

Advance Care Planning: Practice Preferences & Guide

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Introduction to Advance Care Planning (ACP)

Advance Care Planning (ACP) constitutes a fundamental process in modern healthcare ethics and practice, designed to ensure that a person's future medical care aligns precisely with their established values, goals, and preferences. It transcends the mere completion of legal documents, representing instead a structured, iterative series of communications between the patient, their loved ones, and healthcare providers. The primary objective is to facilitate **congruence** between the patient's expressed wishes and the treatment they ultimately receive, particularly during periods when they lack the capacity to make decisions due to critical illness or cognitive impairment. This process requires a deep exploration of personal beliefs, definitions of quality of life, and specific attitudes toward life-sustaining treatments (LST), such as mechanical ventilation, artificial hydration and nutrition, and resuscitation efforts. Effective ACP shifts the focus from reactive, crisis-driven decision-making to proactive, values-based planning, thereby reducing the burden of complex choices placed upon surrogate decision-makers (SDMs) and minimizing moral distress among clinical staff.

The evolution of medical technology has made the identification of specific practice preferences more critical than ever before. While historical approaches often focused on binary choices (e.g., Do Not Resuscitate, or DNR), contemporary ACP requires nuanced deliberation regarding the trajectory of illness and the potential outcomes of specific interventions. Patients are encouraged to define their personal thresholds for acceptable functional status and quality of existence, ensuring that preferences are not generalized but highly personalized. For instance, a patient might specify a preference for a time-limited trial of intensive care followed by mandatory reassessment, rather than an indefinite commitment to aggressive treatment. These detailed discussions help translate abstract values into concrete, actionable medical directives, guiding providers when the prognosis is uncertain or when multiple treatment pathways exist. The quality of the ACP discussion, therefore, directly dictates the clarity and utility of the resulting documented preferences.

In operationalizing ACP, "practice preferences" encompass how the planning is executed across diverse clinical settings--including primary care clinics, hospital systems, long-term care facilities, and hospice environments. The preference is not just **what** care is wanted, but **how** that care is delivered, addressing issues like the preferred location of death, the level of pain management desired, the involvement of spiritual advisors, and the extent to which family members should be included in clinical updates. These logistical and relational preferences are often as important as the clinical decisions themselves, profoundly affecting the patient's experience and the family's bereavement process. Therefore, standardized yet flexible protocols for initiating, documenting, and honoring these complex preferences are essential for ensuring ethical and patient-centered care delivery throughout the healthcare continuum.

Defining Practice Preferences in the Context of ACP

Practice preferences within ACP are defined as the specific, articulated desires of the patient concerning their future medical management, extending far beyond the basic legal requirements of a living will. These preferences must be detailed enough to guide clinical action during acute crises, covering a spectrum of considerations that include, but are not limited to, the acceptance or refusal of specific life-prolonging treatments. Crucially, a meaningful preference includes stipulations about the conditions under which a treatment should be initiated, withdrawn, or limited. For example, a patient might express a strong preference for mechanical ventilation if the expected recovery is full and rapid, but an equally strong preference against it if the expected outcome is a severe, permanent neurological deficit requiring long-term institutionalization. The goal is to capture the patient's nuanced assessment of trade-offs between longevity and quality of life, recognizing that these values are highly subjective and dynamic.

A significant challenge in defining preferences lies in addressing the gap between a patient's initial, often optimistic, understanding of their illness and the evolving reality of advanced disease progression. Preferences stated early in the disease course may become inconsistent or impractical as prognosis worsens. Therefore, ACP is ideally a continuous process involving periodic review and revision, ensuring that previously stated preferences remain relevant to the current clinical status. Healthcare professionals must skillfully navigate this fluidity, utilizing tools like values clarification exercises to help patients understand and articulate their preferences in hypothetical, yet clinically relevant, scenarios. This process often involves discussing the likelihood of specific outcomes, such as the probability of surviving cardiopulmonary resuscitation (CPR) given the patient's comorbidities, thereby grounding preferences in realistic medical expectations rather than abstract hopes.

