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Improving Medical-Legal Advance Care Planning

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Abstract

The importance of advance care planning (ACP) has been increasingly recognized by health systems. However, 46%–76% of patients report engaging in ACP with lawyers, whereas only a minority report doing so with physicians. In the U.S., ACP with lawyers focuses on advance directive documents, naturally occurs outside of health care contexts, and is often uninformed by the clinical context, such as one's prognosis and clinical trajectory. These forms are regularly stored at home or at a lawyer's office and not available at the bedside when needed in a medical crisis. Yet, in contrast to clinicians, lawyers hold sophisticated knowledge about their states' advance directive law. Lawyers may also understand clients' socioeconomic context and plans more broadly, which are known to be critical for contextualizing and personalizing patient care but are often not well captured in health care. Aligning medical and legal approaches to ACP is important to ensuring the quality and value of those efforts. As an important first step toward this goal, we convened an interprofessional panel of medical and legal experts to elucidate the state of medical-legal ACP and begin to identify strategies to improve and align practices within and across professions. This article describes the historical disconnects between the medical and legal practice of ACP, recommendations and products of the interprofessional panel, and recommendations for future medical-legal collaboration.

Keywords

Advance care planning; advance directives; interprofessional; workforce; law

Introduction

Advance care planning (ACP) conceptualization and practice has shifted in recent years, with a surge of attention from health care researchers, providers, payors, and systems.[1]

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Although traditionally only focused on legal documentation of end-of-life procedures, such as cardiopulmonary resuscitation, ACP has expanded to include a broader focus on decisionmaking processes across the course of serious illness, including the preparation of patients and surrogates for meaningful communication about values and goals for medical care. Clinicians and health systems are making greater efforts to engage patients in ACP and such conversations are now a reimbursable part of care.[2,3] Yet patients are likely or more likely to engage in ACP with lawyers than with health care providers. In two studies of patients in the U.S., 49%–76% reported engaging in ACP with a lawyer, versus just 6%–7% reporting such engagement with physicians.[4-6] Community lawyers, by which we mean those who assist individuals with ACP as part of life or estate planning, as opposed to those who represent health systems, are key stakeholders in improving ACP policy and practice.[7] Not only do they constitute a significant component of the ACP workforce, but they can also be important influencers of law and policy at the state level. Thus, aligning medical and legal approaches is critical. To begin to improve medical-legal collaboration concerning ACP, we convened an interprofessional group of national experts to elucidate commonalities and differences in approaches to ACP and to begin to identify strategies to bridge the professions. This article will describe the historical disconnects between medical and legal practice of ACP, the work of the interprofessional workgroup, and recommendations for future medical-legal collaboration.

Historical Context

Advance directives were developed in the 1970s as formal legal mechanisms to address two concerns: 1) to provide legal immunity to health care providers concerned about liability for withdrawing life-sustaining therapies from patients who lacked capacity to state such a preference and 2) to establish legal formalities (e.g., witnessing requirements) to alleviate fears that patients or families were being pressured into such decisions.[8] These fears were acute at that time, when life-sustaining technologies and their clinical, ethical, and legal implications were still emerging into the public consciousness.[9] The high-profile *Quinlan* and *Cruzan* cases, both involving patients in persistent vegetative states, clarified the legal right of incapacitated patients to request withdrawal of life-sustaining therapies but underlined the importance of clear, legally recognizable documentation of those wishes.[10] ACP practice subsequently focused on documentation of specific wishes for hypothetical future medical decisions such as persistent vegetative state and used legal formalities such as mandated legal language, witnessing or notarization, and signatures.[11] Community lawyers adopted this practice of ACP as a routine component of estate or life planning with clients, under the belief that such documents would be relied upon by their clients' health care providers in delivering end-of-life care.

