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Acute Care of the Elderly Column

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# Crucial conversations: Discussing advance care planning with older adults and their families

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*Scenario: Mrs. Murphy, a 78-year-old woman has a history of heart disease. In the last 2 years, she has been hospitalized 3 times for a series of small heart attacks. Last night, she was rushed to the intensive care unit with a massive heart attack, disoriented, weak and confused. She had no advance directives (ADs) in her possession and there were none in her medical record. The admitting intensivist, worried that her heart may stop due to the extensive damage over the years, wrote an order for full resuscitation.*

*Reviewing previous records for history, her nurse found a note from her previous hospitalization's discharge planner. It quoted Mrs. Murphy saying, "I will not be coming back to the hospital for any reason. My heart is worn out and can't get better. I am going to stay home with my dog and get help if needed from people in my church. I want to die there in peace. I will get with my lawyer and do the paperwork". As the nurse finished reading the note, an alarm sounded. Mrs. Murphy was asystole.*

*Does this sound familiar?*

A reality that acute care nurses face on a regular basis is that many of their older adult patients receive care they do not want. On average, 50% of patients in the hospital are older adults; an estimated 75% do not have advance directives (ADs) at the time of hospital admission. Unfortunately, many older adults acknowledge to not giving thought or having previous conversation regarding their preferences for health care, either with their health care providers or family.[1] Advance Care Planning (ACP) is the means for individuals to convey and document their values and preferences as they age to ensure that the care they receive matches their wishes during serious and chronic illnesses, and particularly at the end of life.[2] Although the concept of ACP seems logical and fairly straightforward, it is a multifaceted and oft times a difficult process resulting in the low rates of completion.

## Evolution of advance care planning (ACP)

The major shift in authority and responsibility for health care decision making has occurred during the lifetime of the current older adult population. Thus, to understand the ongoing challenges of ACP it is helpful to consider its historical roots and ethical foundations.

Prior to the 1970s health care decision making was primarily authoritarian, i.e., 'paternalistic'. Physicians were highly regarded as the expert authorities who made the health care decisions for their patients, often without the patients' explicit consent. The concept of informed consent research and health care arose in the post WWII era as a result of the Nuremberg trials, which began a shift in the public consciousness from physician paternalism to respect for the individual's autonomy.[3] By the 1970s the issue of patients' rights came to the forefront and in 1973 the American Hospital Association (AHA) enacted *The Patient's Bill of Rights* that addressed informed consent and patients' right to refuse treatment.[4] In 1976 California enacted the Death with Dignity or Living Will Act. This was the first legislation to acknowledge the rights of the terminally ill to refuse medical treatments and interventions. The living will was the first AD allowing individuals to express their wishes regarding care.

Congress enacted The Patient Self-Determination Act (PDSA) in 1991. Based on the ethical principle of autonomy, this law required health care providers to give all patients written information about

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their rights in making decisions about their medical care including ADs.[4] As the shift to patient-centered care continued, the AHA replaced *"The Patient Bill of Rights"* with *"The Patient Care Partnership"* in 2003. This document further defined patients' rights, responsibilities and expectations while receiving services in a health care facility and emphasizes the individual's health care goals, values and beliefs as part of the decision-making process.[5]

## ACP trends—how are we doing?

In the U.S., people express strong views when asked about the kinds of care they would want when seriously ill and approaching death. Many older adults wish to remain in charge of the decisions about their care.[6] Nevertheless, despite supportive legislation, the growth of the palliative care movement, and even financial incentives from the Centers of Medicare & Medicaid Services, the numbers of older adults who have ACPs remains low. According to *Becker's Hospital Review*[7] there has been only marginal improvements over the past decades. Most Americans (~80%) still do not have ADs and the most common rationale is lack of knowledge or familiarity. Indeed, recent studies confirm that older adults are uninformed and lack understanding of the ACP process.[8] Thus, there is an obvious, ongoing need for older adults and their families to be informed of their choices and rights regarding health care and educated on the means to express their wishes. Communication is key, however, there are significant barriers.

## The advance care planning process

How does ACP work? Some view ACP as a task, that is, filling out the forms based on the patient's stated preferences. Although that is an important piece, ACP is a two-step process. It supports patients in identifying and sharing their personal values, life goals, and preferences regarding future medical care. These guide the individual and become a basis for decision making.

