

Expanding and Enhancing Advance Care Planning to Promote Goal-Concordant Care

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Advance care planning (ACP) is associated with benefits for seriously ill patients, caregivers, and clinicians. As ACP usage expands, there should be greater emphasis on supporting an ongoing communication process among patients, families, and clinicians, as well as removing barriers for advance directive document completion and retrieval.

Every day, families throughout North Carolina face challenging decisions when seriously ill loved ones lose the ability to communicate their preferences for medical treatment. These families and their health care teams can be left guessing what the patient would want, risking conflicts over the use of life-sustaining interventions. As the older adult population expands and the nation reckons with the additional strain of COVID-19, seeking clarity regarding patient values takes on even greater urgency. Engaging patients and their families in discussions about their treatment goals and values prior to loss of decisional capacity to ensure goal-concordant care is possible through advance care planning (ACP).

ACP has been defined by the Institute of Medicine as “the whole process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders” [1]. It is associated with higher levels of goal-concordant care [2], greater patient satisfaction with care [3], and reduced distress for caregivers [4]. For some individuals, ACP includes creating advance directives (ADs), which are documents that enable expression of care priorities in advance of decision-making incapacity, including designating a health care proxy and preferences related to use of potentially life-prolonging interventions.

Despite the promise of ACP, only around a third of American adults have completed an AD, and there is ample research suggesting its potential has not been fully realized due to multiple factors [5]. Too often, ACP has consisted only of an AD as part of estate planning with an attorney, resulting in families and clinicians being left with outdated, stagnant documents and little understanding of the values and goals that guided the decisions or how they may have changed. Many clinicians are hesitant to engage in ACP discussions, finding them challenging given time limitations with patients and a lack of training [6].

In recent years, both health professionals and the general

public have shown greater willingness to engage in conversations about ACP. The expansion of palliative medicine and hospice services, as well as contributions from physician-authors including Atul Gawande (*Being Mortal*) and Paul Kalanithi (*When Breath Becomes Air*), have lessened the taboo around end-of-life care. Conversations about what constitutes a “good death” have become more common, and health professionals and patients have taken steps that enable them to avoid unwanted interventions and suffering. ACP initiatives have become organizational priorities at health systems across the country and gained even greater prominence with the inclusion of a Medicare billing code for ACP in 2016. It is thus more vital than ever that ACP is done in an effective and accessible manner.

In this article we provide a basic history of ACP, analyze its status in North Carolina, and highlight five guiding principles for successful ACP that can be applied at the individual, health care system, and state levels. In doing so we hope to put forth a framework for transitioning from a restrictive, legal-document-based model to an iterative, interdisciplinary one that emphasizes flexibility and accessibility for all people.

ACP and Advance Directives in the United States and North Carolina

The 20th century saw a dramatic transformation in the United States as deaths associated with acute illnesses at home increasingly transitioned to hospital deaths from chronic conditions. With this shift came a greater ability to prolong survival through increasingly complex interventions, including cardiopulmonary resuscitation, hemodialysis, and mechanical ventilation. Subsequent patient rights cases gave rise to judicial decisions recognizing patients’ right to autonomy over medical decisions, even while incapacitated, through use of loved ones’ substituted judgments and prior declarations [6].

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To promote use of standardized tools, state legislatures authorized a patchwork of state-specific ADs that vary in their exact language and requirements. The federal government subsequently passed the Patient-Self Determination Act of 1990, requiring facilities receiving Medicare and Medicaid funds to inform patients about ADs and record their presence if completed [6].

Two document types emerged as the standards of ADs: living wills, which allow patients to record end-of-life care preferences, and health care power of attorney forms, which enable individuals to designate another person to make medical decisions on their behalf if they lose decision-making capacity. In North Carolina, both types of documents require notarization and the signature of two witnesses who meet criteria stipulated in state law. Family members and health care professionals or their employees are prohibited from serving as witnesses.

