

Advanced Directives and Family Practice: Implications and Ethics for “Greying” Family Systems and Interdisciplinary Collaboration

by

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I. Introduction

In recent articles in this Journal, the American Academy of Matrimonial Lawyers has addressed the aging of families and the impact of competency, guardianships, estate planning, and trusts on clients who may be separating or divorcing.¹ A serious topic, which remains unexplored, is the role of family law lawyers assisting clients who may have pre-existing medical conditions or

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¹ See Matthew Branson, Comment, *Guardian-Initiated Divorces: A Survey*, 29 J. AM. ACAD. MATRIM. LAW. 171 (2016); Jonathan E. Fields, *Grey Divorce: Tips for the Matrimonial Practitioner*, 29 J. AM. ACAD. MATRIM. LAW. 57 (2016); Nancy Levit, *Elder Law: An Annotated Bibliography, 2011-2016*, 29 J. AM. ACAD. MATRIM. LAW. 221 (2016); Rebecca C. Morgan, *Family Matters in an Elder Law Practice*, 29 J. AM. ACAD. MATRIM. LAW. 109 (2016). Other specialty journals have addressed this practice area as well. See Paula G. Kirby & Laura S. Leopardi, *The Challenging Phenomenon of Gray Divorces*, 50 FAM. L.Q. 3 (2016).

have families engaged in sustained high conflict with planning and executing advance health care planning (ACP) instruments, or advanced directives (ADs),² as a function of the “counselor” aspect of being a family lawyer.³ The demographic and social reality today is that the traditional notion of intact nuclear families is much less prevalent.⁴

² This article uses the terms “advance care planning” and “advance directives” interchangeably as there are differences in nomenclature between the states. See Rebecca Carabez & Megan Scott *Nurses Don’t Deal with These Issues: Nurses’ Role in Advance Care Planning for Lesbian, Gay, Bisexual and Transgender Patients*, 25 J. CLINICAL NURSING 3707, 3707 (2016) (“Living wills, in combination with health care proxies, are referred to as advanced directives.”).

³ The debate concerning lawyer as advocate and lawyer as counselor has been the source of decades of discussion. See Arthur T. Vanderbilt, *The Five Functions of the Lawyer: Service to Clients and the Public*, 31 ABA J 31, 31 (Jan. 1954) (“First of all, a truly great lawyer is a wise counselor to all manner of men in the varied crisis of their lives when they need disinterested advice”); see also Joseph A. Rosenberg, *Adapting Unitary Principles of Professional Responsibility to Unique Practice Contexts: A Reflective Model for Resolving Ethical Dilemmas in Elder Law*, 31 LOY. U. CHI. L.J. 403 (1999). (“Ethical dilemmas that arise in representing older people and their families are difficult for attorneys to resolve because they concern fundamental issues involving property, health care, family relationships, and mortality. Lawyers must apply norms of professional conduct within a murky landscape of human frailty and emotional turmoil in an atmosphere permeated with the dread of mental incapacity, the possible need for long-term care, and the inevitability of death.”).

⁴ For example, professionals and organizations have had to adjust to changes in the legal definition of marriage and shifting notions of who is a spouse or parent. See Lance Wahlert & Autumn Fiester, *Mediation and Surrogate Decision-Making for LGBTQ Families in the Absence of an Advance Directive*, 9 J. BIOETHICAL INQUIRY 365, 366-67 (2012) (“While the Obama memorandum secured visitation rights for LGBTQ persons in hospital and clinical settings that receive federal Medicare and Medicaid funding, it did little to affect the surrogate decision-making powers of these parties when they do not have legally honored documentation for an advance directive, health care proxy, or durable power of attorney in place—standards to which many heterosexual couples are not beholden in the United States.”). The legal literature has explored alternative methods of assisting families and health care professionals resolve disputes and decide who can or should have proxy authority. See Duncan Joseph Moore, *Medical Surrogacy Mediation: Expanding Patient, Family, and Physician Rights and Reformulating the Virginia Health Care Decisions Act*, 10 VA. J. SOC. POL’Y & L. 410 (2002); DenardVeshi & Gerald Neitzke, *Advance Directives in Some Western European Countries: A Legal and Ethical*

Given vulnerable clients already caught in the throes of litigation, or families whose fortunes and future were shaped by divorce even decades ago, clients need to understand the profound relationship between their family system and the consequences of planning estates and end-of-life decision making.⁵ The conventional notion of a son and daughter arriving at the hospital (or hospice) and making end-of-life decisions collaboratively and empathically may be a less frequent reality today. The primary caregiver for a client now aged and infirm may be an ex-daughter-in-law or legal authority may be vested in an estranged biological child rather than step-children present for years. The impact of remarriage or even extended cohabitation for people in their 50s and 60s implicates all manner of legal confusion when there is divorce or cohabitation and medical decisions to be made. Law and policy have struggled to recognize, within constitutional and statutory prerogatives, the legal status of non-biological relationships from child custody to elder guardianships which have historically been given presumptive legal status.⁶

This article addresses ADs as a function of the interdisciplinary relationship between attorneys and medical and health care providers. From a policy perspective, this article begins with a general discussion of the demographics of aging in the United States. This discussion is framed within the contemporary fragility and fracturing of family relationships common to the practice of family law attorneys and health care and mental health profes-

Comparison Between Spain, France, England, and Germany, 22 EUR. J. HEALTH L. 321 (2015).

⁵ See Gina Bravo, et al., *Promoting Advance Planning for Health Care and Research Among Older Adults: A Randomized Controlled Trial*, 13 BMC MED. ETHICS 1, 2 (2012) (“Such decision-making is all the more difficult when the wishes of the decisionally-impaired person have never been documented or discussed with family members. Indeed, the scientific literature provides ample evidence that close relatives are unable to accurately predict elderly patients’ preferences for care and willingness to engage in clinical studies of varying levels of risk and benefit.”); Jennifer Moyer, et al., *Evaluation of the Capacity to Appoint a Healthcare Proxy*, 21 AM. J. GERIATRIC PSYCHIATRY 326, 326 (2013) (“Evaluations of the capacity to appoint a healthcare surrogate are an important area of clinical practice. The incidence of diminished capacity to make healthcare decisions will continue to grow in our aging society along with the increasing prevalence of dementia and other factors affecting cognition.”).

⁶ For an early discussion of this topic, see Dallas M. High, *Families’ Roles in Advance Directives*, 24 HASTINGS CENTER REP. S16-S18 (1994).

sionals. The article then explores differences in the language and impact of state policies and the role of providers in assisting clients and patients.

