

Older Adults and Health Care Decision-Making in Clinical Settings

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David Godfrey, American Bar Association Commission on Law and Aging

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The American Bar Association Commission on Law and Aging (ABA COLA) is a collaborative and interdisciplinary leader of the Association's work to strengthen and secure the legal rights, dignity, autonomy, quality of life, and quality of care of aging persons.

The Commission accomplishes its work through research, policy development, advocacy, education, training, and through assistance to lawyers, bar associations, and other groups working on issues of aging.

Introduction

When older adults lack capacity and have nothing in writing naming a person to make health care decisions, how are these decisions made in clinical settings?

Over the past 40 years, nearly every state has passed statutes on health care decision-making.¹ Though the laws vary from state to state, many statutes include standard forms for "living will directives" or "Powers of Attorney for Health Care," and specify signing requirements for the advance directives to be valid. Most states have statutes defining a default health care decision-maker to make decisions when no one is named in writing, and many of the statutes define conditions under which life prolonging or life sustaining care can be withheld or withdrawn.²

With these state laws now in place, it is time to ask:

1. Have state health care decision-making statutes made a difference?
2. Do the statutes offer meaningful guidance in health care decision-making in a clinical setting?
3. What works and what does not?
4. What other options are available through training and policy development?

In 2016 with funding from the **Retirement Research Foundation**, the **American Bar Association Commission on Law and Aging**, in collaboration with the **Society for Critical Care Medicine** and **Society for Hospital Medicine** undertook a study to gain insight into the issues. This Advanced Issue Brief for the National Center on Law and Elder Rights explores the information generated from that study and interprets it for a legal services and aging network audience.

Health Care Consent History

Health care providers have been seeking patient consent for medical treatment as long as humans have practiced medicine.³ Criminal and tort law classify medical treatment without consent as battery.⁴ When the patient has the ability to say yes or no, this is fairly straight forward. However, it is an especially challenging issue when the patient lacks the ability to make and communicate a choice.⁵ While laws developed over the past 50 years allow adults with capacity to name someone in writing to make health care decisions, the vast majority of American adults have not initiated this process.⁶ Determining who may give consent when the patient lacks this capacity is an ongoing challenge in both medicine and the law.

Why is Health Care Decision-Making Important for Older Adults?

Health care decision-making impacts the quality of life and quality of care of older adults. In an ideal world, we would all live a long and active life and die suddenly uttering last words that express profound wisdom. But the reality is that about 70% of us will experience at least a brief period of time when we are unable to communicate before our deaths.⁷ The majority of Americans say they want to die at home, however, 70% of Americans will die in an institutional setting.⁸ The standard of care in health care facilities is to provide all available care short of futility, unless there is consent to provide less. Despite this being the standard of care, studies show that 98% of patients, if offered a choice, would prefer less aggressive treatment when death is imminent.⁹ Delays or conflict in obtaining consent can result in patients receiving medical care that they do not want, or medical care that is intrusive, unpleasant or expensive.

The American Bar Association Commission on Law and Aging Survey

The ABA COLA in collaboration with the Society for Hospital Medicine and the Society for Critical Care Medicine, emailed an online survey to about 45,000 health care professionals and received 527 responses. The survey started with a fact pattern that asked respondents to assume that the patient lacked capacity (ability) to make and or communicate health care decisions, and there was nothing in writing naming a person to make health care decisions. The survey asked a series of questions of increasing complexity, with differing combinations of family and friends available to discuss health care options and to ask for consent, and questions about health care decisions when there is no readily available family or friends. This issue brief details the key survey findings and recommends potential training and practice changes for legal services, the aging and disability network, health care providers and policymakers to better facilitate health care decision-making for older adults who lack capacity.

Statutory Clarity Helps Promote Alignment Between the Law and Clinical Practice

The study revealed a key finding regarding the importance of clear legal guidance: **when there is a clear answer, the law and clinical practice mirror one another.**

44 states have statutory provisions creating a preference for next of kin to make health care decisions for a patient who lacks capacity, unless there is a designation in writing naming a different person as a health care surrogate.¹⁰ The survey results demonstrated that health care professionals overwhelmingly defer to next of kin when seeking consent for a patient who lacks capacity *when state statute clearly directs* the professional to do so. For example, one hypothetical situation posited a disagreement between the spouse of the patient and an adult child of the patient. In this situation, over 90% of the respondents indicated that they would frequently ask the spouse for consent. Similarly, when presented with a disagreement between the patient's only adult child and a close friend of the patient—nearly 80% of respondents said that they would accept consent from the adult child (the legal next of kin as presented in the facts for that question).

Survey results indicate that the common statutory preference for legal next of kin as the health care decision-maker aligns well with clinical practice.

Based on this reality, to better facilitate health care decision-making for older adults who lack capacity, health care associations, policymakers, legal services organizations and the aging network should consider:

- Providing training for health care providers on state specific default health care surrogate rules, with a focus on legal next of kin in most states;
- Training legal providers to consider the importance of family harmony; and
- Creating or updating family default surrogate laws so that they mirror clinical health care practice.