The limited scope of many ADs served as the impetus behind the creation of Physician Orders for Life Sustaining Treatment (POLST) to enable clinicians and patients

(or their surrogate decision-makers) to both express general care goals and make specific decisions regarding treatment for seriously ill patients through a set of medical orders covering topics including the use of cardiopulmonary resuscitation, antibiotics, and artificial fluid and nutrition [6]. When signed by both clinicians and patients or health care agents, the POLST is intended to serve as a medical order transferable among all health center locations. Forty-eight states have implemented some version of the POLST; in North Carolina this form is called Medical Orders for Scope of Treatment (MOST).

Broadening the Vision for ACP in North Carolina

To promote concordance between patients' goals and their care, and consequently improve end-of-life care, ACP must become the norm for all adults, particularly individuals with life-limiting conditions. The historical emphasis on ADs at the expense of ongoing communication between patients, their families, and their clinicians has resulted in an ineffective process that fails to provide flexibility for decisions

not covered in ADs or for updating as a patient's condition changes. As a result, many clinicians have come to recognize that patients benefit most from a more expansive ACP process that emphasizes iterative communication as its central tenet [7]. To further societal and health care system changes already underway, we present several guiding principles for health care leaders and policymakers to expand ACP.

Equip Health Care Teams to Engage in Effective Care Planning Conversations

For physicians and advance practice providers (APPs) who care for seriously ill patients, ACP training should be a required component of both medical school education and continuing medical education akin to current requirements related to opioid prescribing. Many patients may be unaware of the decisions that may need to be made at the end of life, so providers need to be equipped for both initial communication to share information, address emotions, and elicit care goals, and subsequent decision-making conversations. Multiple online and in-person skills-based education resources for clinicians exist through organizations including the Center to Advance Palliative Care, Respecting Choices,

VitalTalk, and the Serious Illness Care Program at Ariadne Labs. While only 2.2% of Medicare beneficiaries had a billed ACP note in 2017, utilization of this billing code is expected to increase in coming years with physician and APP training [8].

Nurses and social workers may also meaningfully contribute to many ACP components, including patient education assistance about ACP decisions and eliciting patients' preferred health care decision-makers and general care goals. In one national survey, 96% of social workers who work in hospice and palliative care settings reported engaging in ACP discussions with families [9]. It is essential that these professionals also receive ongoing access to training that supports ACP skills development.

Engage Communities in Flexible, Culturally Competent ACP Approaches

Disparities in ACP completion and end-of-life care mirror those seen in other facets of health care. Despite the fact that more Americans of all races express a preference for dying at home rather than the hospital, African Americans and Latinos are more likely to die in the hospital compared with white patients and are less likely to utilize hospice ser-

vices [10, 11]. Researchers have attributed these disparities to a complex mix of factors, including a lack of trust in the medical system, religious beliefs, and an emphasis on trusting family over clinicians [12], as well as poor communication by clinicians [13]. ACP holds promise for addressing these patterns, but disparities persist in ACP completion rates. In one national survey of patients over 50 years old, 44% of white participants had completed an AD, compared to only 24% of African American participants and 29% of Latino participants [14]. To address these disparities, ACP facilitators should prioritize flexibility and cultural humility, taking into account cultural values, variable health literacy, and language barriers, especially when seeking to engage populations with lower AD completion rates [15].

Recent research has demonstrated that moving ACP education beyond hospital and outpatient clinic walls can serve as a powerful tool for patient engagement, particularly for underserved populations [16]. Partnerships with religious, civic, and fraternal groups allow for additional avenues for

considering ACP options. The use of lay navigators in partnership with trained educators can tap into existing trusted social networks and hold promise for working to address disparities seen in ACP. Additional research focused on addressing ACP disparities is vitally needed. One example is the EQUAL ACP study, currently underway, which seeks to gain a better understanding of the most effective strategies for increasing ACP completion rates among African Americans while promoting more equitable palliative care outcomes [17].