Like our colleagues in other professional disciplines, we must adapt to the needs of our clients and society. The changing landscape of family law practice suggests that lawyers may have to discuss these options with clients at the time of separation and divorce. Although painful to explore with already vulnerable clients, the reality of their family system may never be as clear and a client then has an opportunity, with his or her lawyer, to consider a mechanism within an AD which may reduce conflict in the future. In this sense as well, contemporary law practice may require lawyers to better understand and collaborate with medical and mental health care professionals connecting these decisions for clients who, by way of cognitive or mental health or addiction, may possess a legal capacity to consent but may not possess the capacity to consider the power and effect of ADs without careful explanation.⁷

II. The Demographics of Greying

Compared with earlier cohorts,

baby boomers have higher levels of education and more years of work experience, which should increase their lifetime earnings and economic security as they reach age 65 and beyond but fewer children and high divorce rates means that more may live alone in old age without

⁷ This article does not reprise the numerous books and scholarship devoted to the cases that drew so much media attention to this topic of policy and ethics around the globe but the risks and values that shape the debate should never be lost. See Thomas A. Faunce & Cameron Stewart, *The Messiha and Schiavo Cases: Third-Party Ethical and Legal Interventions in Futile Care Disputes*, 183 *MED. J. AUSTRALIA* 261 (2005); Katrina George, *A Woman's Choice? The Gendered Risks of Voluntary Euthanasia and Physician-Assisted Suicide*, 15 *MED. L. REV.* 1 (2007). The philosophical and legal debate about proxy authority as substituted judgment or best interests is complex and is the subject of international study and legislation. See Nina A. Kohn & Jeremy A. Blumenthal, *Designating Health Care Decisionmakers for Patients Without Advance Directives: A Psychological Critique*, 42 *GA. L. REV.* 979 (2007); Benjamin H. Levi & Michael J. Green, *Too Soon to Give Up: Re-examining the Value of Advance Directives*, 10 *AM. J. BIOETHICS* 3 (2010); Anthony Wrigley, *Proxy Consent: Moral Authority Misconceived*, 33 *J. MED. ETHICS* 527 (2007).

either the financial and social support or informal caregiving provided by a spouse or child.⁸

Older adults have an increased risk of developing multiple chronic illnesses and many develop cognitive and mood disorders, including dementia and depression, which negatively impact their physical health.⁹ Older adults commonly have more complex health care needs, and health care is often uncoordinated among providers, which requires that the patient, families, or friends informally coordinate and advocate for the patient's care.¹⁰

As Mark Mather and co-authors posited, there are also wide disparities in the economic and physical welfare of older adults by gender and across different racial and ethnic groups. Older women are more likely to live alone than men and are twice as likely to be in poverty, and by age 50, black men and women still have lower life expectancies than their white counterparts.¹¹ Most adults in the United States still marry at least once but since 1960, less than 10% of older men and women have never been married. Increases in divorce rates beginning in the 1960s have resulted in an increasing percentage of older adults who are divorced.¹² The current growth of the population ages 65 and older is “unprecedented in U.S. history, and has important social, economic, and health implications.”¹³

Indeed, and particularly relevant for separation and divorce planning, recent changes in marriage patterns and family structure may exacerbate challenges by reducing the availability of family caregivers by geography, finances, or estrangements, for older relatives. The effects of these demographic trends will depend in large part on the policy choices that Americans make in the coming years. As Andrew Cherlin summarized the demographic literature relevant to this article, he concluded that:

⁸ Mark Mather, et al., *Aging in the United States*, 70 POPULATION BULL. 1, 2 (2015).

⁹ Symone A. McKinnon, et al., *The Effects of Age, Mental Health, and Comorbidity on the Perceived Likelihood of Hiring a Healthcare Advocate*, 14 CAL. J. HEALTH PROMOTION 45 (2016).

¹⁰ Mather et al., *supra* note 8.

¹¹ *Id.*

¹² *Id.*

¹³ *Id.*

When older persons need care themselves, how will recent demographic trends affect the likelihood that they will receive it? Family members still do most of the care of frail older people; so the changes in family patterns in recent decades – the higher level of divorce than at midcentury, the proportion of children born outside of marriage, the increase in childbearing among cohabiting partners, and the rise in multiple-partner fertility – may influence care. All of these changes have created a greater degree of complexity in family life.¹⁴

This contemporary pattern of family fragility conjoins with a generation trapped in rates of foster care, guardianships, kinship care, addiction, the school to prison pipeline from the 1980s, underemployment, and other shifts in mental health and economic and emotional capacity of parents to parent their own children.¹⁵ In addition, what the data show are that significant portions of the population were criminalized and imprisoned at younger ages with little chance of rehabilitation or relief from stigma. Among young people without resources, family structures like marriage or cohabitation are difficult to form or sustain. And endemic underemployment and unemployment, with increasing educational, technological, and wage disparities, and intergenerational poverty, create further barriers. In addition, embedded cognitive, behavioral, mental health and trauma histories and more complex substance abuse or addictions (legal or illegal) may coincide with complex and shifting forms of interpersonal violence. Finally, data reveal that almost one-fifth of young adults today live in poverty, more than double the percentage in 1973.¹⁶

¹⁴ *Id.*

¹⁵ See Lindsey A. Baker, et al., *Grandparents Raising Grandchildren in the United States: Changing Family Forms, Stagnant Social Policies*, 7 J. SOCIE-TAL & SOC. POL'Y 53 (2008) (“Definitions of ‘the family’ that idealize past, and most likely forgone, kinship structures impede the development of policies that serve families as they are currently configured. Conceptions of the modal family as nuclear with two opposite-sex parents and dependent children is now out-dated, and policies based on this model are bound to under-serve families with alternative structures.”); Bert Hayslip Jr. & Patricia L. Kaminski, *Grandparents Raising Their Grandchildren: A Review of the Literature and Suggestions for Practice*, 45 GERONTOLOGIST 262 (2005) (“Custodial grandparents, adults who are caring for their grandchildren on a full-time basis, are becoming more prevalent.”); see also Esme Fuller-Thomson & Meredith Minkler, *African American Grandparents Raising Grandchildren: A National Profile of Demographic and Health Characteristics*, 25 HEALTH & SOC. WORK 109 (2000).

¹⁶ See JUNE CARBONE & NANCY CAHN, *MARRIAGE MARKETS: HOW INE-QUALITY IS REMAKING THE AMERICAN FAMILY* (2014); HEATHER HAHN, *FED-*

The law is slow to recognize the complexity or reality of these relationships because it is often safer to presume that biology will control choice and destiny within family systems rather than to examine nuanced and complex factors in litigation or conflict. For example, research suggests that, “filial commitment of adult stepchildren to their aging stepparents has been shown to be particularly fragile.”¹⁷ But that analysis of outcomes may not factor in the lack of legal standing or the legal leverage created when an elderly parent is too fragile to push back or express consent and informed judgment. What this means to professionals is that the time to discuss and explore ADs and other forms of protection for the aging population may be at the time of divorce. For family law practitioners this may require a change in practice, although some firms already integrate estate planning and assistance for clients. This is true because family law practitioners have more knowledge and information about a family system and the barriers and challenges a client may face in the future.

III. Advanced Health Care Planning

In the United States, ACP falls within the province of state legislatures to enact as law, resulting in substantial variability between states as to types of documents available, definitions for terms utilized, and the legal requirements for valid execution of

ERAL EXPENDITURES ON CHILDREN: WHAT BUDGET POLICY MEANS FOR CHILDREN’S POLICY, SOCIETY FOR RESEARCH IN CHILD DEVELOPMENT (2015); Sheela Kennedy & Larry Bumpass, *Cohabitation and Children’s Living Arrangements: New Estimates from the United States*, 19 DEMOGRAPHIC RES. 1663 (2008); Steven Ruggles, *Patriarchy, Power, and Pay: The Transformation of American Families, 1800–2015*, 52 DEMOGRAPHY 1797 (2015); U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES ADMINISTRATION FOR CHILDREN AND FAMILIES ADMINISTRATION ON CHILDREN, YOUTH AND FAMILIES CHILDREN’S BUREAU, CHILD MALTREATMENT DATA (2015), <https://www.acf.hhs.gov/cb/resource/child-maltreatment-2015>.