**Step 1. The crucial conversation**. Conversation is the fundamental first step of ACP. It is often difficult to think of one's mortality and hesitation is natural for all parties involved. However, according to a survey conducted in the Conversation Project, 92% of Americans are eager to talk about their end of life care.[9]

Patterson and colleagues gave us the term "crucial conversation", defined as "a discussion between two or more people where the stakes are high, opinions vary, and emotions run strong".[10] This definition is a fit for the discussions that occur in ACP. Conversation is required between an individual (patient), the family, and health care providers to identify and understand the person's goals, values, religious and cultural beliefs and preferences. There are high stakes in this discussion: making personal decisions about life and death; how one lives (quality of life) and how one dies (comfort and dignity). Anticipating death or the dying process is an emotionally charged topic that many shy away from thinking about and/or sharing their thoughts openly. Denial, sadness, grief, loss, anger, depression are all common emotional reactions in patients and families as they anticipate end of life care.[11]

Many individuals do not have ACP's upon hospital admission. During an acute illness episode in an unstable or crisis situation patients find themselves needing to make immediate decisions without time or contemplation. Even if a patient presents ADs at the time of hospital admission, a crucial conversation needs to occur to review and reevaluate the patient's goals and preferences for treatments considering the acute and changing health status.

Content to be included in ACP conversations follow a recommended sequence, whether it be a first-time conversation or a review of an existing plan: (a) identify one's values, (b) choose a surrogate decision maker, (c) discuss values with surrogates and clinicians, and (d) complete the advance directives.[12,13] Each step of the process creates a foundation for the next. Ideally, ACP should be completed prior to hospital admission, but the nurse is likely to find this has not been the case. During this conversation, patients and families need to be encouraged to realize they are making the best possible decisions with the information they have at hand at the present time. As the patient's situation or health condition changes, additional conversations need to take place to re-evaluate and make appropriate changes in the ACP. An ACP does not have an end date. Once set in place it is considered valid until changes are purposefully made. If an ACP is present, it's likely that an acute care nurse will encounter a patient that had ADs written at some time in the past that are no longer appropriate for the patient's current condition. Thus, a crucial conversation must occur to review and provide the older adult the opportunity to update the plan.

**Step 2. Completing the ADs**. The second step of the ACP process is the documentation of the patient's wishes using established standards and legal documents known as Advance Directives (ADs). ADs communicate the individuals' wishes for care when they are no longer able to speak for themselves.[13] The legal documents include a living will and a durable power of attorney for health care (DPAHC). A living will identifies the treatments (e.g., feeding tubes) that an individual wants or does not want when terminally ill or permanently unconscious and can no longer make his or her wishes known. Health care providers use the living will as a guide to honor the individual's wishes when decisions need to be made about treatments and care.[14] A living will does not give medical orders for nurses or emergency service providers to follow. Rather, specific orders related to the information documented in the living will must come from a medical provider (physician, nurse practitioner or physician assistant). The DPAHC is an individual legally chosen by an individual to make decisions on his/her behalf in the event the person can no longer make his or her own decisions.[14]

POLST (Physician Orders for Life Sustaining Treatment) is a tool for patients with a serious life-limiting medical condition to communicate end of life wishes for treatment in the form of medical orders. These orders are formally signed by a medical provider that provide direction to emergency personnel and hospital workers. Although the forms vary by state, they cover the same information including resuscitation, whether to hospitalize, and the use of artificial nutrition and hydration. As of 2018, POLST is used or undergoing development in 47 states.[15]

Do Not Resuscitate (DNR), also known as 'no code' or 'allow natural death', is a legal order that indicates that a person does not want to receive resuscitation, advanced life support, or other aggressive interventions if his/her heart stops or if he/she stops breathing. Note that the legal status and processes surrounding DNR orders also vary from state to state.[16]

There are advantages and limitations of ADs. The advantages include: increased patient comfort, dignity and satisfaction with care, decreased anxiety for all parties involved with respect to making a decision in an urgent situation, increased knowledge of the provider in understanding patient's wishes and decreased cost to the healthcare system.[17,18] Limitations of the documents are generally related to their language. The AD documents have significant potential to be misinterpreted due to the lack of clear detail. Additional factors that increase potential misinterpretation include: use of broad language that is too general for any specific intended meaning, the document's inability to address the range of patient literacy levels, complex terminology and medical jargon. Other flaws of the AD documents affecting their use is the lack of inclusion of patients' values and beliefs, and the lack of availability when needed.[8]

## Barriers to ACP communication

The Institute of Medicine's (IOM) report, *Dying in America* (2015), identified common obstacles that negatively impact communication in the ACP process.[19] They exist at multiple levels with varying degrees of complexity. On a personal level, individual patients, families and providers are reluctant to discuss or accept death as a natural process of life. Organizations lack structural supports that promote and facilitate the ACP process. Fragmentation of the health care system diffuses the responsibility and accountability for completing the ACP.

Additionally, communication with older adults is often complicated by the age-related changes of the sensory systems. Vision and hearing impairments may require specific verbal and nonverbal communication strategies for older adult's participation and engagement in ACP conversations. Cognitive impairment may also hamper communication.

