

Hamline Law Review

Volume 36

Issue 2 *Symposium Issue: Legal, Medical, and Ethical
Issues in Minnesota End-of-Life Care*

Article 11

1-30-2014

Peeking Inside the Black Box: One Institution's Experience Developing Policy for Unrepresented Patients

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Recommended Citation

Volpe, Rebecca L. and Steinman, Deborah (2013) "Peeking Inside the Black Box: One Institution's Experience Developing Policy for Unrepresented Patients," *Hamline Law Review*: Vol. 36: Iss. 2, Article 11.
Available at: <http://digitalcommons.hamline.edu/hlr/vol36/iss2/11>

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**PEEKING INSIDE THE BLACK BOX:
ONE INSTITUTION'S EXPERIENCE DEVELOPING
POLICY FOR UNREPRESENTED PATIENTS**

Rebecca L. Volpe and Deborah Steinman***

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I. INTRODUCTION

An unrepresented¹ patient is a patient who is alone; no one cares whether she lives or dies. Unrepresented patients have no decision-making capacity, no advance directive, and no surrogate decision-maker.² They are isolated and vulnerable.³ They are also increasing in number.⁴

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¹ The convention in the law is to call these patients 'unbefriended.' The convention in the medical ethics literature is usually to call them 'unrepresented.' We will use 'unrepresented' here because we believe it is a more accurate representation of their situation.

² Douglas B. White et al., *Life Support for Patients Without a Surrogate Decision Maker: Who Decides?*, 147 ANNALS INTERNAL MED. 34, 34 (2007) (stating that some patients who lack decision-making capacity do not have a surrogate and have not completed an advance directive).

³ Charles P. Sabatino, ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: LEGAL AND POLICY ISSUES 30 (2007), available at <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.htm>; see also Thaddeus Mason Pope & Tanya Sellers, *Legal Briefing: The Unbefriended: Making Healthcare Decisions for Patients without Surrogates (Part 1)*, 23 J.

In this paper, we have three overarching goals: 1) to consider the strengths and weaknesses of three broad procedures for dealing with unrepresented patients, 2) to look closely at the internal decision-making policies of five local guardianship companies, and 3) to describe one institution's solution to the challenge of unrepresented patients.

II. BACKGROUND

The population of incapacitated people who lack surrogates in the U.S. is increasing every day: between 2010 and 2030, the size of this group is expected to rise dramatically due to the aging Baby Boomer generation, the expanding population of elderly with dementia, and the growing number of seniors who live on their own.⁵ Two separate studies from 2006 found that 16% of patients in hospital Intensive Care Units (ICUs) lacked decision-making capacity and a surrogate decision-maker.⁶ A later study found that 5.5% of deaths in ICUs involved patients who were unrepresented, which indicates that about one in twenty deaths in the ICU is an unrepresented patient.⁷ Additionally, about 3% of nursing home residents are unrepresented.⁸ These percentages might seem small, but if there are a total of 500,000 deaths in ICUs each year, that means 27,500 unrepresented patients die in the ICU every year; and, if there are 3 million people living in skilled nursing facilities, 105,000 seniors living in nursing homes are

CLINICAL ETHICS 84, 86 (2012) (stating "[u]nbefriended patients are vulnerable to many undesirable, and possibly dangerous or life-threatening, situations").

⁴ Marshall B. Kapp, *Medical Decisionmaking for Older Adults in Institutional Settings: Is Beneficence Dead in an Age of Risk Management?*, 11 ISSUES L. MED. 29, 33–34 (1995) (explaining that "[d]emographic factors point to a proliferation of individuals in this category over the coming years").

⁵ Naomi Karp & Erica Wood, *Incapacitated and Alone: Healthcare Decision Making for Unbefriended Older People*, 31 ABA HUMAN RIGHTS, no. 2, 2004, available at http://www.americanbar.org/publications/human_rights_magazine_home/human_rights_vol31_2004/spring2004/hr_spring04_incapacitated.html (explaining the increase in the elder population).

