

American Academy of Nursing on Policy

Advance Care Planning at Life Milestones

Abstract

Much progress has been made in advance care planning (ACP), especially related to end of life and palliative care. These advances have moved thinking about ACP from a checklist approach to an upstream recognition that ACP is an iterative process that should begin early in adulthood and be revisited with each milestone or life-changing event. It is recognized that there are many stages and milestones in adult life that contribute to changing loci of responsibility and life goals. These changes impact how individuals view their lives, the complexity of health care, and the myriad of health conditions they may encounter. ACP discussions should routinely be started and reexamined at the time of key life events like starting a career or a marriage and not delayed until hospitalization, the occurrence of a serious accident, or the development of a catastrophic illness.

Keywords: advance care planning, advance directives, consensus, life milestones, nursing, policy

Advance Care Planning at Life Milestones

The American Academy of Nursing (AAN) has a 10-year history of endorsing advance care planning (ACP) discussions as an important way for individuals to make their preferences known to family and healthcare providers throughout their lives. ACP is an iterative process that supports adults at any age or stage of health to share their values, life goals, and preferences regarding future health care that is not limited to the end of life (Sudore et al., 2017). Engaging in ACP helps ensure that people receive the care they want, improves ongoing and end of life care and satisfaction with care, and may reduce unwanted treatment (Houben et al., 2014; ACP Decisions, 2020). Despite decades of effort to increase engagement in ACP, misconceptions persist, and many people have not had these conversations nor formally documented their preferences.

ACP discussions should begin in early adulthood and be revisited with each adult milestone or a life-changing event like marriage, divorce/separation, new jobs, military deployment, retirement, being diagnosed with a major chronic disease, or a major relocation. Importantly, ACP discussions should not be delayed until hospitalization, the occurrence of an accident, or the development of a catastrophic illness which may force patients and families to make decisions urgently and without knowledge of the patient's preferences.

The purpose of this paper is to advocate for nursing's role in engaging in ACP discussions routinely throughout adulthood and helping to change the focus of ACP from crisis discussion to dialogue at life milestones. Normalization of ACP discussions provides opportunities to review options, explore values and preferences, and address

changes that may occur over the course of one's life. Regular consideration of an individual's choices facilitates a person-centered approach to care.

Background

Policy recommendations and publications of the AAN are presented to provide context for a life milestones approach to ACP. Then a brief history of the development of ACP recounts the technological advances, court cases, legislation, and federal regulations that led to current ACP practices and engagement by the public.

Publications in *Nursing Outlook* illustrate the strong trajectory of the AAN's advocacy and policy work to support ACP (AAN, n.d.; Tilden et al., 2012). Consistent with developments in ACP policy recommendations at the national level, an AAN policy brief by Meghani et al. (2015) highlighted the five major recommendations from the Institute of Medicine (IOM), now the National Academy of Medicine (NAM) report, *Dying in America*. The "life-cycle model of ACP" approach was a component of the recommendation related to patient-clinician communication. Subsequently, the AAN (2015) recognized the importance of the development of policies and procedural guidelines for more flexibility in do not resuscitate (DNR) orders of patients undergoing surgeries. Collaboration among representatives of several AAN expert panels analyzed research and funding efforts addressing palliative and end of life care. Their analysis included examining ACP among individuals who are underserved and marginalized, revealing a significant evidence gap in practice and policy strategies (Wicks et al., 2018). More recently, Whitehead et al., (2021) in a scoping review of nurse-led advance care planning, issued a call to action for an evidence-based ACP training model led by nursing.

Technological advances, such as mechanical ventilation in the 1960s and 1970s, blurred the line between saving life and prolonging suffering and death. In the late 1960s, Luis Kutner created the first living will. He argued that patients may not be subjected to treatment without their consent and that individuals have a right to refuse treatment even if the treatment would prolong life (Kutner, 1969). Thereafter, two highly publicized court cases, *Cruzan v. Director, Missouri Department of Health* (1990) and *Quinlan* (1976), prompted a national discussion about being kept alive by artificial means versus unnecessarily prolonging painful, expensive, and burdensome care at the end of life. These cases established an individual's right to make treatment decisions on end of life care. As a result of these highly publicized cases, the public was encouraged to communicate and document their preferences by completing an advance directive.