Furthermore, a distinction must be maintained between the patient's **stated preferences**, which are the wishes communicated verbally during the ACP discussion, and the **documented preferences**, which are the legally formalized instructions recorded in medical charts or specific advance directive forms. The integrity of ACP relies on the accurate translation of the former into the latter. Inconsistencies between verbal communication and documentation can lead to significant ethical conflicts and legal disputes when decisions must be made urgently. The documented preferences often take the form of portable medical orders (such as Physician Orders for Life-Sustaining Treatment, or POLST), which translate patient preferences into immediate, binding medical instructions that must be honored by emergency medical services (EMS) personnel and hospital staff, ensuring that preferences effectively guide practice across various care settings.

Patient Autonomy and the Role of Preferences

The ethical bedrock of Advance Care Planning is the principle of **autonomy**, recognizing the inherent right of every individual to self-determination regarding their medical treatment. Patient preferences serve as the direct, tangible expression of this autonomy, providing the moral and legal mandate for providers to follow the patient's directives, even when those directives conflict with the provider's personal beliefs about optimal care. This respect for autonomy is particularly crucial in end-of-life care, where the balance of power often shifts dramatically toward the medical team. Through ACP, patients proactively reclaim control, ensuring that their voice remains central to decisions made when they are most vulnerable. The discussion must be framed not as a checklist of procedures to accept or reject, but as an opportunity for the patient to communicate their life story, their fears, and their goals for the future, allowing preferences to emerge organically from a deeper understanding of their personal identity.

The practical application of autonomy requires careful assessment of the patient's **decisional capacity** at the time preferences are established. Preferences must be informed and voluntary, requiring the patient to understand the nature of their illness, the risks and benefits of proposed treatments, and the foreseeable consequences of their choices. When capacity is impaired or lost, the documented preferences become the primary mechanism by which the patient's prior autonomous choices are honored. The surrogate decision-maker (SDM) is then ethically and legally obligated to act according to the patient's known preferences, rather than substituting their own judgment or pursuing what they believe is the patient's "best interest." This reliance on documented preferences underscores the need for ACP discussions to be comprehensive and predictive, preparing for scenarios that might seem distant at the time of the conversation.

Furthermore, patient preferences solidify the right to **informed refusal**, allowing patients to decline treatments that may be medically sound but conflict with their personal values or quality-of-life goals. This includes the right to refuse treatments that might prolong life but impose significant suffering or result in a state of existence deemed unacceptable by the patient. For instance, a patient may refuse dialysis or feeding tubes, asserting their preference to prioritize comfort and dignity over the maximum possible duration of life. Providers must respect these choices, even if they perceive the outcome as detrimental from a purely medical standpoint. The role of the physician shifts from prescribing maximal treatment to acting as a facilitator who ensures the patient's autonomous choices are implemented consistently and compassionately, upholding the core tenet that patient preferences drive care delivery.

Provider Perspectives and Clinical Implementation Challenges

Healthcare providers face numerous systemic and psychological challenges in effectively implementing and honoring ACP practice preferences. One of the most frequently cited barriers is

the perception of **time scarcity** within busy clinical environments. High patient volumes, combined with inadequate reimbursement models for dedicated ACP time, often lead providers to prioritize immediate medical crises over proactive future planning. Moreover, many clinicians report feeling inadequately trained in the complex communication skills required to facilitate high-quality ACP discussions, which demand empathy, vulnerability, and the ability to tolerate emotional distress. This discomfort can lead to avoidance of the topic, superficial documentation, or delegation of the discussion to less experienced staff, undermining the quality and depth of the elicited preferences.

A significant ethical tension arises when patient preferences clash with the provider's professional obligation to promote **beneficence**--the duty to act in the patient's best interest. This conflict is most acute in situations involving requests for medically futile care. While providers are ethically bound to respect autonomy, they are not required to offer interventions that are deemed scientifically non-beneficial or harmful. Navigating these conflicts requires clear institutional policies and strong communication skills to explain why a preferred intervention may not be medically appropriate, ensuring that the patient's underlying goals (e.g., avoiding suffering) are still met through alternative, beneficial means (e.g., aggressive palliative care). The challenge is ensuring that the provider acts as a translator, helping the patient align their preferences with realistic medical possibilities without dismissing their deeply held values.