¹⁷ See Merrill Silverstein & Roseann Giarrusso, *Aging and Family Life: A Decade Review*, 72 J. MARRIAGE & FAM. 1039, 1039 (2010) (“Research has found that norms of obligation toward older stepparents were consistently weaker than they were toward older biological parents. Indeed, research has demonstrated that many stepchildren do not define their stepparents as parents or even as family, which suggests a potentially muted intergenerational response to elderly stepparents with exigent needs.”).

ACP.¹⁸ The literature suggests that there was a transformation of ACPs in the 1970s from private decisions between medical care providers' "communications approach" to a more legalistic "transactional approach" in which the best interests and wishes of the patient must conform to specific legal requirements such as writings in a form adopted by legislation or rule.¹⁹ The problem that arose for clients was that health care providers often did not even know if such a form was completed and family members may not have been aware or willing to acknowledge its existence or validity.²⁰ And that confusion can be further enhanced when parties execute property settlements and revoke some but not all documents executed during or after a marriage or re-marriage.²¹ The focus of this section begins with the variability across states in ACP documents, which causes confusion in utility and efficacy.

¹⁸ Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88 MILBANK Q. 211, 218 (2010) ("In regard to the substantive elements of health care decision making, federal law has generally deferred to state substantive law, including the selection and authority of appointed agents and default surrogates. There is one exception, however. In 1996, Congress enacted a federal advance directive option solely for military personnel that explicitly preempts state law (see 10 U.S. Code § 1044c).").

¹⁹ *Id.* at 219 ("Legal formalities are intended to impress on the parties the seriousness of the transaction and its potential consequences. And because this is a legal tool that often will be signed and used without the advice of legal counsel, detailed standardized formalities are relied on to ensure the user's voluntary, knowing, and competent execution of the transaction, as well as to ensure its recognition and compliance by health care providers.").

²⁰ *Id.* at 227 ("The essence of advance care planning is captured by a broader concept of patient-centered care and the quality of communication among the individual, family, and health care providers. The conventional measures of effectiveness—that is, the accuracy of surrogate predictions or even the existence of a written advance directive, or whether there is any congruence between the directive and the care actually given—all are insufficient to capture the multiple dimensions of good communication and deliberation.").

²¹ *See In re Marriage of Keller*, 222 P.3d 1111, 1114 (Or. Ct. App. 2009) (vacating the trial court decision which found that, "It is quite interesting that decedent, on a timely basis, changed his Will after the Dissolution, revoked the Power of Attorney to his ex-wife and his Advanced Directive, giving her authority regarding his final illness. He did not change the beneficiary designation on the insurance policies.").

A. Definitions

In general, advance directives (ADs) document ACP, designate surrogate decision makers, and promote dialogue around treatment decisions.²² Advance directives may consist of living wills and health care powers of attorney that provide documentation that offer patients a legal and ethical means to avoid unwanted care in the event of incapacity.²³ The following are the American Bar Association (ABA)²⁴ definition of variations of these documents:

ADVANCE CARE PLANNING – A process for setting goals and plans with respect to medical care and treatments. It requires conversations between the individual and his or her family, key health care providers, and anyone else who may be involved in decision-making. It can begin at any point in a person's life, regardless of his or her current health state and, ideally, is documented in an advanced directive or recorded in your medical record, revisited periodically, and becomes more specific as your health status changes.

HEALTH CARE ADVANCE DIRECTIVE – The general term for any document in which you provide instructions about your health care wishes or appoint someone to make medical treatment decisions for you when you are no longer able to make them for yourself. Living wills and Durable Powers of Attorney for health care are both types of health care advance directives.

LIVING WILL – A type of advance directive in which you state your wishes about care and treatment you want or do not want if you are no longer able to speak for yourself. Normally, living wills address one's preferences about end-of-life medical treatments, but they can also communicate your wishes, values, or goals about any other aspect of your care and treatment.

DURABLE POWER OF ATTORNEY FOR HEALTH CARE (OR HEALTH CARE PROXY) – A type of advance directive in which you appoint someone else to make all medical treatment decisions for you if you cannot make them for yourself. Agent, proxy, representative, or surro-

²² See Rebecca L. Sudore, et al., *An Advance Directive Redesigned to Meet the Literacy Level of Most Adults: A Randomized Trial*, 69 *PATIENT EDUC. & COUNSELING* 165 (2007).

²³ See Kuldeep N. Yadav, et al., *Approximately One in Three US Adults Completes Any Type of Advance Directive for End-of-Life Care*, 36 *HEALTH AFF.* 1244 (2017).

²⁴ American Bar Association, *Living Wills, Health Care Proxies, & Advance Health Care Directives* (2015), https://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/living_wills_health_care_proxies_advance_health_care_directives/.

gate is the name given to the individual who will make these decisions for you.

FIVE WISHES – A document like an advance directive, which makes a person's wishes known ahead of time and addresses all of a person's needs; including medical, personal, emotional, and spiritual. (Aging with Dignity)

PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)/ MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT (MOLST)/ PROVIDER ORDERS FOR SCOPE OF TREATMENT (POST) –A set of standardized medical orders written by the health care provider after having a conversation with a seriously ill or frail patient. Implementation of these orders occurs whenever there is a medical emergency and individuals cannot speak for themselves. Orders should be consistent with the patients' goals for care and reflective of shared medical decision-making and communication between health care professionals and patients with advanced, progressive illness or frailty (National POLST Paradigm).²⁵

B. *Law and Policy Summary*

In 1991, implementation of the Patient Self-Determination Act (PSDA) was intended to ensure that healthcare institutions (primarily hospitals, nursing homes and home health agencies) and practitioners recognized, and gave patients information about, their rights under state law to complete a written AD. Federally funded health care institutions must ask patients if they have an AD. Advance directives allow adults who have the ability to decide and communicate health care wishes to give directions for future care in the event of incapacity. Passage of the PSDA occurred despite limited research about ACP in long-term care facilities; and the potential risks from impaired families, domestic violence, or elder abuse.²⁶ Even without that context, one commentator aptly summarized “on the one hand, the PSDA is relatively simple as a matter of content but, on the other hand,

²⁵ See CHARLES P. SABATINO & NAOMI KARP, *IMPROVING ADVANCED ILLNESS CARE: THE EVOLUTION OF STATE POLST PROGRAMS* (2011).

²⁶ See Joan Teno, et al., *Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention*, 45 J. AM. GERIATRICS SOC'Y 500 (1997).

the PSDA is remarkably ambitious in that it envisions the education of millions of people about complex legal rights.²⁷

This policy encompasses delicate conversations when individuals choose to transfer their rights, in the form of an AD, to a family member or, as is allowed by some states, to non-relative third parties.²⁸ Due to constraints with the medically-compromised or dying patient and the vagaries of family dynamics and demographics, the cognitive and emotional process of “informed consent” is often neglected or minimized by legal professionals or, when present, viewed as a legal problem today by medical and mental health professionals. Moreover, much more attention needs to be given to cultural competencies and the influences of race and poverty in any policy and research discussion of ADs and the intersection of informed consent (individual or proxy) with health care institutions, medical and mental health professionals, and family systems.²⁹

Professionals are obligated to respect self-determination as the right of patients “to participate fully in decisions made about them so as to ‘promote individual autonomy’ and “encourage rational decision making.”³⁰ The substitution of judgment by one human being for another implicates more than mere approval for convenience. The painful and profound lessons learned about abuses of power and authority when another person, such as someone with chronic illness or the elderly, is vulnerable have resonated through ethics and law for decades now in the realm of social justice and social welfare.³¹ Indeed, the medical profession

²⁷ Edward J. Larson & Thomas A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 WAKE FOREST L. REV. 249, 250 (1997).