Support Surrogate Health Care Decision-makers to Engage in Iterative Planning

Many individuals find discussing ACP with their surrogate decision-makers challenging, which may result in uncertainty regarding patients' care goals and specific treatment preferences. Thus, it is vital that surrogate decision-makers are fully engaged in the ACP process whenever possible. If they understand the reasons and values behind

a patient's overarching goals and preferences, they may be better prepared to honor their loved one's wishes when confronted with crucial decisions, including those that do not clearly fit within the specified parameters of AD forms. When done well, this can enable decision-makers to make the best possible "in the moment" medical decisions while respecting the values of their loved ones [18]. Encouraging surrogates to be engaged in conversations can also facilitate ongoing ACP dialogue, recognizing that an individual's wishes may change along with their condition. Ensuring that these changes are understood by their surrogates is important for ensuring goal-concordant care throughout the serious illness trajectory from diagnosis until death.

Make Documentation Easy to Understand While Removing Barriers

For those who wish to do so, it should be easier to document wishes in writing. In recent years, a form developed by legal and medical leaders in the state entitled, "An Advance Directive for North Carolina: A Practical Form for

All Adults," has gained widespread use [19]. This form is designed to comply with North Carolina state law for both a living will and health care power of attorney while using simpler language than previous legal documents. This and other programs that provide education and simplified ADs utilizing simplified language, including Prepare for Your Care and Five Wishes, have proven useful for engaging communities with lower health literacy and diverse values and should be considered as additional documentation options.

Reconsideration of North Carolina's AD legal requirements is also warranted. North Carolina's present requirements for a notary and two qualified witnesses for ADs arose from well-intended concerns over the risk of elder abuse, but they are among the most stringent in the nation [20]. Requiring a notary can be a barrier to AD completion for some individuals. Forty-two states, including three of North Carolina's four neighboring states, recognize documents signed by two witnesses without a notary [20]. The notary requirement and witnessing rules have been suspended during North Carolina's COVID state of emergency;

removing the notary requirement permanently would ease the AD completion process in North Carolina and emphasize that these documents function primarily as clinical rather than legal tools [7].

Ensure Ready Accessibility of ACP Documentation

To maximize the impact of completed ADs, families and clinicians need to be able to access them when asked to engage in decision-making on behalf of patients. Some electronic health records (EHRs) have created a distinct ACP note for clinicians to document communication content and any relevant decisions. These notes can be accessed separately from all other documentation, which can be especially important during emergency situations and also facilitate billing for this service. All EHRs should be encouraged to implement the ACP note as part of the medical record with mechanisms in place to access it across systems.

Many health care systems encourage patients to provide copies of their ADs for inclusion in their EHR, although upload rates remain low [21]. Even when ADs are included in the EHR, clinicians may be unable to locate them if there is not a standard location for this information. A tab for all ACP materials, including clinician notes and patient-completed documents, enables clinicians to more easily access information relevant to care planning and decision-making for seriously ill patients and should be included where possible [22].

Several years ago, North Carolina created an AD registry run by the Secretary of State's office, but this program is outdated and cumbersome, requiring individuals to file documents via mail or fax, along with a \$10 fee. Hospitals and families are then expected to contact the registry and provide an identification number in order to receive a copy of the documents. Hospital systems across the state have abandoned use of the antiquated system and serious consideration should be given to shifting efforts toward online sharing of ACP documentation. North Carolina's Health Information Exchange, NC HealthConnex, may serve as a mechanism for exchanging ACP information among multiple health care systems and EHRs. An electronic version of the MOST form should also be included in this system given its growing utilization.

Conclusion

Even when all the outlined steps are completed, families and clinicians will continue facing difficult decisions for seriously ill incapacitated patients that are fraught with emotions and uncertainties. However, by engaging in robust ACP, clinicians and families can gain a deeper and more nuanced understanding of individuals' values and wishes, which can help ensure that care aligns with their goals. **NCMJ**

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