⁶ Mark Siegel, *Alone at Life's End: Trying to Protect the Autonomy of Patients Without Surrogates or Decision-Making Capacity*, 34 CRITICAL CARE MED. 2238, 2238–39 (2006); Douglas B. White et al., *Decisions to Limit Life-Sustaining Treatment for Critically Ill Patients who Lack Both Decision-Making Capacity and Surrogate Decision-Makers*, 34 CRITICAL CARE MED. 2053, 2053–59 (2006) (finding that sixteen percent of patients admitted to the medical ICU of this hospital lacked both decision-making capacity and a surrogate decision-maker).

⁷ White et al., *supra* note 2, at 36 (stating the percentage of patients who were admitted to the ICU during the study who were incapacitated and lacked a surrogate decision maker).

⁸ Tracy E. Miller et al., *Treatment Decisions for Patients Without Surrogates: Rethinking Policies for a Vulnerable Population*, 45 J. AM. GERIATRICS SOC'Y 369, 369 (1997) (discussing existing law governing treatment decisions for patients without surrogates); see also Sumeeta Varma & David Wendler, *Medical Decision Making for Patients Without Surrogates*, 167 ARCH. OF INTERNAL MED. 1711, 1711 (2007) (stating "no surrogate or next of kin could be identified for 3% of nursing home residents").

currently unrepresented.⁹ In Minnesota, the exact number of unrepresented patients is unknown.¹⁰

Professional organizations differ in their recommendations for medical decision-making for unrepresented patients.¹¹ For example, the American College of Physicians, in their statement on the physician-patient relationship advises, “Courts should be used when doing so serves the patient, such as to establish guardianship for an unbefriended incompetent patient, to resolve a problem when other processes fail, or to comply with state law.”¹² Yet, the Code of Medical Ethics created by the American Medical Association suggests that, for unrepresented patients, “a physician may wish to consult with an ethics committee to . . . facilitate sound decision-making.”¹³ The American Geriatrics Society (AGS) suggests two different models, depending on the setting.¹⁴ For non-urgent decisions, the AGS suggests that “a group of individuals who care for the patient may appropriately determine goals.”¹⁵ For urgent, life-threatening situations the AGS advises that healthcare providers and institutions “should develop methods to make decisions for incapacitated patients without surrogates. These methods might include allowing the attending physician and a consulting physician to make certain choices within established protocols subject to retrospective review.”¹⁶

Although every state provides for guardianship—in fact it is the only mechanism in most states—the details vary.¹⁷ Twelve states explicitly authorize the attending physician to decide; Florida, Texas, Oregon and Mississippi empower clinicians other than physicians to decide (e.g., social workers or ethicists); and Alabama, Georgia, California, and Arizona

⁹ See Miller et al., *supra* note 8, at 369 (using 3% of unrepresented nursing home patients statistic to display the large number of seniors living in nursing homes who are unrepresented).

¹⁰ *Strengthening our Commitment to Minnesota Seniors: Promoting Independent Living Through the Older Americans Act Reauthorization*: Hearing Before the Special Committee on Aging, 111th Cong. 2 (2010) S. Hrng. 111–861, 2d Sess. (Minn. 2010), available at <http://www.gpo.gov/fdsys/pkg/CHRG-111shrg64224/html/CHRG-111shrg64224.htm>.

¹¹ White et al., *supra* note 2, at 34 (discussing the various approaches taken by professional organizations for making medical decisions for unrepresented patients).

¹² American College of Physicians, *Ethics Manual*, 128 ANNALS INTERNAL MED. 576, 580 (1998) (exploring the need for a guardianship to be established when disagreements cannot be resolved).

¹³ AMA COUNCIL ON ETHICAL & JUDICIAL AFFAIRS, CODE OF MEDICAL ETHICS OF THE AMERICAN MEDICAL ASSOCIATION 252 (2008–09 ed.)

¹⁴ *AGS Position Statement: Making Treatment Decisions for Incapacitated Elderly Patients Without Advance Directives*, AM. GERIATRICS SOC. (2002).

¹⁵ *Id.* at 1.

¹⁶ *Id.* at 3.