Changing Role of Advance Directives in Clinical Care

Subsequent evidence has emerged, however, that advance directive forms have played little role in clinical care, and that their promise of immunity for following patient wishes does not necessarily change provider decision making.[12,13] Studies suggest a poor correlation between the documented wishes of patients and the care they receive, with one large study estimating that 92% of patients documenting a preference for comfort-focused care did not receive such care.[14] There may be many reasons for the lack of efficacy of advance directive documents. Given the inability of health systems' electronic health records to communicate effectively and the lack of historical collaboration between medical and legal experts, these forms are often not available at the bedside when needed. In addition, when the forms are available, they may be years old and their checkbox format my not provide the nuanced information needed for providers to understand the reasoning behind patients' preferences and whether they reflect overarching and stable goals and values for health care. During a medical crisis, this may lead providers to worry that documented preferences are neither an accurate nor current expression of patients' wishes. Clinicians may, at the time of decision making, feel that surrogates, who are provided updated clinical details when faced with specific medical decisions, are able to better articulate a choice reflective of the patient's wishes than a potentially outdated legal form.

It is also possible that clinicians' consideration of liability may play a role in medical decision making. Clinicians often perceive a greater risk in mistakenly withholding care than in mistakenly continuing treatment, and default to continuing treatment despite patient wishes.[15] Similarly, when faced with family members stating preferences contrary to a patients' documented wishes, clinicians often perceive that following family members' wishes will result in lower risk of liability.[15] These studies suggest that providers are either unaware of, or are unassured by, the fact that advance directives promise legal immunity if providers follow the patient wishes contained within them. Provider perceptions and behaviors around advance directives, including following or not following the wishes documented, have been largely unchallenged as very few end-of-life decisions ever lead to litigation and even fewer result in provider liability.[16] Of the approximately 2.5 million deaths in the U.S. each year, only 913 legal cases contesting end-of-life care decisions have been reported in total since 1914.[17]

Thus, although end-of-life decisions may be fraught for providers and surrogate decision makers, few decisions ever result in a disagreement that invokes court review. These trends, along with acceptance of person-centered care as core to modern medical standards of practice, suggest that legal immunity for medical providers is outdated as a primary function of advance directives.

Although advance directives as legal documents do not, in and of themselves, seem to affect clinical care, they can still be an important component of advance care planning when used in a manner consistent with current evidence of advance care planning best practices. "Advance care planning" has emerged as a broader, more process-focused conceptualization of end-of-life decision making in the medical community. While the focus of advance directives is legal documentation of surrogates and/or specific wishes, advance care planning emphasizes the entire process of preparing patients and their families for medical decision making and communication. This includes having meaningful conversations about a patient's goals, values, and preferences over the course of their serious illness, not just at the end of life.[18] Documentation of these conversations, either by clinicians in the medical record or in advance directive documents, is a necessary but insufficient component of this process. Thus, advance directives are useful to the extent they help prepare patients and families, help stimulate conversations, contain accurate and up-to-date content, including patients' overall values and goals and not just check box determinations of code status, and are available and relevant to clinicians when needed.[19,20] Emerging consensus around these best practices is beginning to translate into practical implementation in health systems and is supported by new reimbursement mechanisms and value-based care payment models incentivizing clinicians to adopt them.[3]

A Need to Bridge the Medical and Legal Communities

Although these changes in culture and practice have been unfolding in health care, the community lawyers who regularly draft advance directives with clients have been largely unaware of and disconnected from these changes. Although consistent with the spirit and letter of current state law, attorneys' efforts to assist clients with advance directives are unlikely to be effective unless they are cognizant of the clinical realities and emerging best practices of ACP within health systems.

Clinicians, health care systems, and the legal community share the goal that patients should have a voice in care at the end of life and that ACP is an important activity to undertake. To ensure that ACP efforts are effective, evidence-based, and legally recognized, it is important that the medical and legal communities engage with one another to align their approaches. Such efforts could improve practice among lawyers and clinicians by establishing a shared understanding of the goals of ACP and to clarify the appropriate role of lawyers and clinicians. In addition, because community lawyers are often active in state bar associations or specialty practice areas, such as elder or estate planning, this collaboration could also help generate the medical-legal consensus needed to ensure state advance directive laws reflect current ACP best practices.