By the late 1980s advocacy groups, concerned about the failure of providers and organizations to promote advance directives, supported the Patient Self-Determination Act, which was passed in 1990. This legislation promoted the use of advance directives by requiring healthcare institutions receiving Medicare/Medicaid funding to have staff ask patients whether they have completed an advance care directive and provide written notice to patients about their right to control their healthcare decision-making, including accepting or refusing treatment. These staff policies evolved into admission questions that used a check-list approach in which providers simply asked about the presence or absence of formal documents such as living wills. However, the NAM and AAN are examples of organizations that support ACP as an ongoing process to support adults at any age or stage of health to share their values, life goals, and preferences regarding health care, and have those preferences are documented.

Ongoing engagement in ACP is associated with improved patient and family experiences with health care near the end of life, greater concordance between patients' preferences and care they receive, and fewer unwanted intensive treatments (ACP Decisions, 2020). Unfortunately, few people engage in these conversations about their values and preferences, and even fewer document their preferences in formal advance directives. A national survey indicated that for adults aged 18 years and older, only 26.3% had an advance directive; rates were even lower among African American (17%) and Hispanic/Latino (16.7%) samples (Rao et al., 2014). The disparities in the use of advance care planning also extend to those with multiple chronic conditions, people living on the lower end of the socioeconomic spectrum, and other underserved populations (Wicks et al., 2018). The early onset of major chronic conditions among individuals marginalized by race and ethnicity makes it even more imperative to address ACP (Carr, 2012). Others, often marginalized and found to have low engagement with ACP include individuals who are homeless (Kaplan et al., 2020), incarcerated (Ekaireb et al., 2018), or have low health literacy (Nouri et al., 2019).

The absence of documented ACP preferences leaves people susceptible to receiving unwanted care that is inconsistent with their values or wishes. Healthcare providers need to be aware of the potential for low engagement in ACP in general. They should also be particularly aware of individuals who have been marginalized because of past bad experiences or outright racism, have culturally diverse views on decision-making and life and death, and lack culturally or linguistically tailored ACP educational materials (Sudore et al., 2016).

In the United States, numerous professional associations, consumer groups, and advocacy groups support ACP as a best practice when individuals are facing advanced illnesses. There is growing recognition that ACP should begin earlier in life, and that cyclic reviews should occur regardless of health status. This idea of a cyclical review is consistent with the definition by Sudore et al. (2017) noted at beginning of this paper and aligns with the IOM (2015) recommendations. ACP discussions should begin at a major developmental point when there is a shift in responsibility for decision-making or changes in life context and then continue regularly throughout a person's life (IOM, 2015).

Evidence on Timing

The ACP and related advanced directives literature has shown steady growth over the last 30 years. The early literature focused on "advanced directives" with an increase in the use of the term ACP occurring in the 1990s and thereafter. Often the focus has been on advance directives rather than the broader term, ACP. A search using the terms "systematic review" and "advance care planning" yielded over 250 articles with 230 of those published in the last 10 years, illustrating the exponential growth in knowledge about ACP. Much of the research has focused on discrete aspects of ACP (e.g., advance directives or healthcare power of attorney) instead of using a holistic evaluative approach that considers ACP's intricate working mechanisms, the effects of systems and contexts, and the impacts on multilevel stakeholders (Jimenez et al., 2018). Although the timing of ACP discussions has been addressed in some individual studies, it has been identified as a major gap in systematic reviews (Enguidanos, et al., 2018; Jimenez et al., 2018).

Timing is often embedded in the study of specific populations like patients with cancer or at the end of life, older adults, or caregivers. For example, in a review of 16 studies in patients with a cancer diagnosis, there was no consensus among providers related to the best time to start ACP discussions (Johnson et al., 2016). When end of life discussions occurred earlier in the disease trajectory for persons with advanced cancer, the healthcare costs were lower in the last 30 days of life, there was less likelihood of acute and intensive care at the end of life, and there was a greater likelihood of death outside of the hospital (Starr et al., 2019).

The timing of ACP that is addressed in systematic reviews points to positive outcomes. In a systematic review and meta-analysis of 55 studies conducted in outpatient settings by Houben et al. (2014), who noted that the timing of ACP discussions was important, and having those discussions when patients were stable had a beneficial impact on the ACP process. The authors emphasized having ACP discussions during scheduled visits is essential for good outcomes. Another systematic review of randomized control trials and observational studies conducted by Canadian Health Quality Ontario concluded that patient care planning discussions that occurred early in the course of the illness trajectory resulted in better outcomes than discussions that occurred late in the illness (Baidoobonso, 2014).

