

# Advance Care Planning: The Nurse's Role

A consistent, system-wide approach can normalize the process, dispelling fears and misconceptions.

This series on palliative care is developed in collaboration with the Hospice and Palliative Nurses Association (HPNA; <http://hpna.advancingexpertcare.org>). The HPNA aims to guide nurses in preventing and relieving suffering and in giving the best possible care to patients and families, regardless of the stage of disease or the need for other therapies. The HPNA offers education, certification, advocacy, leadership, and research.

Many nurses witness family members struggling to make end-of-life care decisions for their loved ones. The family members often do not know what care the patient would want in a given situation. Nurses have also seen patients receiving seemingly futile treatments and have wondered if the patients wanted this care or if they had the opportunity to discuss and communicate their preferences.

Does this sound familiar? Have you wanted to speak up and act as an advocate for the patient—but instead hesitated? What can you do to prevent difficult decision-making situations like this? Assisting patients and their families in advance care planning (ACP) is an important nursing responsibility and can better prepare families to make decisions that honor patients' preferences.

ACP is increasingly recognized as an essential component in providing the end-of-life care a person would want.<sup>1</sup> While the public and health care professionals are becoming more aware of its importance, challenges to implementing ACP in everyday care persist. I am involved in a system-wide effort to implement ACP in a large academic medical center and have encountered multiple challenges. In the process, I have learned that ACP is everyone's business, from primary care to intensive care settings, and *all* nurses, regardless of where they work, are in a critical position to lead the practice changes for ACP.

The purpose of this article is to describe what you as a nurse can do to help patients and their families implement ACP in order to improve end-of-life care. The challenges nurses face and the strategies used to overcome them will be described, with a focus on the nurse's role in leading ACP practice

and on the culture change that needs to occur to promote it.

## ACP: WHAT IT IS AND WHAT IT ISN'T

ACP is a process of planning for future care in the event one becomes unable to make one's own decisions. Because such events can occur not only to older adults or patients with serious illnesses but also to healthy persons, ACP is recommended for all adults, whatever their age or health status.<sup>1,2</sup> Ideally, individuals should start conversations about ACP at home with family members and/or close others when they are not seriously ill. The Conversation Project (see <http://theconversationproject.org>) provides an excellent starting point for families exploring this topic. The process can start at any time and the plan should be revisited as health status and living circumstances change.

ACP usually includes two components:

- identification of a surrogate decision maker who will make medical decisions in case of the person's incapacity
- description of medical care the person does or does not want under certain conditions

Over the past two decades, the focus of best practices in ACP has shifted from *having an advance directive document* to *encouraging ongoing conversations* between the person, surrogate decision makers, and health care providers to clarify and communicate the person's values in relation to future health care decisions.<sup>3</sup> Such conversations are about identifying what's important to the person, so that surrogates and health care providers are prepared to make meaningful decisions about care that reflect the person's values when she or he is not able to.<sup>4</sup>



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While having documents or medical orders is *not* considered a primary goal or requirement of ACP, written statements are useful tools or “frameworks” to communicate a person’s values and preferences across time and in the health care system.<sup>5,6</sup>

**Advance directives** (sometimes called living wills) are documents describing preferences for future care and designating someone who can make medical decisions in case of the person’s incapacity. This person serves as the individual’s health care agent; a document called a durable power of attorney for health care, or DPOA-HC, may be used for this purpose in some states.

Advance directives are legal documents, and people may complete them at any time and in any state of health. Although it may be beneficial to discuss advance directives with health care providers, their completion does not require health care provider involvement.

**POLST, MOLST, and other medical orders.** Unlike advance directives, medical orders related to ACP, such as physician orders for life-sustaining treatment (POLST) or medical orders for life-sustaining treatment (MOLST), must be written and signed by a provider (usually a physician, NP, or physician assistant, depending on state law). (For more information, see <http://polst.org> or individual states’ MOLST sites, such as <http://molst-ma.org>.)

These documents are actual medical orders for the care a person receives near the end of life. Medical orders for end-of-life care are appropriate only for people with serious illness or frailty whose death is in the foreseeable future; they are not for everyone.

Other medical orders related to ACP may include do not resuscitate, or DNR; do not intubate, or DNI; or do not hospitalize, or DNH, orders. These orders are usually written in a health care facility to prevent those treatments that may be provided as the default care unless the patient or family members request otherwise.

While these documents are tools to promote conversations about what is important, direct the care a person wishes to receive, and communicate a person’s preferences among the people and settings involved in care, having documents and/or orders in place is *not* ACP.