Effective implementation of ACP preferences also demands robust **standardization and integration** into the clinical workflow. Preferences must be readily accessible to all members of the interdisciplinary team--including emergency department staff, specialists, nursing staff, and social workers--to ensure seamless continuity of care. The lack of standardized protocols for initiating and recording ACP, coupled with fragmented electronic health record (EHR) systems, often results in preferences being buried or ignored during transitions of care or acute medical crises. Successful systems integrate ACP documentation directly into actionable medical orders (POLST), require mandatory screening for ACP status upon admission, and provide ongoing training to ensure that the entire team understands their role in reinforcing and executing the patient's documented wishes.

Cultural and Ethical Considerations Governing Preferences

Cultural context profoundly shapes how individuals perceive illness, death, and the appropriate involvement of family in medical decision-making, significantly influencing ACP practice preferences. In many individualistic Western cultures, the emphasis is placed on the patient's singular autonomy and the direct communication of prognosis. Conversely, in many collectivistic cultures, the family unit often assumes the primary decision-making role, and preferences may be expressed collectively rather than individually. Furthermore, some cultural groups may prefer that difficult truths about prognosis or end-of-life options be withheld from the patient to protect them from distress, a practice that directly challenges conventional Western bioethical norms regarding

informed consent. Providers must therefore approach ACP with **cultural humility**, recognizing that a one-size-fits-all approach will fail to capture truly meaningful preferences.

The ethical imperative is to adapt the ACP process to align with the patient's cultural framework, ensuring that the preferences elicited are authentic to their worldview. This may involve engaging the designated family spokesperson or elder as the primary conduit for the discussion, or focusing on preferences related to spiritual rituals, burial arrangements, or post-mortem care, which may hold greater importance than clinical interventions. Providers must be trained to ask open-ended questions that explore the patient's understanding of their family's role and their definition of a "good death," rather than relying solely on standardized forms designed for individualistic decision-making. Failure to acknowledge these cultural nuances can lead to distrust, miscommunication, and ultimately, the implementation of care that violates the patient's deeply held, culturally informed preferences.

Language barriers present an additional significant challenge, requiring meticulous attention to ensure that the delicate nuances of ACP preferences are accurately conveyed and understood. Using untrained family members as interpreters can compromise the integrity of the discussion, potentially leading to bias, omission of uncomfortable details, or inaccurate translation of complex medical terms (e.g., confusing "palliative care" with "hospice" or misunderstanding the invasiveness of a procedure). Professional medical interpreters are essential to guarantee that the patient is truly informed and that their preferences regarding location of care, specific treatments, and comfort measures are documented without linguistic distortion. Ethical ACP practice demands that every effort is made to eliminate these communication barriers, ensuring that the preferences recorded are genuinely the patient's own, irrespective of their linguistic or cultural background.

The Impact of Documentation and Legal Frameworks

Documentation is the critical interface that translates abstract preferences into legally binding and clinically executable orders. The efficacy of ACP is heavily reliant upon the quality and specificity of the documents used. Primary legal instruments include the Living Will (instructional directive) and the Durable Power of Attorney for Healthcare (proxy directive). However, these documents often contain overly generalized language that proves difficult to interpret during a medical crisis. For instance, a phrase like "I do not want to be kept alive artificially" requires subjective interpretation by the clinical team regarding what constitutes "artificial" life support, potentially leading to disagreement among providers or family members.

To enhance specificity, many jurisdictions utilize portable medical orders, such as the Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Scope of Treatment (MOST) forms. These forms are designed to be completed by a healthcare professional following an ACP discussion, translating preferences into specific, physician-signed orders regarding CPR, the level

of medical intervention (e.g., full treatment, limited treatment, or comfort care), and artificial nutrition. The **actionability** of these forms is their greatest strength, as they are immediately recognizable and legally binding across various care settings, including pre-hospital emergency services. This structured documentation ensures that the patient's preference for a specific scope of treatment can be implemented rapidly and consistently, preventing unwanted aggressive interventions.

Despite advancements in form specificity, challenges remain regarding the **portability and accessibility** of ACP documentation. Preferences documented in one hospital system or state may not be readily available or legally recognized in another, particularly when patients travel or receive emergency care outside their primary network. This lack of interoperability can render meticulously planned preferences useless during a critical event. To address this, there is a growing movement toward centralized electronic registries for advance directives. These registries allow authorized healthcare providers to access the most current version of a patient's preferences instantly, ensuring that the documented wishes drive practice regardless of geographic location or time of day. The future of effective ACP implementation depends heavily on the seamless integration and universal accessibility of these legal frameworks.