¹⁷ Thaddeus Mason Pope & Tanya Sellers, *Legal Briefing: The Unbefriended: Making Healthcare Decisions for Patients without Surrogates (Part 2)*, 23 J. CLINICAL ETHICS 177 (2012) (explaining that mechanisms to address the issue of decision making for unbefriended patients are not uniform).

recommend the involvement of an institutional committee such as the ethics committee.¹⁸

Within these professional guidelines and state laws, then, arise three divergent methods: relying on the courts, using a committee, and allowing the physician or other healthcare provider to decide. This article will examine the advantages and disadvantages of each.

III. THREE BROAD OPTIONS

There are many types of medical decisions that need to be made for unrepresented patients. For emergency medical decisions, the law provides for treatment without informed consent.¹⁹ The common law emergency exception to informed consent is based on the doctrine of implied consent.²⁰ In order to meet the threshold of implied consent 1) a medical emergency must exist, 2) treatment is required to protect the patient's health, 3) it is impossible or impractical to obtain consent from the patient or other authorized person, and 4) there is no reason to believe the patient would refuse treatment.²¹ Once informed consent has been obtained for an intervention, consent for each of the small tasks associated with that intervention is not necessary.²² Finally, for procedures and treatment decisions which are elective in nature and therefore do not have to be made in a timely manner, decisions should await the appointment of a court-appointed guardian if another surrogate is not identified in the meantime.

However, when *urgent but not emergent* medical decisions need to be made for unrepresented patients, there are often no clear guidelines to offer providers.²³ Examples of these decisions might be whether or not to intubate a patient who appears to be experiencing mild respiratory distress, or to adopt comfort care goals for a patient who is moribund.

The remainder of this paper will focus on three divergent processes for making urgent but not emergent medical decisions for unrepresented patients in states such as Minnesota and Pennsylvania, where there is no guiding state law. Because the correct decision is often uncertain, the process by which the decisions are made assumes greater importance.

A. Physician Consensus

In their 2003 report on decision making for unrepresented patients, the American Bar Association (ABA) notes many institutions “fly below the

¹⁸ *Id.*

¹⁹ 61 AM. JUR. 2D *Physicians, Surgeons, Etc.* § 165 (2013).

²⁰ *Id.*

²¹ *Id.*

²² *See Foflygen v. Zemel*, 615 A.2d 1345, 1354 (Pa. Super. Ct. 1992).

²³ Pope & Sellers, *supra* note 3, at 90–91.

radar screen.”²⁴ By this they mean that physicians serve as ad hoc guardians for unrepresented patients.²⁵ Empirical research supports the ABAs suspicions: Douglas White and his colleagues found that, of forty-nine unrepresented patients in the ICU, withdrawal of life-sustaining medical treatment was considered an appropriate option for eighteen patients.²⁶ Of those eighteen unrepresented patients, thirteen eventually had a Do Not Resuscitate (DNR) order written.²⁷ For four of the thirteen, the attending physician made the DNR decision alone; for seven of the thirteen, the attending physician sought the agreement of a second physician; for one, the ethics committee was involved; and for one, the court was petitioned to appoint a guardian.²⁸

The advantages of the physician consensus approach are obvious: it is fast and convenient. These advantages are not insignificant, especially in a setting where the stakes are high and bureaucratic time-tables can make the difference between life and death.²⁹

However there are also significant disadvantages to the physician consensus approach.³⁰ Treatment decisions in general—and end-of-life decisions in particular—are acutely personal.³¹ These decisions are not merely medical judgments: they are social and ethical decisions.³² If left to individual physicians, the implicit message is that these life and death choices are reducible to the medical facts.³³ One potential rebuttal to this argument is that the physician does not merely consider the medical facts; instead, they reflect on quality of life and other values-based markers when

²⁴ Naomi Karp & Erica Wood, *Report Urges Laws and Practices To Address Problems of Elderly Patients Incapable of Making Health Care Decisions*, 25 BIFOCAL 2 (2003), available at <http://apps.americanbar.org/aging/publications/bifocal/251.pdf> (stating that often times states fail to authorize clear and ethical mechanisms to deliver or discontinue treatment for unrepresented patients, forcing practitioners to “fly below the radar screen”).