Time restrictions impact communication. ACP discussions are often involved, and nurses must be able to respond to patient's and family's needs to talk, process and plan within the nurses' workload. Planned interdisciplinary meetings are helpful which the nurse can help coordinate. Commonly in the acute care environment. ACP conversation opportunities occur spontaneously due to extraneous factors such as availability of other health care team members. Moments of opportunity may occur during other nurse-patient interactions; for example a patient may raise a knowledge seeking question during medication administration which naturally unfolds as a lengthier conversation.

Nurses themselves have identified uncertainty of their role in ACP. Discomfort stemming from a lack of knowledge and education about the purposes, legalities, documents and ACP processes are barriers to nurses' involvement. Nurses express concern of not knowing what to say and fear of saying the wrong thing.[19] Perceived lack of skills and confidence create reluctance and avoidance of ACP discussions with the patient and family. There is need for efforts and quality improvement on all levels to improve systems, structure, procedures, clinician knowledge, skills and resources so the patient can receive optimal support.

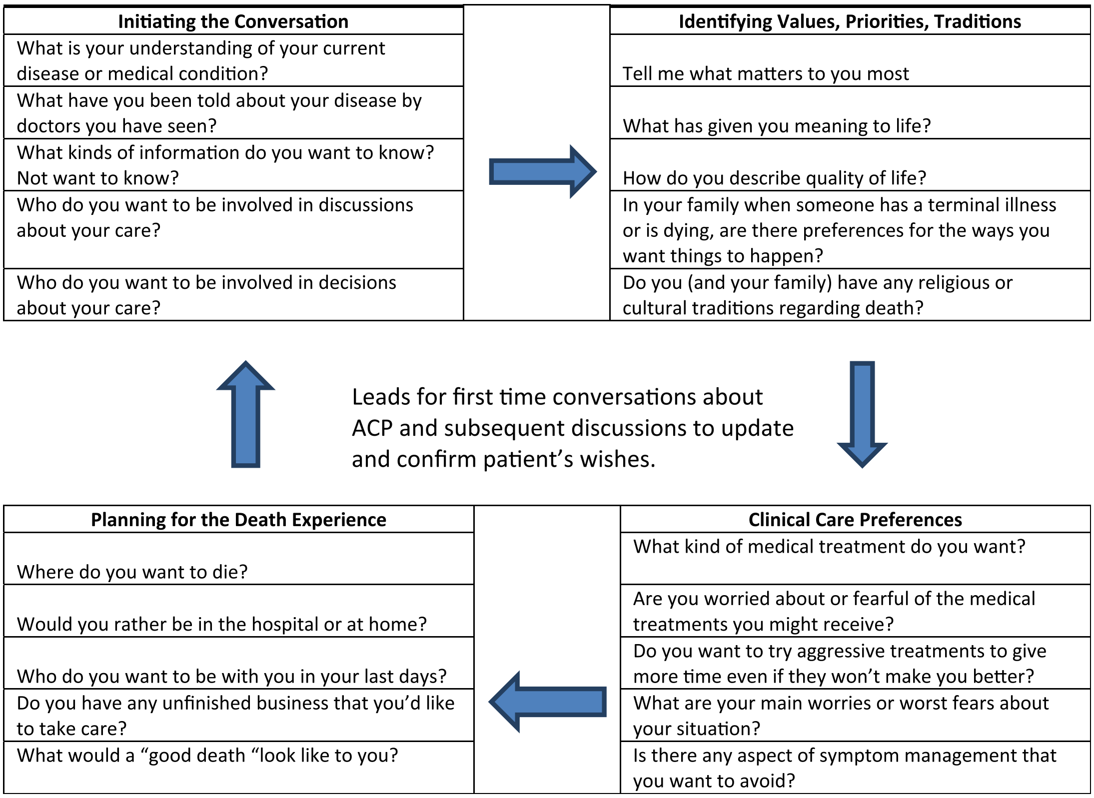
## The role of the nurse in ACP

Nurses in all fields of practice have an important role to promote patient autonomy and completion of ADs, and ensure quality care for all people, regardless of age or current state of health.[20] The American Nurses Association (ANA) clearly defined several roles and responsibilities for nurses providing care and support to patients and their families at end of life including (1) promoting advance care planning conversations, (2) contributing to conversations about end of life care and decisions focused on patients' preferences with respect for the patients' autonomy, (3) providing resources and support for patients and families at the end of a patient's life and in the decision-making process that precedes it, and (4) being knowledgeable about the benefits and limits of various AD documents. The ANA also emphasized the importance of nurses' communication skills in assisting patients with ACP.[21]

Nurses at the bedside are instrumental in ACP and end of life care.[22,23] Although physicians are most typically responsible for communicating diagnoses and prognosis information, nurses typically have the most contact time with the patients and families. Nurses build relationships with patients and families gaining their trust and confidence with interpersonal and communication skills. Patients often turn to nurses for information, clarification and support. Nurses are in a prime position to begin or engage in crucial conversations as patients and families anticipate and plan for end of life care.