²⁸ See *supra* note 4.

²⁹ See Karen Bullock, *The Influence of Culture on End-of-Life Decision Making*, 7 J. SOC. WORK IN END-OF-LIFE & PALLIATIVE CARE 83 (2011); LaVera Crawley, et al., *Palliative and End-of-Life Care in the African American Community*, 284 JAMA 2518 (2000); Kimberly S. Johnson, et al., *What Explains Racial Differences in the Use of Advance Directives and Attitudes Toward Hospice Care?*, 56 J. AM. GERIATRICS SOC'Y 1953 (2008).

³⁰ Cheryl Regehr & Beverley Antle, *Coercive Influences: Informed Consent in Court-Mandated Social Work Practice*, 42 SOC. WORK 300, 302 (1997).

³¹ See L. Rene Bergeron, *Self-Determination and Elder Abuse: Do We Know Enough?*, 46 J. GERONTOLOGICAL SOC. WORK 81 (2006); John Solas, *Is It Just Enough?*, 45 J. SOCIOLOGY & SOC. WELFARE 141 (2018).

has been quite sensitive to a physician's duty to a patient who lacks decisional capacity, particularly when the surrogate refuses what the medical profession considers a beneficial treatment.³² Since the enactment of the PSDA, nearly three decades ago, the evolution of state-by-state practices concerning ADs remains inconsistent and fragmented.

C. *Research-Based Experience*

A recent Government Accountability Office study in 2016 reviewed documents and survey data of the Centers for Medicare and Medicaid Services, reported by state survey agencies regarding provider implementation of the PSDA requirement.³³ The study found that implementation times varied. Hospital-based providers inform patients about ADs during the admission process, while Medicaid managed care plans inform patients during enrollment. Challenges faced by providers included discomfort with end-of-life discussions and lack of staff time.³⁴ Despite best efforts of the PSDA and Medicare's decision to reimburse physicians for ACP counseling effective January 2016, only one-third of the U.S. population have an AD.³⁵

A recent systematic review of 23 studies from 1994-2016 regarding professional knowledge of ACP revealed professionals knew some aspects of ACP but had minimal knowledge of the PSDA and Advance Directives.³⁶ In a study regarding inter-professional care teams of physicians, nurses, and social workers,

³² See Paul S. Mueller, et al., *Ethical Issues in Geriatrics: A Guide for Clinicians*, 79 *MAYO CLINIC PROC.* 554 (Apr. 2004); Rosamond Rhodes & Ian Holzman, *The Not Unreasonable Standard for Assessment of Surrogates and Surrogate Decisions*, 25 *THEORETICAL MED. & BIOETHICS* 367 (2004).

³³ Government Accountability Office, *Advance Directives, Information on Federal Oversight, Provider Implementation, and Prevalence*. GAO-15-416 (2016), <https://www.gao.gov/assets/670/669906.pdf>.

³⁴ See Sharda D. Ramsaroop, et al., *Completing an Advance Directive in the Primary Care Setting: What Do We Need for Success?*, 55 *J. AM. GERIATRICS SOC'Y* 277 (2007).

³⁵ See Kuldeep N. Yadav, et al., *Approximately One in Three US Adults Completes Any Type of Advance Directive for End-of-Life Care*, 36 *HEALTH AFF.* 1244 (2017).

³⁶ See Ile Kermel-Schiffman & Perla Werner, *Knowledge Regarding Advance Care Planning: A Systematic Review*, 73 *ARCH. GERONTOLOGY & GERIATRICS* 133 (2017).

62% of participants did not know the rules or policies related to ACP. Two-thirds of participants said that addressing ACP is a high priority, but clinical settings also lack systematic routines to support ACP. To improve these routines, researchers recommend training staff to be able to educate the patients and their families.³⁷

A recent survey study in an academic medical center, reported frequency of end-of-life discussions among nurses (n=349). Nearly 39% reported rarely or never discussing end-of-life (EOL) wishes with patients.³⁸ Some barriers regarding health professionals facilitating ACP discussions are patients finding the documents intimidating to complete³⁹ and the process for appointing a legal authorized decision maker burdensome.⁴⁰ Additionally, requiring witnesses or notaries for ACP documents impedes the completion and updating of these documents.⁴¹ A recent overview of eighty systematic reviews of more than 1660 original articles synthesized ACP research. Results demonstrated that many factors influenced ACP implementation, decision-making, and completion, such as patients' and providers' attitudes, and perceptions toward life and mortality.⁴²

Often the language on ACP forms makes it difficult for clients, lawyers, or patients to make their wishes known to medical providers, and the forms themselves are inaccessible when needed.⁴³ Rates for completion of ADs are even lower with pa-

³⁷ See Kelly Arnett, et al., *Advance Care Planning: Understanding Clinical Routines and Experiences of Interprofessional Team Members in Diverse Health Care Settings*, 34 *AM. J. HOSPICE & PALLIATIVE CARE* 946 (2017).

³⁸ See Peggy White, et al., *End-of-Life Discussions: Who's Doing the Talking?*, 43 *J. CRITICAL CARE* 70 (2018).

³⁹ See *supra* note 31. Studies have been replicated in various states. See Susan L. Schrader, et al., *South Dakota's Dying to Know": A Statewide Survey About End of Life*, 12 *J. PALLIATIVE MED.* 695 (2009).

⁴⁰ See Ramsaroop, et al., *supra* note 34.

⁴¹ See Joshua A. Rolnick, et al., *Delegalizing Advance Directives-Facilitating Advance Care Planning*, 376 *NEW ENG. J. MED.* 2105 (2017).

⁴² See Geronimo. Jimenez, et al., *Overview of Systematic Reviews of Advance Care Planning: Summary of Evidence and Global Lessons*, 56 *J. PAIN & SYMPTOM MGMT.* 436 (2018).

⁴³ See Jared Chiarchiaro, et al., *Reengineering Advance Care Planning to Create Scalable, Patient-and Family-Centered Interventions*, 313 *JAMA* 1103 (2015).

tients from lower socio-economic status.⁴⁴ One national survey (n=7946) demonstrated that only 26.3% of respondents had an AD. Completion was associated with older age, more education, and higher incomes, and was less frequent with non-white respondents, indicating racial and educational disparities in AD completion.⁴⁵ Current ADs may not be meeting the literacy needs of most clients or patients.⁴⁶ In addition to underutilization of ADs, another barrier to AD completion is the increased number of individuals moving to different states, and state statutes limiting their portability. The last systematic review comparing similarities and differences in the content of state AD documents was over a decade ago which demonstrates the need for a more standardized form.⁴⁷

One recent study reviewed fifteen ACP pamphlets or literature and found that there was a focus on choosing a surrogate decision maker and informing users about legal and medical documents. However, fewer than half of these resources facilitated patient clarification of values regarding quality of life (QoL) issues.⁴⁸ In shared decision-making, providers seek to understand patients' values and preferences for integration when fateful health care decisions must be made.⁴⁹ A recent study (n=304) found patient's preferences regarding dignity, pain, and burden to be present in the language of living wills and to impact EOL treatment.⁵⁰ However, the impact of religion, longevity of life, and family wishes may require additional ACP discussions and research to assess their impact on treatment decisions.