Examining providers' likelihood to engage in ACP, Lewis et al. (2016) found that some healthcare providers were uncertain about the most appropriate timing for addressing ACP with patients and families. They noted, however, that approaching the topic of ACP at times of health crisis when people are often frail or under stress is less than ideal. Ke et al. (2015) found that some nurses believed that discussing ACP was

within their scope of practice, while others did not; however, nurses often acted as mediators with others such as families and providers, promoting awareness and providing education. Nurses also reported they were unclear about the best timing of ACP conversations and noted there was variation in other healthcare team members' views on the timing of ACP discussions. Likewise, Enguidanos et al. (2018) summarized physicians' struggles with the timing of ACP discussions. For example, some physicians expressed the belief that addressing ACP too early could impact patients' sense of hope and, therefore, they waited for patients to bring it up.

In a 2018 review, Tilburgs and colleagues examined the barriers and facilitators of experienced practitioners approaching ACP with patients who had dementia and found that both timely ACP initiation and stakeholder engagement were important. Further, they found that uncertainty of timing for having discussions was found to be a barrier along with the challenges in assessing decision-making capacity and changing preferences of people with dementia. Recommendations included not focusing discussions on ACP alone, but including ACP with discussions of maintaining function and activities of daily living, quality of life, and patient preferences and goals (Tilburgs et al., 2018). Combes et al.'s (2019) study of frail older adults indicated that while ACP is often not begun early in this population, it is important to recognize potential triggers such as poor prognostic indicators, life transitions such as a change in living arrangements, or the addition of in-home services as times to discuss ACP. They also recommended that professionals facilitate ACP using a system-wide approach to help with care transitions across settings.

Best Practices

While the roots of ACP as a best practice can be found in hospice and palliative care settings where it is often pragmatically addressed at a time of crisis, ACP has evolved to a more upstream cyclic process that includes goals, values, and decision making about future healthcare choices that are not limited to end of life (IOM, 2015; Sudore et al., 2017). The AAN (2015) supports the findings and recommendations of the 2015 IOM report, *Dying in America*. This seminal document highlighting an upstream approach makes ACP more patient-driven, transparent, and routine, which may help bypass an often-cited barrier to ACP, the uncertainty of the disease, and prognostic trajectory (Lund et al., 2015).

The Centers for Disease Control and Prevention (2018) also views ACP broadly and frames ACP as a window of opportunity for public health education. Indeed, public engagement and education are central to numerous community-based ACP programs like *Respecting Choices*® and the *Conversation Project*®. Prince-Paul and DiFranco (2017) pointedly advocate framing ACP as a public health issue that is discussed as part of routine health promotion. Medicare now reimburses for ACP discussions as part of annual wellness visits (Centers for Medicare and Medicaid Services [CMS], 2020). Acknowledging that the “what if’s” in life are not always foreseeable or easy to talk about, the Canadian Hospice Palliative Care Association led the development of a pan-Canadian ACP framework that provides resources for an upstream approach to ACP. These efforts included the launching of the ACP Life Milestones campaign, a practical and proactive strategy that highlights talking regularly and routinely about ACP. This campaign, launched in 2020, was developed through the collaborative efforts of more than 300 stakeholders. Suggested milestones like starting post-secondary education,

marriage, and organ donation registration are identified on the ACP Life Milestones Campaign website (<https://www.advancecareplanning.ca/news/acp-milestones-campaign-fall-2020/>; Advance Care Planning Canada, 2020).