Disputes Between Surrogates of the Same Class Require Legal and Clinical Clarity

When clinicians turn to the next of kin to make a decision, there are often multiple family members of equal relationship to the older adult, making the decision-maker more difficult to determine. The survey presented this hypothesis and asked who the health care provider would accept consent from when the available decisions-makers were the patient's three adult children, with two of the three being in favor of a DNR (do-not-resuscitate) order and one disagreeing. The majority of clinicians said they would seek guidance from an ethics committee or risk management/legal counsel. In the narrative comments, many respondents said that they would consult with a wide array of experts to try to reach consensus.

This practice counters the fact that over one-third of states have a statutory provision that allows for majority rule in the event of this type of dispute.¹¹ In five of the six states that have majority rule provisions, respondents were more likely to “never” accept majority rule, than to do so “frequently.” **Clearly, the provision in the law intended to resolve this type of dispute has not changed clinical practice.**

To improve clarity when there is a dispute between surrogates between the same class, health care providers should:

- Improve training programs in states that have majority rule provisions;
- Strengthen and empower ethics committees; and
- Engage experts in building understanding and reaching agreement.

Policymakers may want to consider updating laws to recognize the value of consensus and family harmony—allowing for alternative resolution before court action.

The Challenges of Patients with No Readily Identifiable Family or Friends

When an older patient lacks capacity and has no readily identifiable family or friends they are sometimes referred to as “unbefriended”¹² or unrepresented. In the survey, clinicians indicated that patients without readily identifiable family or friends to make health care decisions present a huge challenge to health care providers.

Respondents were offered six answer options for when asked whom they would seek consent from for a patient who lacked capacity and had no available family or friends. (See chart below.)

Data from all states	Frequently
Seek the opinion of a second physician.	55.25%
Seek guidance from an ethics committee or consultant.	58.19%
Seek guidance from hospital risk management, or legal department.	45.23%
Seek court-ordered guardianship.	39.29%
Make a decision yourself, abiding by professional ethics and standards.	10.53%

The data demonstrates more by a lack of a leading answer, than it does by the answers received. The narrative comments said that in some hospitals ethics committees are very helpful, and in other facilities ethic committees are not at all helpful. Several comments talked about the difficulty and time involved in seeking guardianship.

Fifteen states have statutory provisions for making health care decisions when the incapacitated patient does not have available family or friends. The survey looked at state-by-state data from five of those states.

- Georgia and Texas allow the treating physician in consultation with a second physician to make health care decisions. In Georgia this option came in a distant third, in Texas it tied for second choice, with data showing very little preference for one model over another.
- In Florida the statutory model of seeking guidance from an ethics committee or consult was selected by a little more than half of respondents, but an equal number said that two physicians would make health care decisions, a process not recognized by Florida law.
- In North Carolina the statutory provision allowing the treating physician alone to make health care decisions came in dead last with only 8% of respondents indicating that they would frequently do this.

*= preference under state law

Frequently would	All Data	Florida	Georgia	North Carolina	Texas
Seek the opinion of a second physician. - Frequently -	55.25%	56.25%	*28.57%	69.23%	*70.00%
Seek guidance from an ethics committee or consultant.	58.19%	*56.25%	57.14%	38.46%	75.00%
Seek guidance from hospital risk management, or legal department.	45.23%	46.67%	33.33%	41.67%	70.00%
Seek court-ordered guardianship.	39.29%	60.00%	25.00%	33.33%	20.00%
Make a decision yourself, abiding by professional ethics and standards.	10.53%	6.25%	28.57%	*8.33%	14.29%

Clearly, patients who lack capacity and do not have readily identifiable family or friends continue to provide the greatest challenge in clinical health care decision-making. The attempts to provide statutory answers to this challenge do not appear to be making a significant difference in front line practice. The narrative comments demonstrate that strong ethics committees are helpful. The comments also reveal that often careful investigation will identify family or friends for seemingly unbefriended patients, and that guardianship is time consuming—with the patient receiving all available care while the process slowly moves forward. The comments indicated that filing for emergency guardianship is frequently not available. This is due to the fact that as long as the patient is in the hospital, there is no imminent threat to the patient to base an emergency request on.

To improve clarity when there is no identifiable family or friend, health care providers should be encouraged to:

- Identify persons at risk of not having family or friends to make decisions and encourage/facilitate advance care planning, including identifying potential surrogates; and
- Train their health care providers on statutory provisions for making health care decisions for this population.

In addition, policymakers should consider streamlining the guardianship process when health care decisions need to be made.

Conflicting Legal and Clinical Practice Standards

Health care providers and lawyers differ in how they discuss health care decisions. When health care providers were presented with a fact pattern with more than one person being interested in the health and well-being of a patient who lacked capacity, one question asked respondents “With whom do you discuss treatment

options and seek consent?” and other questions asked, “Who would you seek consent from?” The responses from health care providers showed a marked difference in the responses between the two overlapping questions. When asked who to discuss treatment options with, about 55% of respondents said they would consult with both the spouse and adult child. When the facts were changed to a conflict between the spouse and adult child, and the question was narrowed to “who would you seek consent from?,” over 90% of respondents indicated that they would ask the spouse.