⁴⁴ See Laura C. Hanson, et al., *The Use of Living Wills at the End of Life: A National Study*, 156 ARCH. INTERNAL MED. 1018 (1996).

⁴⁵ See Jaya K. Rao, et al., *Completion of Advance Directives Among US Consumers*, 46 AM. J. PREVENTIVE MED. 65 (2014).

⁴⁶ See Rebecca L. Sudore, et al., *An Advance Directive Redesigned to Meet the Literacy Level of Most Adults: A Randomized Trial*, 69 PATIENT EDUC. & COUNSELING 165 (2007).

⁴⁷ See Gail Gunter-Hunt, et al., *A Comparison of State Advance Directive Documents*, 42 GERONTOLOGIST 51 (2002).

⁴⁸ See Douglas B. White & Robert M. Arnold, *The Evolution of Advance Directives*, 306 JAMA 1485 (2011).

⁴⁹ See Michael J. Barry & Susan Edgman-Levitan, *Shared Decision Making—The Pinnacle of Patient-Centered Care*, 366 NEW ENG. J. MED. 780 (2012).

⁵⁰ See Laraine Winter, *Patient Values and Preferences for End-of-Life Treatments: Are Values Better Predictors than a Living Will?*, 16 J. PALLIATIVE MED. 362 (2013).

The following section is a comprehensive review of current documents utilized in each state and explores major QoL terms found in ACP. Document types reviewed included: Health Care Advance Directives, Living Wills, Durable Powers of Attorney for Health Care (Health Care Proxy), *Five Wishes*, and Physician Orders for Life-Sustaining Treatment (POLST).

D. *The State Experiences*

First, three states, Massachusetts, Michigan, and New York, only offered a Health Care Surrogate form. There were multiple sites and options to obtain state ADs: Everplans, Caring Info (part of the National Hospice and Palliative Care Organization), and the American Bar Association (ABA).⁵¹ Though the ABA site was the most comprehensive, the following states were problematic in obtaining documents: Idaho, Louisiana, Nebraska, North Dakota, Oklahoma, Oregon, South Dakota, and Washington, and, therefore, not available through the ABA link. In addition, the link provided by the ABA for Nebraska did not contain the AD documents; therefore, we analyzed documents from Nebraska Department of Health and Human Services, which matched the state's statute. Washington's documents were obtained from the Washington State Medical Association. Oklahoma and Oregon states' documents were obtained from the Oklahoma Department of Health and Oregon Department of Human Services. Both documents were consistent with the one provided in the state's statute.

We also found that documents linked to *Honoring Choices* were not always consistent with documents listed with the state agencies and chose to use *Everplans* (Idaho, North Dakota, and South Dakota). Finally, the search revealed state administrative/government sites (i.e. Health and Human Services, Department of Health), and state medical or other government organizations were likely to represent the standard of care. Therefore, for those states listed on the ABA site that did not meet these criteria, we either used Everplans or found state legal sites. Finally, Louisiana only links to a Living Will so state statutes were reviewed to

⁵¹ See American Bar Association, *State Specific Advance Planning Forms* (2018), https://www.americanbar.org/content/dam/aba/administrative/law_ag ing/2018-lnks-to-st-spcifc-advnc-drcvtv-frms.authcheckdam.pdf.

obtain the Health Care Surrogate form. We carefully compared each document provided by the ABA to documents provided by Everplans, any state government agency, and documents provided within the state's statute.

There was considerable variation between the documents for the states in which the ABA used *Honoring Choices* and, therefore, we used alternative documents. These states, and the source of the document used were Florida (Agency for Health Care Administration), Idaho (Office of the Attorney General), Minnesota (Office of the Revisor of Statutes), North Dakota (MD Medical Association), Tennessee (Division of Tennessee Care), and Wisconsin (Department of Health Services). The document the ABA provided for California was missing section 2.2, which was included in the state's statute. See Table 1.

Table 1: Alternative Sources*

STATE	STUDY SOURCE	STUDY SOURCE WEBSITE
California	UCLA School of Law-Attorney General Form	https://oag.ca.gov/
Idaho	Idaho Secretary of State-Health Care Registry	https://sos.idaho.gov/
Louisiana	Everplans	https://www.everplans.com/sites/default/files/Louisiana_Advance_Directive_Form.pdf
Mississippi	Mississippi State University-Health Services (matches statute and Everplans)	http://www.health.msstate.edu/healthcenter/forms/advance_healthcare_directive.pdf
Nebraska	Nebraska Dept. of Health and Human Services	http://dhhs.ne.gov/Pages/default.aspx
Oklahoma	Oklahoma Government Website	https://www.ok.gov/
Oregon	Oregon Healthcare.gov	https://healthcare.oregon.gov/Pages/index.aspx
South Dakota	South Dakota State Bar	http://www.statebarofsouthdakota.com/p/cm/ld/fid=194
Washington	Washington State Medical Association	https://wsma.org/WSMA/Resources/Advance_Care_Planning/Advance_Directives/Advance_Directives.aspx

Second, there was variation in the structure of AD documents from state to state. Some states offered one document containing both the Living Will and Power of Attorney for Health Care, some offered two separate documents, and others offered both combined and separate documents. Furthermore, two states, Hawaii and Vermont, offered a long and short form of the AD document. Iowa and North Carolina offered both combined

and separate documents. Both state statutes contained two separate documents, therefore the separate forms were used. Virginia and Vermont offered a combined document or a separate Power of Attorney for Health Care only. The combined documents for these two states were used in the analysis. For the two states that offered a long and short form of the AD document, the long forms were analyzed. The long forms included the same information as the short forms, but also included some additional instructions, ACP terms, and options. Hawaii's long form was included in the state's statute and used in the analysis. Vermont's statute did not include the document, but since the purpose of the study was to analyze the document's content, the long form was used.

1. Form Variations

There was variation in the structure of AD documents from state to state. Some states offered one document containing both the Living Will and Power of Attorney for Health Care, some offered two separate documents, and others offered both combined and separate documents. Furthermore, two states, Hawaii and Vermont, offered a long and short form of the AD document. Iowa and North Carolina offered both combined and separate documents. Both state statutes contained two separate documents; therefore, the separate forms were used. Virginia and Vermont offered a combined document or a separate Power of Attorney for Health Care only. The combined documents for these two states were used in the analysis.

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2. Results

There were four major focus areas in the documents for advance care planning (ACP): prolonging life, addressing pain, quality of life, and end-of-life issues. The graphic representation in Figure 1 illustrates the importance of using these topics to guide discussions with clients, families, and providers. The over-

lapping concentric circles provide a visual representation of the fluidity of these essential content areas.

