapacitated patient (durable power of attorney for health care or health care proxy). Most states give end-of-life treatment decision-making authority to family members (often listed in order of priority beginning with the closest kin) even without a formal advance directive in place, making the informal aspect of the ACP process even more important. Advance directives completed without meaningful discussion involving the identified decision-making surrogate, other family and social supports, and health care providers may not be very helpful in guiding care. For example, without provider input, patients may draft advance directives that are so unclear or ambiguous that their content cannot be substantively integrated into a patient care plan.⁵⁸ Nurses can be key in encouraging patients to thoroughly discuss their preferences and values with key individuals.

If patients do complete formal advance directives, they should be encouraged to keep the documents in an accessible place and to give copies to their physicians, specialists, decision-making surrogates, and key loved ones and family members. Once an advance directive is completed, the process of ACP does not stop. It should be made clear to patients that they can change the content of their advance directives at any time. Given their unique role in patient care, nurses can help to ensure patients’ current treatment preferences are addressed and appropriately represented in their advance directives by having ongoing discussion about values, goals, and medical treatment choices, particularly when

there is a change in patient condition or circumstance, which are key times to revisit ACP issues.

Table 3 displays questions that can help nurses begin and maintain ACP discussions. The questions address the domains of previously discussed: patient understanding of the illness, goals, values, personal experiences with illness

TABLE 3.
Suggested Questions for Advance Care Planning Discussions

Patient understanding of illness	
What do you understand about where things stand right now with your illness?	
What do you know about your treatment options? What is unclear to you about your treatment options?	
Patient goals	
What is important for you to accomplish at this point in your life?	
As you think about the future, what is most important to you (what matters the most to you)?	
What are your hopes/fears for the future?	
If you were to die sooner rather than later, what would be left undone?	
What type of legacy do you want to leave your family/ loved ones?	
Patient values	
What makes life worth living?	
What would have to happen for your life to be not worth living?	
What nourishes your spirit?	
How do you feel about quality versus quantity of life?	
To what extent do you want your family/loved ones to have input in decisions that are made about your health care?	
What are your thoughts about pain control? Would you want your pain controlled even if it meant that you might not be as alert?	
Personal experiences with the medical system, illness, death, and dying	
What have your experiences with the medical system been like?	
Has anyone close to you died of an illness? What happened? What was it like for you?	
What other significant losses have you experienced?	
What would you consider a “good death”?	
Spirituality/existential issues	
What thoughts have you had about why you got this illness at this time?	
Is faith (religion, spirituality) important to you in this illness and has it been important to you at other times in your life?	
Would you like to explore religious/spiritual matters with someone? Do you have someone to talk to about these things?	
Do you have any spiritual/religious beliefs that should be taken into consideration by your healthcare providers?	

Data from refs 13, 34, and 53.

and death, family/social system support of patient goals and values, and spirituality.^{34,51-53} In addition, Quill⁵³ suggests that most end-of-life discussions also include advance directives, do-not-resuscitate orders, life-sustaining therapies such as mechanical ventilation, feeding tube, antibiotics and hemodialysis, management of pain and other symptoms, relief of suffering, and creating an opportunity to address unfinished business. This is an ongoing process that ideally continues throughout the patient's treatment.

CONCLUSION

Palliative care is a holistic and respectful approach to meeting the physical, emotional,

practical, and spiritual needs of patients and families coping with advanced illness. To provide the highest quality care possible, nurses who work with patients with advanced malignancies are called upon to communicate with them, their families, and other health care providers clearly, compassionately, and effectively. To do so, personal awareness about one's emotional reactions provoked by interactions with others is necessary so that positive behavioral choices can be made and burnout avoided. Nurses who are able to examine their own inner lives and develop successful communication practices are integral in promoting effective ACP among patients with advanced illness and their families.

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