#### CHALLENGES TO IMPLEMENTING ACP IN A HEALTH CARE SYSTEM

In the course of our team’s efforts to implement ACP in our medical center, we learned that a number of cancer patients with poor prognoses received chemotherapy or treatment in critical care settings during the last two weeks of life. Conversations about end-of-life care often do not happen until very late, and patients and their families arrive at difficult decision-making

points unprepared by any prior conversations. We learned that ACP either rarely happens or, if it does, is not documented. In addition, only a third of deceased patients had an advance directive or POLST in the electronic health record.

These findings were perceived as an opportunity to improve the quality of end-of-life care in our organization and, consequently, we initiated a system-wide quality improvement (QI) project. A root-cause analysis indicated that there were no standard practices to facilitate ACP conversations and no documentation systems to support the ongoing process. While the lack of an effective documentation system poses a technical challenge to ACP practice, our team members identified the reluctance or resistance of clinicians to embrace it as a greater barrier. We identified several sources of this barrier, which are described below; what follows are also suggestions for overcoming them based on our experience.

**Misunderstanding ACP.** Clinicians' resistance to ACP was mostly rooted in misunderstanding or confusion about what it is. Our observations are consistent with the existing literature.

*Many clinicians as well as patients and families associate ACP with dying.* They interpret planning for end-of-life care as if they are making the actual end-of-life decision in the moment.<sup>7</sup> Comments from clinicians such as "My patients with benign cancer don't need to do that" or "It is not the time for this patient yet" illustrate the misconception that ACP is only for dying patients or patients with life-limiting illness. Patient responses such as "I am not that old" or "Are you telling me something I don't know?" also indicate misconceptions that ACP is only for older or dying persons.<sup>8,9</sup> ACP should be future-oriented planning shaped by hypothetical "what if" questions. Decision making when a patient's death is near is not ACP. Unfortunately, because in current practice the first conversation about a patient's values and preferences for end-of-life care frequently happens near the end of life, not months or years earlier, many clinicians, patients, and families misunderstand and believe that an ACP conversation is the same as an end-of-life conversation.

*Lack of understanding about different stages of ACP adds confusion.* Some guidelines and literature recommend ACP discussions with health care providers when the patient has less than a one-year prognosis.<sup>10</sup> While it is appropriate to discuss the need for medical orders when a patient enters an advanced stage of illness, a general ACP conversation to discuss the patient's values and preferences, and to determine surrogate decision makers, should happen long before then. ACP does not need to wait until the patient's prognosis is determined.

*Lack of knowledge about ACP-related legal issues is another barrier.* Policies governing ACP and the legality of different types of documentation vary by states and institutions. State forms for advance directives are often written in legal terms and are difficult to understand.<sup>9</sup> For example, many patients and health care providers do not know whether advance directives need to be notarized, witnessed, or filed in an attorney's office. The apparent complexity of certain aspects of ACP discourages both patients and providers from starting the process.<sup>8,11</sup>

**Myths that ACP is harmful to patients.** Another reason health care providers are reluctant to initiate ACP conversations is the perception that patients and families do not want to discuss death and dying, ACP, or end-of-life care.<sup>12</sup> Providers believe such conversations will make people depressed and take away their hope, or that patients do not want to upset or burden their families by bringing up unpleasant topics. Some providers believe it is culturally inappropriate to talk about dying and end-of-life care.<sup>8,9,13</sup> In some cases, this is true for certain people and in certain circumstances. However, there is no evidence that ACP is harmful to patients or their families.<sup>10,14</sup> Instead, there is increasing evidence supporting the benefits of the process, including a higher rate of patients receiving value-concordant care—in which patients' end-of-life wishes are more likely to be known and followed—and a reduction in "decisional conflict" and anxiety and depression experienced by family members.<sup>15,16</sup>

At our institution, some health care providers in oncology clinics echoed the concern that "we don't want patients to get the wrong message" (that there's a recurrence or worsening of their cancer, for example) through initiation of a conversation about ACP. They believed patients associate such conversations with bad news and indications that the end of life is near. It's likely that health care providers are not confident or comfortable explaining ACP and its benefits to patients because, like the patients, they also associate it with bad news of death and dying.

**Lack of clarity in roles.** We also learned that a lack of clarity regarding who should take responsibility for ACP is another barrier to its implementation. Physicians in acute care settings often believe that ACP initiation is a responsibility of the primary care provider who knows the patient well and should be done in the primary care setting. Some primary care providers think specialists who manage life-limiting illness (oncologists, cardiologists, and others) are better positioned to have such discussions. Specialists, believing their job is to treat the illness but not to engage in ACP conversations, may recognize the need for it but expect social workers or nurses to do it.