## Conversation considerations

The nurse's role in facilitating and participating in ACP conversations requires skill and strategy to achieve positive outcomes. Patterson et al. describe goals and strategies to help crucial conversations be productive and effective.[10] Ground rules must be established at the beginning. Whether the conversation is a one on one with the patient and nurse or a planned meeting with the patient, family and



| Initiating the Conversation |
|---|
| What is your understanding of your current disease or medical condition? |
| What have you been told about your disease by doctors you have seen? |
| What kinds of information do you want to know? Not want to know? |
| Who do you want to be involved in discussions about your care? |
| Who do you want to be involved in decisions about your care? |

| Identifying Values, Priorities, Traditions |
|---|
| Tell me what matters to you most |
| What has given you meaning to life? |
| How do you describe quality of life? |
| In your family when someone has a terminal illness or is dying, are there preferences for the ways you want things to happen? |
| Do you (and your family) have any religious or cultural traditions regarding death? |

Leads for first time conversations about ACP and subsequent discussions to update and confirm patient's wishes.

| Planning for the Death Experience |
|---|
| Where do you want to die? |
| Would you rather be in the hospital or at home? |
| Who do you want to be with you in your last days? |
| Do you have any unfinished business that you'd like to take care? |
| What would a "good death "look like to you? |

| Clinical Care Preferences |
|---|
| What kind of medical treatment do you want? |
| Are you worried about or fearful of the medical treatments you might receive? |
| Do you want to try aggressive treatments to give more time even if they won't make you better? |
| What are your main worries or worst fears about your situation? |
| Is there any aspect of symptom management that you want to avoid? |

**Fig. 1.** Conversation leads in advance care planning.

members of the health care team it is helpful to openly acknowledge the purpose and goals of the discussion in mutual terms. The ultimate purpose of the conversation to help the patient process and identify his/her preferences for care to address the question "What do you really want for yourself?" A primary goal from the perspective of the health care team is to identify "How can we best provide care to meet your needs and preferences?" The ACP conversation should be approached with a positive tone and respect for patients' responses and reactions as they engage. Honesty and sincerity are encouraged, along with respect for others' thoughts and feelings, acknowledging differences. An optimal conversation will allow open dialogue with the expectation to get all the relevant information out in the open. This must be balanced with the patient's readiness to hear and ability to intellectually and emotionally process.

For many nurses, starting a conversation is the hardest part of the process. Although these important conversations cannot be scripted, the following sentences may help nurses get started or engage in a discussion with the patient and/or family (Fig. 1). As part of the insecurity of initiating dialogue about the severity of illness or end of life transition, some nurses worry that bringing up these subjects may be upsetting to the patient and family with a possible outpouring of emotion, grief and sadness. The nurse must anticipate and be prepared for emotional displays and reactions. Remaining present with the use of therapeutic communication skills, the nurse is often able to guide and facilitate conversation assisting the patient through the ACP process.

While it may be easier to only engage with the patients superficially, there can be negative consequences. Failure to discuss, understand and complete an AD can result in confusion, distress, and guilt in family members, increased patient suffering and unwanted procedures, and clinicians' moral distress.[8] In the case of Mrs. Murphy that began this article, the nurse is now torn between the knowledge that Mrs. Murphy would not want full resuscitation and the medical order to provide that care. As active participants either leading ACP conversations or involved in a supportive role nurses have tremendous opportunity to positively impact their patients' and families' lives as they anticipate and face their mortality. Table 1 provides a list of resources and additional ACP materials.

**Table 1**
Additional ACP resources.

| Additional ACP resources for nurses |
|---|
| American Academy of Hospice and Palliative Medicine |
| Web Site: www.aahpm.org |
| American Association of Colleges of Nursing |
| End-of-Life Nursing Education Consortium (ELNEC) Project |
| Web site: www.aacn.nche.edu/elnec |
| National initiative to improve end of life care. CE courses, train trainers |
| The Center to Advance Palliative Care |
| https://www.capc.org |
| Ongoing training and professional training palliative care/end of life |
| The Conversation Project |
| Website: https://theconversationproject.org |
| Advance care planning education and tools |
| Five Wishes |
| Web site: https://fivewishes.org |
| A comprehensive program to assist patients, families and their health care team communicate in order to prepare advance directives |
| Respecting Choices |
| Website: https://respectingchoices.org |
| Professional training, comprehensive resources on "Person-Centered Decision Making in Health Care" |
| VitalTalk |
| https://www.vitaltalk.org |
| Communication skills for health providers caring for patients with serious illness |

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