²⁵ Naomi Karp & Erica Wood, *Trends in Health Care Surrogacy for Isolated Elders; Public Guardianship*, ABA COMMISSION ON LAW AND AGING, Oct. 21, 2004, available at apps.americanbar.org/aging/cle/docs/NALC10-04.ppt.

²⁶ White et al., *supra* note 6, at 2055 (finding that withdrawal of life-sustaining treatment was appropriate for 18 unrepresented patients).

²⁷ *Id.* (stating the number of DNR orders among unrepresented patients).

²⁸ *Id.* at 2055–56. (discussing how the DNR decisions were made).

²⁹ See Miller et al., *supra* note 8, at 372–73 (explaining the need for policies on treatment decisions for incapacitated patients without surrogates).

³⁰ See *id.* at 371; Insoo Hyun et al., *When Patients do not have a Proxy: A Procedure for Medical Decision Making when there is no one to Speak for the Patient*, 17 J. CLINICAL ETHICS 323, 324–25 (2006) (explaining why having a single decision maker such as a physician is not ethically ideal).

³¹ See Miller et al., *supra* note 8, at 371 (discussing existing law governing treatment decisions for incapacitated patients without surrogates).

³² See *id.* at 371 (discussing existing law governing treatment decisions for incapacitated patients without surrogates).

³³ See *id.*; Hyun et al., *supra* note 30, at 325 (stating “medical decision making should not be solely a matter of medical expertise and judgment”).

making their decisions. However, research indicates that healthcare providers have different values than patients and systematically choose a different level of care in end-of-life settings.³⁴ Asking providers to first know that their values are different than their patients and subsequently to separate their own values from their decision-making process seems a tall order indeed, especially in light of the inherently subjective nature of quality of life considerations.

B. Internal Committee

Another common approach articulated in the ABA report is to rely on ethics committees to make, facilitate, or share medical decisions for unrepresented patients.³⁵ Other authors advise simply relying on any multi-disciplinary committee within, or even outside, the healthcare facility.³⁶ Use of the ethics committee, or a subcommittee of the ethics committee, is perhaps the most widely touted solution to the problem of decision making for unrepresented patients.³⁷ Hyun and his colleagues argue that a pre-established subcommittee of the hospital ethics committee—which is to be “comprised of no fewer than two members of the ethics committee who are knowledgeable about the ethics of surrogate decision making,” one of whom should ideally be a community member—should work with a social worker and the attending physician to reach a consensus about treatment decisions.³⁸

Again, the strengths of this method are not to be discounted: it will almost always be a faster process than relying on the courts, and, to the extent that the it is comprised of diverse individuals, committees are uniquely well situated to bring multiple perspectives to the fore.³⁹

The weaknesses of the committee approach are also not to be discounted.⁴⁰ Committees—even small ones—can be unwieldy and present

³⁴ Sara Carmel, *Life-Sustaining Treatments: What Doctors do, What They Want for Themselves and What Elderly Persons Want*, 49 SOC. SCI. & MED. 1401, 1405–07 (1999) (discussing three main differences between physicians’ hypothetical behavior and elderly persons’ preferences for different life sustaining treatment in three different illness conditions).

³⁵ Karp & Wood, *supra* note 5 (recognizing that three states (New York, Texas and Iowa) have authorized *external* committees to make medical decisions for the unrepresented).

³⁶ See, e.g., Miller et al., *supra* note 8, at 372–73 (discussing the committee approach to make medical decisions for unrepresented patients).

³⁷ Hyun et al., *supra* note 30, at 328–30 (setting forth the benefits to the ethics subcommittee approach).

³⁸ *Id.* at 326.

³⁹ Miller et al., *supra* note 8, at 371 (considering the benefits of the community-based committees in making treatment decisions).