**Nurses' participation in ACP.** While providers are pointing to each other about who should be responsible for ACP, other team members are also unclear about their roles and responsibilities. Although nurses and social workers are ideally situated to facilitate ACP, and it is within their scope of practice to promote it by encouraging patient and family participation in decision making,<sup>5,12,13</sup> their perceptions of who should take responsibility for the process differ.<sup>17,18</sup> A recent literature review by Ke and colleagues concluded that nurses play the critical roles of assessor, initiator, information provider/educator, communicator, facilitator, advocate, and manager of ACP.<sup>18</sup> While the authors found that nurses perceived this role as proper to them, they also found that nurses perceived the work environment, time constraints, and teamwork issues as barriers to the exercise of this role. Another 2015 review, by Rietze and Stajduhar, found that acute care nurses' involvement in ACP discussions is low.<sup>12</sup>

In our QI project, over 40% of nurses reported that they were never-to-rarely involved in ACP; 38% reported they were sometimes involved; and 20% said they were often involved. Nurses identified a lack of time as one reason for their limited practice of ACP, but some nurses also expressed hesitation or a lack of intention to address ACP with patients because they perceived that it was not designated as a nursing responsibility in the organization and that physicians had concerns about nurses fulfilling this role. And, in fact, these concerns expressed by nurses in our organization are not without support in the literature.<sup>12,19</sup>

Assisting with ACP is also identified in the scope of social work practice.<sup>13</sup> In our medical center, social workers are more frequently involved in its facilitation than bedside nurses because of social workers' knowledge about related policies and legal issues. Yet, their roles and responsibility in ACP are also not clearly defined, and their involvement in its facilitation varied by teams and settings.

In our QI project, some physicians commented that ACP should be conducted only by physicians, and that nurses should not facilitate it because the conversations with patients involve prognostication and treatment decision making. This comment is based on the misconception that ACP is the same as end-of-life decision making. Ideally, early ACP conversations to determine a surrogate decision maker and to discuss values and preferences in "what if" situations should start at home between patients and families, long before serious illness or the end of life. It would be better if patients and families then shared what they discussed with their health care provider and have it documented in the health record, but this stage of ACP does not need to involve health care professionals.

In light of the exploratory or hypothetical nature of these initial conversations, health care professionals who teach patients about ACP and assist them in thinking about their care preferences and decision making do not need to be physicians. The lack of a clear understanding of what ACP is and who should play what roles in which of its stages can result in missed opportunities; too often, everyone assumes that someone else must or will do it, that "it is not my job to start an ACP conversation." But ACP needs to be everyone's business. It's crucial that all team members from primary care to end-of-life care know their roles and share responsibility, so that patients and their families can receive consistent support throughout the trajectory of their health care and be well prepared for eventual end-of-life decision making.

**Lack of training.** Part of clinicians' resistance or reluctance comes from their discomfort in having ACP conversations. Many, including physicians and nurses, have limited education and training in ACP and end-of-life conversations.<sup>19</sup> The misconception that ACP is the same as end-of-life decision making contributes to providers' worry that they have inadequate training and experience to carry out difficult conversations at the end of life. Facilitation of initial discussions in the ACP process requires a different skill set and different knowledge from that required for decision making at the end of life. Skillful facilitation to encourage patients and families to reflect on their values and integrate them into their care planning does require preparation. There are tools and trainings available to guide the conversation about personal values from the Conversation Project and Respecting Choices (see [www.gundersenhealth.org/respecting-choices](http://www.gundersenhealth.org/respecting-choices)). Education to promote a correct understanding of ACP and to provide appropriate skills for engaging in its discussion is critically needed for practicing clinicians as well as for students who will be future clinicians.

#### **OVERCOMING CHALLENGES: WHAT NURSES CAN DO**

Many of the challenges we face in implementing ACP come from a lack of shared and clear understanding. Clarification of ACP as an ongoing, future-oriented process to identify and honor each person's values and preferences, rather than as actual decision making at the end of life, is fundamental. Key to its successful implementation is for all health care team members across an organization to share the same understanding of and goals for the process. Although achieving this may seem daunting, nurses are in a position from which to disseminate knowledge and change the culture of ACP practice across an organization. Nurses are in all care settings and play the role of the hub on many teams; they can influence and lead

ACP practice from where they are—that is, in every corner of the organization.

#### **Nurses' role in facilitating ACP conversations.**

Nurses must encourage and facilitate ACP conversations with patients and their families wherever they work. ACP should be recommended to all adults, regardless of their age or health status, although the focus of the facilitation may be different depending on the setting and the person's health status. For example, nurses working in a primary care setting with a relatively healthy population would provide information on ACP and encourage patients to start conversations with their families about "what if" events. Presenting ACP as a proactive process and the responsibility of all adults to reduce the burden on their loved ones by decreasing ambiguity and uncertainty at the time of decision making may help people to understand its value.