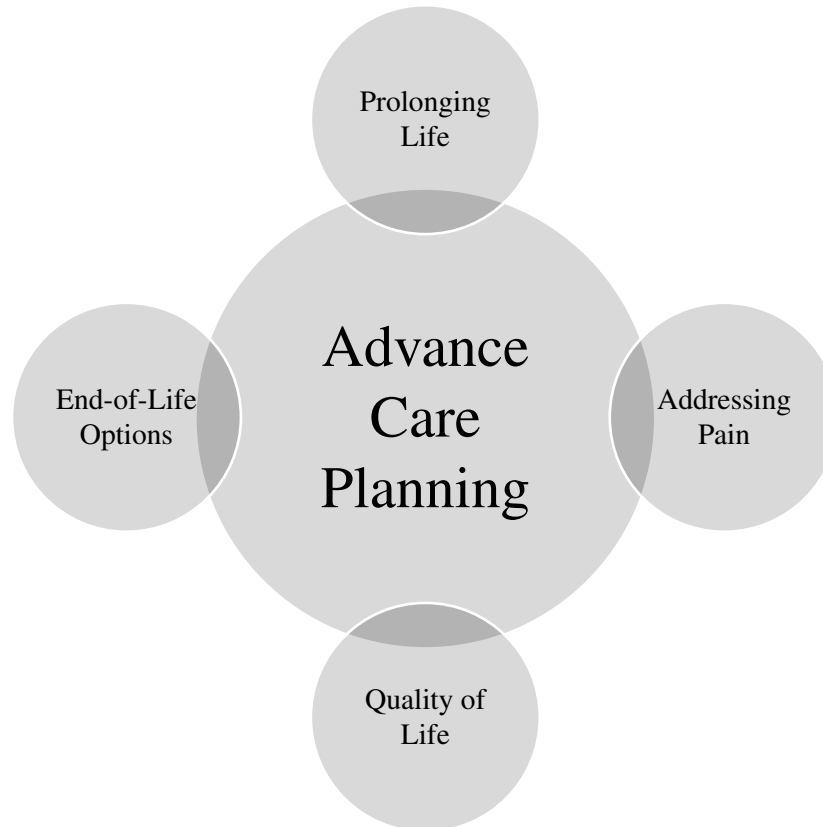


Figure 1. Interconnected ACP focus areas

Each of the focus areas are interconnected in patient care. Quality of Life encompasses the ability to communicate and attend to daily living skills. End-of-Life Options encompass the variability in choices such as use of a ventilator or feeding tube. These areas of focus are intertwined with prolonging life and addressing pain in the end of life period. Within these areas of focus states which addressed these ACP topics were identified. There was variability in the language used around these content areas and the content areas were not included in all states. One approach to guide ACP communication with patients and their families would be to address all four of these major focus areas.

Ongoing ACP discussions should proactively occur with patients and families throughout the life span with associated health changes.

Table 2 contains quotes from the source documents that are representative of each of the focus areas. Examples given for prolonging life demonstrate ambiguity in the language “accepted healthcare standards” or “reasonable health-care standards.” Interpretations vary according to the identified statutory language, including comparisons between states like Missouri, which has a checklist format, or Maine which addresses quality of life concerns such as eating and incontinence or immobility, and Pennsylvania which is oriented around disease pathologies. Table 2 highlights differences in language and approaches to forms and policy which have serious complications for lawyers and health care providers assisting with informed choice and self-determination. Moreover, lawyers, in particular, must consider the mobility of clients moving between states when providing counseling and advice.

Table 2. Quotes from state AD forms representing ACP focus areas

Prolonging Life	Addressing Pain	Quality of Life	End-of-Life Options
<p>Staying alive is more important to me, no matter how sick I am, how much I am suffering, the cost of the procedures, or how unlikely my chances for recovery are. I want my life to be prolonged to the greatest extent possible in accordance with reasonable medical standards. (Illinois)</p> <p>___Choice to Prolong Life—I want my life to be prolonged as long as possible within the limits of generally accepted health care standards. (Hawaii)</p> <p>___Choice to Prolong Life I want my life to be prolonged as long as possible within the limits of generally accepted health-care standards. (Mississippi)</p>	<p>I know that even if I choose not to have life sustaining treatment, I will still get medicines and treatments that ease my pain and keep me comfortable. (Alabama)</p> <p>I further direct that (check all boxes that apply): ___Treatment be given to maintain my dignity, keep me comfortable and relieve pain. (Montana)</p> <p>RELIEF FROM PAIN: Except as I state in the following space, I direct that treatment for alleviation of pain or discomfort be provided at all times, even if it hastens my death (California)</p>	<p>A quality of life that is unacceptable to me means when I have any of the following conditions (you can check as many of these items as you want): ___Permanent Unconscious Condition: I become totally aware of people or surroundings with little chance of every waking up from the coma. ___Permanent Confusion: I become unable to remember, understand or make decisions. I do not recognize loved ones or cannot have a clear conversation with them. ___Dependent on all Activities of Daily Living: I am no longer able to talk clearly or move by myself. I depend on others for feeding, bathing, dressing and walking. Rehabilitation or any other restorative treatment will not help. ___End-Stage Illnesses: I have an illness that has reached its final stages in spite of full treatment. Examples: Widespread cancer that does not respond anymore to treatment; chronic and/or damaged heart and lungs, where oxygen needed most of the time and activities are limited due to the feeling of suffocation (Arkansas)</p>	<p>Nutrition and Hydration, Surgery, Antibiotics, Mechanical Ventilation, Radiation Therapy, Dialysis, Chemotherapy, CPR (Missouri)</p> <p>Artificial Breathing by a Machine Connected to Tube in the Lungs, Artificial Feeding or Fluids Through Tubes, Surgery, Dialysis, Antibiotics, Blood Transfusions (North Dakota)</p> <p>Life Prolonging Procedures be Withheld, CPR, Mechanical Ventilation (Breathing Machine), Dialysis (Kidney Machine), Surgery, Chemotherapy (Pennsylvania)</p>

IV. Policy and Practice Implications

In the United States, the policy debates concerning ACPs have engendered considerable public litigation, which may have impaired the efficacy of ACPs as private matters between patient, family, and medical professionals.⁵² One scholar has summarized the legal history, functions, and purposes of ACPs as follows:

Since the mid-1970s, health care advance directives have been promoted as the primary legal tool to communicate formally one's health care wishes regarding end-of-life care and, presumably, to enhance the likelihood that one's wishes are followed by health care professionals. These documents spell out one's health care goals and instructions and appoint an agent or proxy decision maker in the event of incapacity. Whether advance directives laws offer a viable approach to that goal, however, is still very much an open question.⁵³

Since the 1970s, high-profile court cases involving treatment and right to life/death for persistently vegetative patients convinced many people to sign ADs while Congress passed legislation requiring health care institutions to inform patients about ADs on admission. Whether this was legally or medically a "false promise," as Perkins argued, is a legitimate question.⁵⁴

⁵² See, e.g., *Karpel v. Inova Health Sys. Serv.*, 134 F.3d 1222, 1225 (4th Cir. 1998) ("An Advanced Directive was found later, indicating that Gonzalez did not want resuscitation, and the hospital only gave the white LPN verbal counseling regarding the breach of hospital policy. Karpel claims that the white nursing staff reacted negatively to a black nurse criticizing a white nurse, and began a "campaign of harassment" directed against her."); *In re Estate of Border*, 68 A.3d 946, 955 (Pa. Super. Ct. 2013) ("The essence of the Supreme Court's holding in *In re Fiori*, that a person's right to self-determination does not cease upon incapacity, is echoed in the Health Care Agents and Representatives Act, 20 Pa.C.S.A. § 5421 et seq. (the "Act"), which is Chapter 54 of the larger Probate, Estates and Fiduciaries Code.").