The impact of a sudden unexpected illness and the accompanying uncertainties of life, disease, disability, and death across populations with the onset of the COVID-19 pandemic and its ongoing burdens illustrate the need for upstream and equitable approaches to ACP. Disparities in disadvantaged populations have been exacerbated during the COVID-19 pandemic reflecting long-standing and broader systemic injustices during end of life care (Elbaum, 2020). Recent studies demonstrate that the pandemic created an urgency for ACP discussions, challenging the practice of waiting until the end of life. Auriemma and colleagues (2020), for example, found a 4.9% increase in monthly users of an ACP planning website during COVID-19 pandemic. In a national poll conducted in June 2020, 59% of adults (age 50 to 80) stated they had conversations about care preferences during serious illness; 29% reported their conversations occurred during March through May 2020, and 41% said the reason for the recent conversation was the pandemic (Malani et al., 2021). Several states have initiated a variety of measures that foster ACP with the goal of improving care (Cox-Grage, 2021). The increase in reported discussions of ACP in the context of COVID-19 (Funk et al., 2020) highlights the importance of planning due to the unpredictability of life.

To aid in the shift from an ACP focus at the end of life, Heyland (2020) advocates using the phrase: “advance serious illness preparation and planning” (p. 6), which emphasizes using evidence-based tools with shared decision-making as a step in

helping people to clarify their values and preferences. Consistent with an upstream approach, it is also suggested that all healthcare professionals engage patients in outpatient settings in the ACP process, ask about surrogate decision-makers, encourage discussion with those surrogates, and document wishes of patients; and that healthcare organizations leverage electronic resources to support ACP (Block et al., 2020).

A shift in focus to a life milestone approach may facilitate the unfolding of ACP discussions over time. This unfolding is person-centered versus crisis-centered; thus, increasing ACP deliberation and discussion among the individuals making these choices, their significant others, and their providers. More open and repeated discussions can provide a number of benefits that are harder to achieve during communications that are crisis-centered, like those based on sudden illness or acute injury. These benefits might include greater comfort with ACP discussions, consistency in messaging about ACP, opportunities to be more inclusive of all significant others, meaningful discussions about goals of care beyond advance directives, care choice transparency, and the likelihood individuals may die in their preferred settings.

Effective interventions to assist with initiating ACP include creating educational materials using various methods of delivery, matching messaging with a milestone approach, using computer-generated triggers for primary care providers (PCPs) in the electronic health record, training on the timing of ACP, including multidisciplinary professionals for content delivery, and preparing patients for PCP visits (National Academies, 2021; Solis et al., 2018; Tilburgs et al., 2018). The strategies identified by various researchers provide a starting point for all healthcare professionals to consider when to begin ACP discussions with patients. It is essential that healthcare

professionals, particularly PCPs, utilize every patient encounter as an opportunity to address the preferences of patients (Solis et al., 2018).

Summary and Key Considerations

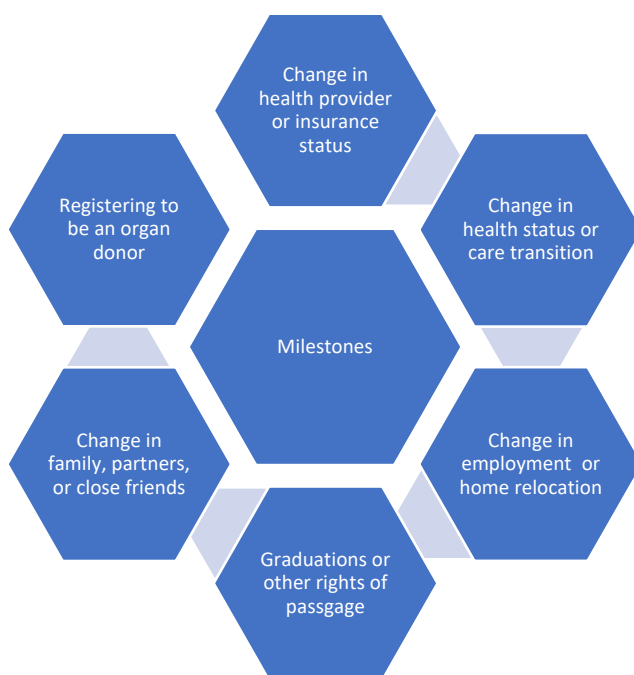
The AAN has a long history of endorsing ACP initiatives for public health, palliative, and end of life care; equity for underserved populations; and for the use of technology like electronic health records to facilitate ACP communication and documentation (Tilden, 2012; Wicks, 2018). Given the contextual complexity of health care and the myriad of health and socioeconomic conditions that impact life and decision-making, much work needs to be done to help the public and healthcare professionals understand their roles in the ACP process. Nurses can model ACP in their own lives, and the lives of their families and friends, along with seeking opportunities to promote ACP across their multiple roles. For example, the Hospice and Palliative Nurses Association (HPNA) created a campaign called, "#ISaidWhatIWant," to promote nurses' use of ACP in their individual lives. Joining in that campaign were over 20 nurses' associations including the American Nurses Association, the AAN, and the National Black Nurses Association among others. Therefore, to assist nurses with the iterative milestone process of ACP, the following recommendations are made related to practice (timing of discussions; patient counseling and education; documentation; diversity, equity, and inclusion) professional education, and research.