The Patient Self-Determination Act of 1990 requires health care institutions to ask adult patients on admission if they have an advance directive, and to provide them with information about advance directives if they do not. Unfortunately, this requirement became a check box, and did not facilitate the ACP conversation as intended. Recent ACP efforts focus on facilitating the conversation rather than checking if a patient has a document or not. Nurses who work in acute care settings where patients are admitted for acute illness or injury ask if patients have an advance directive, and if they do, ensure that it is in the system so the health care team will know the surrogate decision maker and the patient's preferences if the patient loses decision-making capacity while in the hospital. More importantly, admitting nurses should start the conversation by asking patients, "Have you discussed with your family who may make decisions for you if you become too sick to make decisions while you are in the hospital?" "Have you discussed this responsibility with the person you have chosen, and does she or he know what is important to you?"

If patients have not had previous ACP conversations or their health status is changing, it would be appropriate for nurses to teach patients and their families why planning is important and help to initiate the conversation while they are still in the hospital. It is also the nurse's role to communicate with the health care team to determine whether the patient has undertaken ACP that is adequate for her or his current health status (if the patient is entering an advanced stage of illness, for example) and to assist the patient in having further conversations with appropriate health care providers if needed.

If a patient is in an ICU or seriously ill, confirming that the patient's ACP status is known by all team members and is clearly documented is an important first step. In a situation where the patient is unable to

participate in decision making and end-of-life decisions need to be made, nurses must act as advocates to ensure that the patient's ACP is respected in the decision-making process and the patient's values and preferences are honored.

**Nurses' role in educating others on ACP.** For nurses to practice ACP facilitation as described above is not an easy task. Other team members may not support nurses' practice because they think ACP is not necessary or appropriate for their patients. They may believe it can be harmful to patients, or that talking about it is not within nurses' scope of practice.

Step back and reflect on your workplace: what barriers are preventing you from facilitating ACP in your role as a nurse? A barrier may be a misconception among your colleagues that ACP is decision making about end-of-life care that involves prognostication and the disclosure of bad news. If so, work to clarify the confusion and help your colleagues by disseminating correct information about ACP. Nurses who understand its real goal and scope can educate other team members about ACP that is appropriate to their patients in their settings. Nurses may need to educate and reassure other disciplines that assisting patients and their families to make health care decisions by promoting ACP conversations is part of the *Code of Ethics for Nurses*<sup>20</sup> and within the nursing scope of practice.<sup>5</sup> Starting from defining their role in facilitating ACP, nurses can also invite other disciplines to discuss their roles and promote efforts to understand each other's roles and work together as an interdisciplinary team.

In our outpatient clinics, nurses and social workers taught other team members to promote a uniform message and maximize the opportunity to educate patients on ACP. They thought that medical assistants who bring patients into examination rooms and obtain basic health information were well positioned to ask an initial question as to whether a patient has an advance directive and to provide basic information about ACP if the patient does not. Nurses and social workers in the clinic provided education and support to the medical assistants in how to initiate the question in the least threatening manner and how to follow up on the patient's response. Nurses and social workers also provided education and support to the health care providers who see patients in the clinic, including how to follow up with patients after the medical assistants ask whether they have an advance directive and how to support medical assistants on the team. By educating the entire team on the importance of ACP, coordinating the best ways to implement the ACP conversation in specific practice settings, and developing a standard work process around having this conversation, nurses can

lead the practice change that supports and sustains ACP as a routine part of their practice.

Creating a culture in which ACP is a normal part of primary health care for all, rather than an urgent and wrenching decision-making process at the end of life, is critical to increasing its acceptance by patients and families. Sending the same message across an organization, so that patients receive consistent messages from all care providers throughout the trajectory of their illness, would help ACP to be viewed as the norm and would alleviate fears and misconceptions for both providers and patients. Because nurses make up the largest single body of health care providers, we can have a big impact on creating cultural change in organizations' attitudes toward ACP. By collaborating with team members and health care providers across an organization, nurses can create a consistent message so that all health care providers have a similar understanding of what ACP is and how they can best assist patients to engage in it.

## GOING FORWARD

The importance of ACP in clarifying people's values and honoring their wishes is clear. As a result, many health care organizations are looking for strategies to integrate it into their practice. Understanding ACP as a process of ongoing conversations that should continue across time and settings requires a comprehensive approach beyond one setting and single discipline. Nurses' ubiquitous presence within a health care organization and their intimate understanding of patients and their care and concerns make them valuable in leading ACP implementation and in creating system-wide cultural changes to improve end-of-life care. Nurses in all settings are urged to review what ACP is and explore how to facilitate ACP conversations appropriate to the patients they care for. If nurses in a variety of settings send a uniform message and work together with team members, system-wide practice change and a cultural shift to ACP as the norm for everyone becomes possible. ▼

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