⁵³ Sabatino, *supra* note 18, at 212. Professor Nancy Levit kindly shared the point that her colleague, Bill Colby, Nancy Cruzan's family's lawyer, raised in his books, *Long Goodbye*, and *Unplugged*, that the forms matter much less than the conversation among family members. We thank her for sharing that insight.

⁵⁴ See Henry S. Perkins, *Controlling Death: The False Promise of Advance Directives*, 147 ANNALS INTERNAL MED. 51 (2007). For a review of case law and its impact see, Kathy Cerminara, *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases*, 35 STETSON L. REV. 147 (2005).

In 1993, in response to the early cases, the Uniform Law Commission, National Conference of Commissioners on Uniform State Laws adopted the Uniform Health-Care Decisions Act.⁵⁵ The Commissioners argued that, “in an increasingly mobile society where an advance health-care directive given in one state must frequently be implemented in another, there is a need for greater uniformity.”⁵⁶ As of 2018, however, only six states had adopted the Uniform Act.⁵⁷ The reasons for so little progress toward uniformity are many. From a political perspective, the reality is that a uniform approach to ACPs has been stymied by objections from stakeholders and a sense that one size may not fit all since states approached this legislation with varying degrees of political will.

The largest organization of lawyers in the United States, the American Bar Association, published an on-line summary of the law regarding advance planning in 2015.⁵⁸ First, all fifty states permit competent adults to express their wishes regarding medical treatment in terminal illness or traumatic injury situations, including the appointment of a third person to communicate for them in the event they are unable (as the law may define that capacity in each state). Depending on the state, these documents are known by the nomenclature as “living wills,” “medical directives,” “health care proxies,” or “advance health care directives.” The efficacy of these documents in the context of family dynamics, racial and cultural differences, and even the capacity of minors to engage in such planning remain sources of legal and policy discussion in each state.⁵⁹

Some states have a standardized or statutory form, while other states, such as Florida, allow individuals to draft their own

⁵⁵ See Gunter-Hunt, et al., *supra* note 47.

⁵⁶ NATIONAL CONFERENCE OF COMMISSIONS ON UNIFORM STATE LAWS, UNIFORM LAW COMMISSIONERS, *Uniform Health-Care Decisions Act 1* (1994), <https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=ecc54f21-ed44-3b22-7350-4b4861e751c9&forceDialog=0>.

⁵⁷ *Id.*

⁵⁸ American Bar Association, *supra* note 51.

⁵⁹ See Catheryn S. Koss & Tamara A. Baker, *Race Differences in Advance Directive Completion: The Narrowing Gap Between White and African American Older Adults*, 29 J. AGING & HEALTH 324 (2017); Susan P. Shapiro, *Do Advance Directives Direct?*, 40 J. HEALTH POL., POL'Y & L. 487 (2015).

documents. State laws may also have specifications regarding who and how many are required to witness these documents, and some hospitals, as a matter of policy, will not permit employees to act as witnesses. These practices still have unintended negative consequences on patient autonomy and self-determination by virtue of excessive legalistic requirements such as poor readability, agent restrictions, execution requirements, insufficient reciprocity between states and even institutions, and lack of precise attention to religious, cultural, and social issues. These barriers may prevent patients from making and communicating end-of-life wishes and having them honored by families or institutions.⁶⁰

The development of legal restrictions has arguably rendered ADs less clinically useful. Consequently, the legal profession and government have become the gatekeepers of forms and enforceability through complex requirements that make choice and preference more a function of strict formality rather than intent and ethical respect for human dignity at the end of life. A collateral consequence is that these fragmented and complex laws encourage medical professionals and institutions to self-protect from litigation rather than support a patient right to self-determination in a feedback loop unlikely to serve patient interests in an effective manner at a vulnerable time.

Beyond delivery of uniform language and accepted-standards common in all states for defining the medical status of a patient, there is the inevitable risk that any family dispute, no matter how carefully the instrument is drafted, will result in court action.⁶¹ In many respects, this challenge is one that will define a limited number of cases, but those cases will then define the reliability and efficacy of a uniform document. This challenges the health care professions to consider the rights of the patient, rather than the political or familial interests as a private solution. In cases where there is no written document at all, then courts will appoint a guardian or other legal proxy and proceed under state law from that point. Nevertheless, even in that circumstance, clearer definitions as to the state of life or quality of

⁶⁰ See Lesley S. Castillo, et al. *Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care*, 154 ANNALS INTERNAL MED. 121 (2011).

⁶¹ See David M. English, *The Uniform Health-Care Decisions Act and Its Progress in the States*, 15 PROB. & PROP. 19 (2001).

human life may reduce public events, which create so much hardship, expense, and uncertainty. The challenge remains to determine efficacy of expressed intent and wishes in the context of ACPs in the courts when there is so much variation in the forms and criteria for defining quality of life or end of life.⁶²

This is of critical importance, given the modern movement of adults between states and countries; an adult may require different or additional documents even if vacationing, much less spending significant time in another jurisdiction. Specific consideration must be given to the enforceability of these directives for non-married cohabitating couples and same-sex spouses. The U.S. Supreme Court has required recognition of marriage in this area of estate and health care planning, yet challenges to these ADs remain largely uncharted.⁶³ As such, lawyers will need to engage in more professional collaborations at the point of separation and divorce because these changes in family structure for older clients will implicate serious decisions for future care and planning. How to develop such an approach and teach and train lawyers and medical and mental health professionals to speak a language of responsibility and choice over rights and legalisms is a challenge.

V. Future Directions

Interprofessional Collaborative Practice (IPCP) is when multiple health workers from different professional backgrounds work together with patients, families, and communities to deliver the highest quality of care.⁶⁴ One of the major competencies of IPCP encompasses a shared set of values and ethics. This competency focuses on practicing with mutual respect and places the

⁶² See Joshua E. Perry, et al., *The Terri Schiavo Case: Legal, Ethical, and Medical Perspectives*, 143 ANNALS INTERNAL MED. 744 (2005).

⁶³ See Kathy L. Cerminara & Joseph R. Kadis, *Give Me Liberty to Choose (a Better) Death: Respecting Autonomy More Fully in Advance Directive Statutes*, 10 ST. LOUIS U.J. HEALTH L. & POL'Y 67 (2016); Margaret W. Hickey, *Estate Planning for Cohabitants*, 22 J. AM. ACAD. MATRIM. LAW. 1 (2009); Samuel Schoonmaker & Wendy Dunne DiChristina, *Repercussions of the Windsor Decision Beyond DOMA: Family, Tax, Estate, and Employment Issues*, 47 FAM. L.Q. 409 (2013).

⁶⁴ World Health Organization, *Framework for Action on Interprofessional Education and Collaborative Practice* (2010), http://www.who.int/hrh/resources/framework_action/en/.

patient at the center within the context of cultural diversity.⁶⁵ Interprofessional collaborative teams may seek to provide care focused on “What Matters.”⁶⁶ Living Wills (and their variations state-to-state) were created to preemptively alleviate the burden for families and professionals facilitating decisions.