Facilitators and Best Practices for Eliciting Preferences

High-quality ACP discussions, which accurately elicit and document patient preferences, rely heavily on effective communication strategies and dedicated resources. Key facilitators include specialized training for providers, such as programs like VitalTalk or the Serious Illness Conversation Guide developed by Ariadne Labs. These programs equip clinicians with the structured language and empathic skills necessary to initiate conversations about prognosis, values, and goals without resorting to jargon or inducing fear. Best practice dictates that these conversations should occur when the patient is stable and ideally in a non-crisis setting, allowing sufficient time for reflection and dialogue, thereby reducing the likelihood of decisions being made under duress or extreme emotional strain.

The process of eliciting preferences should follow a structured, phased approach to ensure comprehensiveness and clarity.

Preparation: Review the patient's medical history and prognosis, and prepare to address potential clinical scenarios relevant to their disease trajectory.

Introduction and Invitation: Clearly state the purpose of the conversation (planning for the future to ensure congruence of care) and explicitly ask for the patient's permission to discuss these sensitive topics.

Values Exploration: Focus on understanding the patient's core values, their definition of an

acceptable quality of life, and their greatest fears regarding future illness. This forms the foundation upon which specific treatment preferences are built.

Scenario Planning: Discuss specific life-sustaining treatments (e.g., CPR, ventilation) within the context of likely clinical scenarios related to their illness, translating abstract values into concrete choices.

Documentation and Review: Clearly document the preferences in the medical record and on legally recognized forms (e.g., POLST). Schedule a follow-up discussion to confirm the preferences and address any changes in health status.

Furthermore, the successful implementation of ACP is highly dependent on the involvement of the **interdisciplinary team**. Social workers and chaplains often play a vital role in addressing the psycho-social and spiritual dimensions of preferences, which frequently underpin clinical choices. Nurses, who spend the most time with patients, are crucial for reinforcing educational points, clarifying misconceptions, and identifying changes in the patient's emotional or medical status that may necessitate a revision of their documented preferences. By normalizing ACP as a standard component of chronic disease management, the healthcare system can ensure that preference elicitation is not seen as an extraordinary event, but as an essential, ongoing feature of patient-centered care.

Measurement and Evaluation of ACP Quality

Measuring the quality and effectiveness of ACP practice preferences is essential for system improvement and accountability. Traditional metrics often focus on easily quantifiable outcomes, such as the rate of documentation of advance directives within a population or the completion rate of POLST forms. While these volume metrics indicate activity, they fail to capture the true measure of success: **congruence**. Congruence is defined as the degree to which the care received by the patient in their final days or weeks of life matches the preferences they had previously articulated. Achieving high congruence is the gold standard for effective ACP. Metrics used to assess congruence include the rate of unwanted intensive care unit (ICU) admissions, the use of mechanical ventilation or feeding tubes against documented wishes, and the rate of death occurring in the preferred location (e.g., home or hospice unit rather than the hospital).

Beyond quantitative metrics, the evaluation of ACP quality must incorporate qualitative assessment of the conversation itself. This involves measuring the patient's satisfaction with the discussion, their perceived sense of preparedness, and the degree of clarity achieved regarding their future care. Surveys and qualitative interviews with both patients and surrogate decision-makers can reveal whether the discussion was truly values-driven, whether the provider listened effectively, and whether the patient felt their preferences were fully understood. High-quality ACP minimizes decisional conflict among surrogates and reduces the incidence of aggressive, high-intensity care

that is unlikely to achieve the patient's stated goals, thereby reflecting a system that successfully prioritized patient preference.

Finally, the evaluation must consider the economic and resource utilization impact of honoring practice preferences. While ACP is fundamentally an ethical and relational intervention, successful implementation often leads to a reduction in resource-intensive, futile care, particularly in the final months of life. Studies have shown that patients whose preferences for comfort-focused care are clearly documented and honored are less likely to undergo costly interventions such as extended ICU stays or repeated hospitalizations. Therefore, measuring the alignment of resource allocation with documented preferences serves as a critical indicator of system efficiency, ensuring that healthcare dollars are spent on services that truly align with the individual's definition of beneficial care, reinforcing the overall value proposition of robust ACP programs.

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