To begin bridging the medical and legal communities, we convened an interprofessional panel of health and legal experts in March 2018 to better understand the disconnects and begin to develop solutions.

Methods

Interprofessional Panel

The project team identified a panel of 28 advance care planning experts from across the country, with roughly equal representation from lawyers and clinicians who practice in clinical, academic, and private settings encompassing elder and estate planning law, palliative care, geriatrics, social work, and primary care (Table 1). The team interviewed panelists to understand current medical-legal ACP practice norms, barriers, and innovations. These interviews were then summarized and provided to the panel before the convening for review. The summary was again presented to the full panel in plenary session at a daylong convening in Washington, DC. Attendees were also provided with a brief review of ACP research literature, including that related to decision aids, to ensure a baseline of understanding across disciplines. In a plenary session, attendees were asked to reflect on the state of ACP practice in medicine and law, including emerging trends and innovations. Attendees were then divided into breakout groups, with roughly equal representation from medicine and law in each and asked to identify best practices or strategies for improving and aligning ACP within and across professions. Discussions from the plenary and breakout groups were recorded and analyzed by the study team using qualitative thematic content analysis to elucidate major themes. These themes were then shared with attendees during serial e-mail rounds, in which attendees were asked to comment and respond via e-mail or phone conversation with the project team. The panel's insights as to the current state of medical ACP practice are summarized below. In addition, the panel's insights as to emerging best practices and innovations were recorded and synthesized by the project team into a draft set of shared medical-legal ACP principles and a Practice Guide for Lawyers. These drafts were refined through multiple rounds of review and feedback from panelists, submitted by e-mail and phone conversation with the project team. Panelists also had an opportunity to approve the final draft of each document.

Results

The State of Medical-Legal ACP Practice: Key Insights & Lessons

Several key themes emerged regarding the current state of medical-legal ACP practice. A first theme was the *lack of mutual awareness of ACP roles* across the professions. Clinicians were generally unaware of the extent to which community lawyers engage in ACP with clients, whereas lawyers were often surprised to learn that advance directives are considered just one, but not the ultimate, piece of information relevant to clinical decision making at the bedside. Clinicians viewed ACP as the responsibility of health care providers and institutions, whereas lawyers viewed ACP as a legal activity to effectuate individual decisionmaking rights.

A second theme was the *lack of aligned ACP practices* across professions. Although lawyers and clinicians share the same overarching goal of eliciting and respecting patient choices for care, their approaches to that end were quite different. Among lawyers, advance care planning is routinely folded into larger estate planning efforts, in which choices about health care are just some of the many considerations involved in planning for serious illness, disability, and/or death. Estate planning, often encompassing disability or incapacity planning, is the process of assisting clients with planning for living with a serious illness and/or incapacity, and eventual death. It can include providing counseling around health, legal, and financial decisions and drafting advance directives, durable powers of attorney, trusts, wills, and counseling individuals about their rights within programs such as Medicare and Medicaid. In this context, advance directives are just one of many decision points attorneys discuss with clients. Attorneys derive a broad picture of a client's social and familial network, socioeconomic status, needs, and goals but do not have access to information about the client's medical context beyond what a client may self-report.

Attorneys usually tailor advance directive forms for their clients using language adapted from state statutes or draft lengthy narrative documents that comply with state law. They focus on the appointment of a health care agent as well as specific end-of-life treatment decisions that are of particular concern in state law, such as withdrawal of artificial hydration and nutrition in the event of a persistent vegetative state. Many of these decisions and plans are made just once and are not revisited as an individual's health status changes. Although most lawyers urge clients to share documents with family and health care providers, few have routine practices designed to assist clients in doing so.

Among clinicians, ACP is increasingly process-focused and seeks to elicit patient goals of care in a broad sense, rather than specific treatment decisions about potential future care. Clinicians indicated that legal advance directives are often incomprehensible, are too lengthy, or contain specific treatment wishes which are not pertinent to the clinical situation at hand. They preferred forms written in plain, accessible language, rather than legal language, that focus on general goals and values rather than specific hypothetical future treatments, and that focus on appointment of an agent. Clinicians reported that documentation practices in health care vary widely depending on the setting of care and can range from making notes in the electronic health record to completing advance directive forms with the patient and uploading them to the health record.