⁴⁰ *Id.* at 371–73 (recognizing weaknesses to the committee based approach).

practical difficulties.⁴¹ More importantly, however, the committee approach does not overcome the limitations of the physician consensus approach described above.⁴² In particular, there is no reason to believe that a committee would be able to set aside its own systematically different values and make subjective treatment decisions for a patient if an individual physician cannot do so. In fact, the literature on ‘groupthink’ may indicate that committees face an even bigger challenge than individual physicians.⁴³ One potential rebuttal to this perspective is that ethics committees often include a community member.⁴⁴ But the fact of the matter is that the community member voice is often not robust, and in many cases the so-called community member is a retired physician or healthcare attorney—not exactly a representative of the masses.⁴⁵

C. Emergency Guardianship

The final approach to urgent but not emergent medical decision-making for unrepresented patients in states where there is no guiding state law is relying on the courts to appoint an emergency guardian.⁴⁶ Courts will generally appoint an emergency guardian for an unrepresented patient when a failure to do so will result in irreparable harm to the patient.⁴⁷ State laws vary, but in Pennsylvania the guardianship is in effect for up to seventy-two hours, and may be extended for up to twenty days.⁴⁸

The advantages of the emergency guardian approach are numerous, but are most obvious by way of thinking about the disadvantages that this approach avoids. In particular, guardianship completely avoids the fundamental problem of healthcare providers serving in the role of surrogate decision-maker for patients who have systematically different values than

⁴¹ *See id.*; *see also* Hyun et al., *supra* note 30, at 325 (stating “the chief problem with this [committee approach] is that it is normally weighed down with practical difficulties”).

⁴² *See supra* notes 24–34 and accompanying text (discussing the physician consensus approach).

⁴³ Marlene E. Turner & Anthony R. Pratkanis, *Twenty-Five Years of Groupthink Theory and Research: Lessons from the Evaluation of a Theory*, 73 *ORG. BEHAV. & HUM. DECISION PROCESSES* 105, 107–08 (1998) (tracing the history of groupthink research).

⁴⁴ Inclusion of at least one community member on the institutional ethics committee is usually considered a best practice.

⁴⁵ Hyun et al., *supra* note 30, at 330 (acknowledging the need for more diverse community members).

⁴⁶ Karp & Wood, *supra* note 5.

⁴⁷ *E.g.*, 20 PA. CONS. STAT. § 5513 (2012) (permitting an appointment when failure to do so would result in irreparable harm); MINN. STAT. § 524.5-311(a) (2012) (allowing appointment where there is a risk of substantial harm); DEL. CODE ANN. tit.12, § 3901(d) (West 2012) (allowing immediate appointment of guardian upon a finding that the person is “is in danger of incurring imminent serious physical harm or substantial economic loss or expense”).

⁴⁸ 20 PA. CONS. STAT. § 5513 (2012).

they do. The Penn State Milton S. Hershey Medical Center (“MSHMC”) opted to utilize the emergency guardian approach for just that reason: it seemed to be the most value-neutral way of making treatment decisions for unrepresented patients. The utilization of this approach was arrived at by a process of elimination: none of the three primary options is perfect; we felt the emergency guardianship option was the best available choice.

Authors note a number of disadvantages to emergency guardianship.⁴⁹ In particular, it is argued that guardianship is slow, costly, and time-intensive.⁵⁰ Miller and her colleagues go on to argue that, in addition to the aforementioned limitations, the courts are a barrier to reaching the best decision, and that guardians lack appropriate training.⁵¹

Stakeholders at MSHMC had many of the same concerns. In addition, we were worried that the guardians would have an inappropriate bias toward the preservation of life, and that they would be overly concerned about litigation. In an effort to answer some of these open questions, local guardianship companies were contacted and asked a series of standardized questions.

IV. GUARDIANSHIP COMPANIES IN PENNSYLVANIA

Despite an abundance of scholarly literature flogging the emergency guardianship option, there are ongoing efforts to improve the guardianship system in the United States.⁵² We identified six local guardianship agencies and five were asked a series of five questions. The sixth agency did not respond to our call. At each of the agencies we were able to speak to an individual who served in the role of guardian. They were advised that the purpose of the call was to gather information on the credentialing, training and policies at local guardianship agencies.