Client choices and values affecting care remain unknown if these documents are underutilized or seen only as legal documents without regard to the family system. When there is a clear understanding of language and definition of terms, then patients, families, and providers are able to have a more explicit and informed dialogue. The various documents and variability in language makes accessing and completing ACP documents cumbersome for all stakeholders. It is imperative to have meaningful documents for patients, families, and providers to aid in ACP.⁶⁷

There are, as discussed here, barriers to AD completion for lay people, such as terminology, literacy, comprehension and knowledge of forms, mobility of moving to a different state, and health disparities. In an effort to increase AD completion, it is recommended to consider the use of IPCP to share ideas and knowledge with laypersons and develop user friendly models which encapsulate QOL terms to begin the conversation.⁶⁸ If an ACP is not completed, and the patient arrives in an acute setting during a critical illness or EOL care, then a hospitalist versus a primary care physician or lawyer most likely will facilitate the discussion, without any depth of knowledge concerning the patient/client or family system.⁶⁹ Clients may be more apt to in-

⁶⁵ See DAVID G. SATIN, *HEALTH MANAGEMENT FOR OLDER ADULTS: DEVELOPING AN INTERDISCIPLINARY APPROACH* (2009).

⁶⁶ See Michael J. Barry & Susan Edgman-Levitan, *Shared Decision Making—The Pinnacle of Patient-Centered Care*, 366 *NEW ENG. J. MED.* 780 (2012).

⁶⁷ See George R. Luck, et al., *Advance Directives in Hospice Healthcare Providers: A Clinical Challenge*, 130 *AM. J. MED.* e487 (2017).

⁶⁸ See Susan MacLeod Dyess, et al., *Increasing Rates of Advance Care Planning Through Interdisciplinary Collaboration*, 127 *AM. J. MED.* 1142 (2014).

⁶⁹ See, e.g., *In re Guardianship of Tschumy*, 853 N.W.2d 728, 748 (Minn. 2014) (“Courts are ‘ill-equipped to pass judgment on the specialized expertise required of a physician, particularly when such a decision is likely to have a direct impact on human life.’ The district court, of course, has the authority to intervene when the interested parties disagree about the appropriate course of

clude their values and choices when they are healthy or making decisions as comprehensive aspects of their lives at that time.⁷⁰

In addition, the implications of international application of ACPs given globalization and the mobility of modern families requires additional study.⁷¹ Interprofessional teams, including the legal profession, must be culturally sensitive and aware of fragile family demographics and the vulnerability of patients who may have elected ACPs but whose family members may oppose them

action. But in this case, when the guardian, the involved medical staff, and the hospital ethics committee all agreed that it was in Tschumy's best interest to discontinue life-sustaining treatment, the guardian did not need prior court approval to consent to discontinuation of that treatment.") (citation omitted). The dissenting opinion, however, summarized the competing demands and challenges in a society with increasing guardianships for children and adults:

We deal here not with the more typical end-of-life treatment circumstances in which competent adults have expressed their wishes, or better yet, have prepared health care directives, or in which family or even close friends may well know the wishes of the patient. Rather, for many of our fellow citizens who are cognitively impaired, it is a different story. It is not unusual for the disabled to have the assistance of court-appointed guardians. Perhaps those guardians have some training or knowledge on making end-of-life decisions, and perhaps not. Perhaps those guardians have the best interests of the ward in mind, and perhaps not. Perhaps the ward has expressed a view on medical care, and perhaps not. But once the decision is made by the guardian to withdraw medical care, for good or ill, whether for sound motives or base motives, whether that decision is well informed from a medical perspective or otherwise, it will be made in silence and with no check or review of the guardian's judgment.").

Id. at 752 (Anderson, J., dissenting).

⁷⁰ See, e.g., *In re Estate of Allen*, 848 N.E.2d 202, 215 (Ill. App. Ct. 2006) ("Unlike the emergency exception to the informed consent rule, the Act does not outline the prerequisites to the lawful administration of medical treatment without some form of actual consent. Rather, the Act is intended to define the circumstances under which surrogate decision makers can make medical treatment decisions and decisions to terminate or forego life-sustaining treatment on behalf of patients lacking decisional capacity who have not executed advanced directives. 755 ILCS 40/5, 15 (West 1998). Simply stated, the Act provides a means of obtaining consent, while the common-law emergency exception provides a means of obviating consent.").

⁷¹ See Rachel Z. Carter, et al., *Advance Care Planning in Australia: What Does the Law Say?*, 40 AUSTRALIAN HEALTH REV. 405 (2016); Claudia B. Maier, *The Role of Governance in Implementing Task-Shifting from Physicians to Nurses in Advanced Roles in Europe, US, Canada, New Zealand and Australia*, 119 HEALTH POL'Y 1627 (2015).

on religious or other grounds or where bias of professionals may influence decision making.⁷² Finally, cultural differences may present barriers to the availability of information concerning ACPs, a level of comfort with this form of discussion between family members, or an exploration of informed consent which is appropriate for specific cultures, languages, education levels, and values, for example.

For family lawyers, there is a need to examine the traditional “silo” into which much of family law counseling and lawyering falls. Client resistance due to emotional hardship during separation and divorce may prove a barrier to these discussions in many cases. Research does not reveal the responses of clients to even the question of planning for life and death with lawyers; nor is this an inherent part of most family law practices (though it may be in a firm with different specialties).⁷³ What does matter, however, is recognition that contemporary family systems, as well as our communities, have markedly shifted in structure and values which implicates informed consent and substituted judgment with increasing complexity. This suggests a need for all of professions to shift their focus to client needs and experiences with carefully targeted educational programs consistent with the research, which “may help to assuage the fear of death and help patients to develop a greater sense of efficacy with regard to their health regimens. Such steps may help remove cognitive or emotional barriers to end-of-life planning.”⁷⁴

⁷² See Zara Cooper, et al., *Withdrawal of Life Sustaining Therapy in Injured Patients: Variations Between Trauma Centers and Non-Trauma Centers*, 66 J. TRAUMA 1327 (2009).

⁷³ See Gregory C. Sisk & Pamela J. Abbate, *The Dynamic Attorney-Client Privilege*, 23 GEO. J. LEGAL ETHICS 201, 217 (2010) (“In such an integrated practice, the provision of non-legal professional services may become intertwined with and vital to an effective and holistic legal representation. When such interdisciplinary services are performed for the purpose of obtaining legal advice or facilitating the legal representation, they become assimilated with the legal services.”). For an insightful article from a psychologist’s standpoint, see Bruce J. Winick, *Client Denial and Resistance in the Advance Directive Context: Reflections on How Attorneys can Identify and Deal with a Psycholegal Soft Spot*, 4 PSYCHOL., PUB. POL’Y & L. 901 (1998).

⁷⁴ Deborah Carr & Dmitry Khodyakov, *Health Care Proxies: Whom Do Young Old Adults Choose and Why?*, 48 J. HEALTH & SOC. BEHAV. 180, 190 (2007) (“Carefully targeted educational programs or cognitive therapy may

help to assuage the fear of death and help patients to develop a greater sense of efficacy with regard to their health regimens. Such steps may help remove cognitive or emotional barriers to end-of life planning.”).