Both lawyers and clinicians viewed discussion of health care agents as an important component of ACP, though lawyers seem to approach this appointment more routinely and formally than clinicians. Among clinicians, documentation of an agent in an advance directive is highly variable across settings and sometimes viewed as only necessary for patients without next of kin or those with family conflict.

Both lawyers and clinicians felt that medical-legal collaboration in ACP practice was rare, though a few models of collaboration at the individual, system, or community level were highlighted, such as the medical-legal partnership model. The medical-legal partnership model exists in nearly 400 health care institutions nationally and integrates a lawyer into health care teams to provide direct legal assistance to patients that addresses social needs such as surrogate decision making, housing, health insurance, or nutrition and income benefits. In such partnerships, the legal team can complete advance directives with patients' onsite at clinics and hospitals, help facilitate communication of those documents and wishes back to the care team, and provide training and case consults to health care teams on issues such as legal standards of capacity and the need for guardianship. Although this model exists around the country, many panelists perceived that patient/client confidentiality and lack of time or efficiency are generally barriers to medical-legal collaboration. Clinicians in particular saw coordination with lawyers as challenging, given how difficult coordination can be even within existing health care teams.

Perceived risk of litigation was a third important theme of discussion. Both clinicians and lawyers reported a need to try innovative approaches to ACP, such as new forms that include less legal language, but were often reluctant to do so because of perceived risk of litigation. As one example, most of the expert panel agreed that state statutory forms are not patient friendly or provider friendly and should be drafted in simpler language, with less mandatory language about certain kinds of decisions. However, clinicians and some lawyers expressed concern about using nontraditional forms in case they turned out not to be legally recognized and they were exposed to legal liability for following them. Lawyers expressed concern that, even where alternative forms are actually recognized as valid under most states' statutes, hospital administrators and risk managers would reject them out of a preference and custom of relying on state statutory forms. Concerns about conflicts were heightened among the clinicians and lawyers practicing in communities where ACP remains politically and culturally controversial, and where decisions to forgo life-sustaining treatment may be subject to stricter need for formal documentation. For instance, in Oklahoma, the state law explicitly indicates that every patient is presumed to consent to life-sustaining hydration and nutrition unless they complete an advance directive that is “substantially” in the form prescribed by statute.[21]

A fourth theme was that *structural differences* in the way health care and legal services are financed and delivered affect ACP practices. Lawyers reported little difficulty engaging clients in ACP discussion, whereas clinicians described ACP initiation as an ongoing challenge. This may in part be because legal services are generally self-funded and must be more actively sought, leading lawyers to encounter individuals who are already motivated to engage in planning. Estate planners and elder law attorneys generally serve middle- to high-income individuals who have sufficient literacy, self-sufficiency, and resources to seek legal help in the community. Far fewer attorneys encounter low-income individuals with a need for ACP because the demand for free legal assistance far exceeds available resources and legal aid offices often must prioritize urgent legal needs, such as eviction, over advance care planning. By contrast, health care systems serve a broad range of individuals, leading clinicians to encounter patients with varying literacy, resources, and stages of readiness for planning.

Another important difference is that legal services are typically provided by one lawyer at a time in a single office, while health care is delivered in a more fragmented manner, often with patients seeing many specialists and being seen in multiple clinics and hospitals. In a legal office, it is very clear which lawyer is responsible for helping an individual with ACP, while fragmentation in health systems creates uncertainty as to which clinician holds responsibility for initiating or continuing ACP discussions.