Practice

- Timing

- Lead by example. Do not delay personal ACP discussions until hospitalization, a serious accident, or a catastrophic illness occurs within one's own life or circle of significant others.
- Normalize ACP discussions at key milestones with goals that align with maintaining individuals' function, fulfilling activities of daily living, and realizing the quality of life from the individual's perspective
- Routinely examine opportunities for use of ACP milestones with patients within each providers' practice setting (See Figure1).

Figure 1. Milestone markers for normalizing ACP



Adapted from Institute of Medicine. (2015). *Dying in America: Improving quality and honoring preferences near the end of life*. The National Academies Press.

<https://doi.org/10.17226/18748> and Advance Care Planning Canada. (2020). ACP Life Milestones Campaign – Fall 2020.

<https://www.advancecareplanning.ca/news/acp-milestones-campaign-fall-2020/>

- Patient Counseling and Education
 - Use a person-centered care approach with opportunities to practice ACP across settings
 - Collaborate across disciplines to integrate patient preferences, goals, and values, when discussing treatment options
 - Partner with families to help them understand the difference between completing advance directives and the broader iterative process of ACP
 - Routinely incorporate ACP into discussions at milestone events, changing the implicit assumption that ACP is appropriate only for older people or at the end of life
- Documentation
 - Clarify and document when patients say they have completed advance care directives or advance care planning
 - Include a synopsis of ACP discussions in summaries provided to patients.
 - Use as appropriate, the two CMS-approved CPT codes (99497, 99498) to report ACP services
 - Develop an ACP ontology to facilitate standardized data collection about ACP activities that can be captured in electronic health records and be included in health information exchange
 - Understand legal requirements for documentation specific to one's state and organization
- Diversity, Equity, and Inclusion

- Use health literacy principles in discussing ACP and to evaluate educational materials for these principles
- Identify and use decision aids that are culturally and age-appropriate when discussing ACP
- Incorporate the beliefs, values, ethical norms, and culture of the individual and family in the community into tailored interventions
- Examine implicit or unconscious biases that may impact interactions and interventions
- Become informed about specific needs, concerns, and legal issues impacting marginalized populations in one's community (e.g., race, ethnicity, LGBTQ+, immigrants)
- Evaluate patient educational materials or other documents for inclusive language
- Respect that individuals' views of life vary widely even within cultures

Professional Education and Training

- Use an established ACP educational model
- Mentor and model ACP interactions for other nurses and professionals across work settings
- Maximize use of the sociocultural environment by engaging stakeholders from community agencies and faith-based organizations
- Clarify one's values related to ACP
- Incorporate ethical principles and standards of practice in ACP discussions

- Evaluate organizational policies for consistency with standards of practice related to nurses' roles and responsibilities for ACP
- Advocate for healthcare systems to incorporate early ACP into system processes

Research

- Develop a research agenda that examines the impact of using a milestones strategy on patient outcomes, e.g., concordance with preferences, place of death, cost.
- Focus on implementation science to develop evidence-based practices for strategies for the incorporation of ACP discussions at life milestones
- Apply community-based participatory principles to examine interventions designed to facilitate ACP in geographically and racially/ethnically diverse settings at life span milestones
- Develop and test new decision aids that can be used at milestones across the lifespan that employ innovative options like social media, web portals, and phone apps
- Investigate measurable outcomes that can be used to test the success of ACP at life milestones
- Develop a tool that can be used to track ACP decisions across a lifetime.
- Compare strategies and outcomes of ACP at life milestones across age groups (e.g., millennials, old-old)

ACP is an important process that can improve the quality and reduce the cost of

healthcare by providing individuals the opportunity to communicate their preferences to healthcare providers. Due to the complexity of health care and the extent of the issue, a comprehensive and multipronged approach to ACP is essential.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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