Lawyers are trained to protect client confidentiality and privilege. Lawyers are also trained to focus discussion with the person who has legal authority to make a decision and to discourage others from being present when discussing options with a client.¹³ Quantitative and qualitative responses show a strong preference among health care providers for seeking input and promoting consensus of all persons involved or interested in the well-being of the patient. This distinction between how health care providers and legal professionals interact with clients/patients is important.

To resolve this tension in the field, both health care providers and legal advocates would benefit from training on differing professional standards.

Conclusion

While in some areas of health care decision-making legal standards and clinical practice clearly align, in other areas law and clinical practice do not. Where there is a clear next of kin, family consent laws and medical practice reflect one another. It is important to engage in ongoing efforts to familiarize families and health care providers with this practice. The handful of states that lack default health care decision-making statutes can view this research as evidence that family consent statutes reflect prevailing clinical practice. Efforts to establish legal solutions to the challenging issues involving conflicts between surrogates of the same class, or patients who lack readily identifiable family or friends, have been minimally successful. This may be because of a lack of understanding of the legal options available to health care providers, or it may be a result of good clinical practice leading in a different direction than the one prescribed by the law. This research has shed some light on these issues, and should serve to open a dialog between medical professionals, legal professionals, and policy-makers on easing the process of making health care decisions in these most challenging cases.

Additional Resources

- Administration for Community Living: ACL.gov
- American Bar Association Commission on Law and Aging: Resources and Publications on health care decision-making (survey results and report will be posted here by June 1, 2017) americanbar.org/groups/law_aging/resources/health_care_decision_making.html
- American Medical Association: Code of Ethics ama-assn.org/about-us/code-medical-ethics
- Justice in Aging: justiceinaging.org
- Retirement Research Foundation: rrf.org
- Society for Hospital Medicine: hospitalmedicine.org
- Society for Critical Care Medicine: sccm.org/Pages/default.aspx
- Thaddeus Mason Pope, Law Professor and Medical Ethicist: thaddeuspope.com

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Endnotes

- 1 See generally americanbar.org/groups/law_aging/resources/health_care_decision_making.html#legislativeanalysis.
- 2 Health care power of attorney or living will statutes can be found at americanbar.org/content/dam/aba/administrative/law_aging/state-health-care-power-of-attorney-statutes.authcheckdam.pdf.
Default health care decision maker statutes can be found at americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf.
General background materials can be found at americanbar.org/groups/law_aging/resources/health_care_decision_making.html#legislativeanalysis.
- 3 *Is consent in medicine a concept only of modern times?*, P Dalla-Vorgia, J Lascaratos, P Skiadas, T Garanis-Papadatos, *Journal of Medical Ethics*, Vol. 27, Issue 1, 2001. Available at jme.bmj.com/content/27/1/59.full.
- 4 *Schoendorff v. Society of New York Hospital*: [*Schoendorff v. Society of New York Hosp.*, 105 N.E. 92, 93 (N.Y. 1914)]
- 5 *Understanding Informed Consent - A Primer*, Findlaw, accessed on 1/31/2017, at healthcare.findlaw.com/patient-rights/understanding-informed-consent-a-primer.html.
- 6 Just 26.3% of adults in 2013. See: *Completion of Advance Directives Among U.S. Consumers*, Jaya K. Rao, MD, Lynda A. Anderson, PhD, Feng-Chang Lin, PhD, and Jeffrey P. Laux, PhD, *Am J Prev Med*. 2014 Jan; 46(1): 65–70. Available at ncbi.nlm.nih.gov/pmc/articles/PMC4540332/.
- 7 *A Better Approach For End Of Life Planning*, Brittany La Couture, American Action Forum, 2015, available at americanactionforum.org/insight/a-better-approach-for-end-of-life-planning/.
- 8 *70% die in hospitals or long term care facilities: Fact Sheet on End-of-Life Care*, American Psychological Society, Sharon Valente, RN, PhD, FAAN, as view on 2/7/2017 at apa.org/pi/aging/programs/eol/end-of-life-factsheet.pdf.
- 9 *A Better Approach For End Of Life Planning*, Brittany La Couture, American Action Forum, 2015, available at americanactionforum.org/insight/a-better-approach-for-end-of-life-planning/.
- 10 *Default Surrogate Consent Statutes*, ABA Commission on Law and Aging, June 2014, available at americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf.
- 11 *Default Surrogate Consent Statutes*, ABA Commission on Law and Aging, June 2014, available at americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf.
- 12 *Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly*, N. Karp and E. Wood, 2003, American Bar Association, available at americanbar.org/content/dam/aba/administrative/law_aging/2003_Unbefriended_Elderly_Health_Care_Descision-Making7-11-03.authcheckdam.pdf.
- 13 See generally: ABA Model Rule of Professional Conduct, Rule 1.6 and Federal Rules of Evidence, rules 501 and 502.