Finally, electronic health records can heavily shape, or fail to shape, clinical workflows and information retrieval around ACP, while lawyers’ workflows and information retrieval for clients are vastly more agile and straightforward. This is because individuals usually just have one lawyer based at one law office with one client record and system of documentation, whereas they have many clinicians spread across different settings with different records, which may or may not be interoperable. Obtaining a client ACP documentation from a lawyer’s file is thus a much simpler task than obtaining such a history from clinicians. Naturally, lawyers’ records have much more limited information about a clients’ health status relevant to their ACP, but they do hold a great deal of knowledge about patients’ social context and history which informed their planning and is often relevant to understanding their goals. For instance, to create a trust or will, the lawyer must understand the range of people in the clients’ social network that would be acceptable or unacceptable as surrogates or trustees, and why, as well as the full range of current and future economic resources available to the client and her family, such as housing, income, savings, and property. This social picture is one that health care systems increasingly recognize as critical to properly contextualizing patient care but are still struggling to capture meaningfully alongside medical information in patient records.

Recommendations and Practice Guidelines

Based on these discussions, the group identified a number of recommendations for greater interprofessional practice alignment, which the project team recorded and synthesized into a draft set of shared medical-legal ACP principles and a Practice Guide for Lawyers.[22] These were then refined through a process of iterative review and feedback from the panel.

The Practice Principles, summarized at Table 2, provide a shared medical-legal conceptual framework for ACP and serve as the foundation for the Practice Guide for Lawyers. The Principles underscore the need for attorneys and clinicians to move toward a more process and communications-focused approach to ACP. The principles highlight that the most important *legal* component of ACP is the appointment of a health care proxy and that advance directives should reflect a process of careful conversation and discussion that is anticipated to continue over time as circumstances change. Discussions and documentation of wishes should focus on goals and values, rather than specific future treatment decisions, unless those specific treatment decisions are imminent and with sufficient clinical information and context. The Principles emphasize the importance of processes to facilitate these discussions, such as use of decision aids to assist person-centered decision making, and widespread sharing of documents with a patient's health care team and caregivers. The Principles also underscore further need for medical-legal collaboration and alignment, through shared training and coordination of services.

The Practice Guide for Lawyers provides a checklist approach that operationalizes the principles into recommended workflows. In doing so, the guide recommends use of validated, evidence-based person-centered decision support tools, such as the PREPARE for Your Care program, to provide appropriate structure and framing for the conversation.[23] These patient-directed tools have also been shown to help engage individuals in ACP outside of the clinical context.[24] These tools are likely to continue to evolve as more evidence emerges to inform their development. Attorneys can send such tools to clients to review on their own in advance of the meetings, potentially improving conversations between attorneys and clients and saving clients time and cost. The guide also recommends encouraging clients to continue the ACP conversation with their health care teams and provides a sample letter that lawyers can use to send advance directives to their client's health care team. Furthermore, to enhance collaboration and communication between the medical and legal fields, the guide describes the importance of communication between the medical and legal fields and provides lawyers with a templated letter to use in sending advance directive documents to clinical providers, as well as suggested language for requesting advance directives completed in the clinical context.

The Path Forward for Collaboration

These products have been disseminated widely to both the medical and legal communities. In August 2019, the American Bar Association House of Delegates recognized and adopted the ACP practice principles, by overwhelming vote, in Resolution 103B.[25] This demonstrates encouraging progress toward a shared medical-legal consensus around ACP practice, but more is yet to be done.

Our approach contained two limitations. First, the composition and focus of our panel was such that our themes and recommendations are largely focused on addressing practice trends at the clinician and lawyer level. Although panelists did raise systems-level challenges and the need for changes to state and federal law, more extensive discussion and recommendations for such changes were beyond the scope of this panel. Second, because the inclusion of community lawyers in this discussion was novel, and a goal of this project, the Practice Guide, was largely focused on that audience. Similar practical guidance targeted to the range of clinicians engaged in advance care planning would be an important additional step in this work.

The expert panel has laid important groundwork for a path forward, highlighting key strategies and models for bridging this divide. There are important advantages for continuing this interprofessional approach. Although health systems have made progress to improve ACP over the last decade, much work remains to be done and there is increasing recognition that interprofessionalism and community partnerships are key to this work. Community lawyers are an important part of this effort, bringing sophisticated knowledge of their states' law and the potential ability to help shift its future direction. In addition, community lawyers' broader knowledge of patients' socioeconomic environment and their role in broader life planning can be an important asset to clinicians and health systems who increasingly appreciate the importance of addressing social conditions affecting patient care. Greater ACP collaboration and alignment between health and legal professionals could leverage the complementary skills, knowledge, and assets of each and advance the goal of ensuring that each of us has a meaningful voice at the end of life.

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institutions lawyers and community lawyers have distinct specialty training, practice, and culture informing their perspectives surrounding ACP. We draw this distinction to highlight that, while health system lawyers may be more engaged in and aware of ACP trends in healthcare, community lawyers are not so situated and have a distinct role with respect to ACP.

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Table 1

Panelist Expertise and Settings ($N = 28$)

	Number	Percent
Profession		
Medicine	8	26.6
Nursing	5	16.6
Social work	3	10
Law	14	46.6
Total	30	100
Setting		
Academic	18	64.28
Health care practice	2	7.14
Legal practice	5	17.85
Nonprofit/government	3	10.7
Total	28	100
Specialty		
Geriatrics	6	14.63
Hospice/palliative care	13	31.7
Bioethics	5	12.19
Elder law	9	21.95
Health care law	2	4.8
Neurology	1	2.43
Psychiatry	1	2.43
Poverty law	1	2.43
Primary care	1	2.43
Public health	2	4.8
Total	41	100
Geographic region		
Midwest	5	17.85
Northeast	11	39.28
Northwest	3	10.71
Southeast	5	17.85
Southwest	3	10.71
West	1	3.57
Total	28	100

Totals exceeding 28 are due to panelists contributing more than one area of expertise or professional training.

Table 2

Practice Principles

Principle	Definition
Proxy Designation	The most important *legal* component of advance care planning is careful selection and appointment of a health care agent/proxy in a valid power of attorney for health care document. Persons who cannot or do not want to identify a proxy should delineate their wishes in an advance directive.
ACP as Ongoing Process	Advance care planning takes place over a lifetime. It changes as one’s goals and priorities in life change through different stages of life and health conditions. Reflection, discussion, and communication with one’s proxy and clinical professionals, along with family, friends, and advisors, are essential to having one’s wishes understood and honored. These discussions should occur with patients/clients of all ages at all stages of life and health.
Focus on Values, Goals & Priorities	Discussion should focus on one’s values, goals, and priorities in the event of worsening health rather than on specific treatments or clinical interventions for distant hypothetical situations.
Advance Care Planning Tools	Advance care planning tools and guides can provide structure and guidance to the process of reflection and discussion and help individuals identify their values, goals, and priorities and ensure more authentic and useful conversations and advance directives.
Role of Advance Directive	Instructions and guidance documented in an advance directive should result from the process of information sharing, reflection, discussion, and communication and provide enough flexibility in application to allow surrogate decision-makers to respond to new circumstances and complexities.
ACP in Serious Illness Care	If individuals are facing serious diagnoses, such as cancer, or have been told they have a limited prognosis, the focus may then move to specific treatment preferences. In these cases, the person’s primary/key health care provider should also meet with the client and/or their closest loved ones to create a care plan that aligns with the client’s goals, values, and preferences. For advanced illness, medical providers should consider introducing palliative care options and the option of providing medical orders such as Physician’s Orders for Life-Sustaining Treatment (POLST) to ensure the individual’s wishes are translated by medical professionals into actionable medical orders.
Sharing Documents	Documentation of one’s values, goals, and wishes in the form of an advance directive or other record should be shared with one’s proxy, loved ones, significant others, and primary/key health care providers and be included in the medical record, so that they are adequately informed before a crisis arises.
Medical-Legal Coordination	Lawyers and health care professionals should aim for greater coordination of advance care planning efforts through congruent advice and practices in accordance with the principles above, greater willingness to reach out to one another with client/patient consent to obtain information when needed, and greater collaboration in joint continuing education programming.