We learned that, in the state of Pennsylvania, there are no specific criteria for who can become a guardian, although two of the agencies reported that they were certified through a professional organization. Additionally, there is no licensure process for guardians in Pennsylvania. The guardians came from a variety of backgrounds including social work, law, and the banking industry. Several referenced ongoing training in the form of continuing education units, conferences, and training offered through local Area Agencies on Aging.

⁴⁹ Varma & Wendler, *supra* note 8, at 1712 (noting that relying on the courts is costly, time consuming and inconvenient and may be impractical when decisions must be made fairly quickly).

⁵⁰ *Id.*; Kapp, *supra* note 4, at 33; Miller et al., *supra* note 8, at 370 (explaining the realities of the guardianship process).

⁵¹ Miller et al., *supra* note 8, at 370 (stating that guardians generally have little or no training).

⁵² Pope & Sellers, *supra* note 17, 177–92 (describing the measures states have taken to improve the guardianship system).

In only one case, in which the guardian was also an attorney, did the guardian state that he could consent to both hospice and a DNR/DNI order to focus on comfort and dignity and to avoid prolonging the dying process for an unrepresented patient. In the other instances, guardians reported that if the client was in an irreversible end-stage/terminal condition or a persistent vegetative state they would petition the court to limit life-sustaining medical treatment. Quality of life, suffering, and the individual's best interests were mentioned as benchmarks for making decisions. One local company shared their internal policies with us, which discuss, at length, the importance of using a best interests standard of surrogate decision-making.

We were satisfied, based on our interviews, that the guardians did not have an inappropriate bias toward the preservation of life, and that, in fact, they utilized the same standards of surrogate decision-making that are standard in the field of medical ethics (i.e., best interests). Therefore, we felt comfortable proceeding with an institutional policy that relied on emergency guardianship for unrepresented patients.

V. ONE INSTITUTION'S SOLUTION

At MSHMC, the purpose of our new institutional policy is “[t]o expeditiously seek court approval for urgent but not emergent medical treatment when an unrepresented adult patient is unable to consent for himself or when either the parents or guardians of a minor are absent or are opposed to such treatment.”⁵³

The process put forth for obtaining an emergency court order is as follows:

1. The attending physician contacts the social worker.
2. The social worker reviews the situation and attempts to resolve the issue without a court order by conducting a thorough search for a decision-maker. The Department of Social Work developed their own internal policy for organizations that ought to be contacted and steps that should be taken at this phase.
3. If no decision-maker is found, and an urgent but not emergent decision needs to be made, the social worker identifies a guardianship company, and prepares for the court hearing.
4. The attending physician or social worker reviews the case with a hospital administrator and gets approval for the petition.
5. The administrator on call notifies risk management.
6. Risk management petitions the court for an appointment of an emergency guardian. This process entails a phone call with the

⁵³ PA. STATE MILTON S. HERSHEY MED. CTR., *Procedure for Obtaining Court Order for Treatment of a Minor or Incompetent Adult*, HOSPITAL ADMINISTRATIVE MANUAL 1 (2011).

attorney, the physician and the court. A guardian is appointed within one to two days, and the guardianship lasts for seventy-two hours with the possibility of a twenty-day extension.⁵⁴

VI. CONCLUSIONS

Based on conversations with local guardianship companies and judges, we found that many of the oft-cited limitations of emergency guardianship do not apply. In our region, an emergency guardianship can be arranged relatively quickly and is not especially time-intensive for physicians. Guardians generally have appropriate training, and do not usually have an inappropriate bias toward life. In short, the courts do not serve as a barrier to effective and appropriate medical decision-making for unrepresented patients. The courts may in fact represent the best option in some regions.

Given that the choices for decision-making for unrepresented patients are all flawed in some way, scholars are looking at a number of innovative alternatives.⁵⁵ Varma and Wendler propose a population based treatment indicator: a computer based tool that predicts which treatment a given patient would prefer based on the treatment preferences of similar patients in similar situations.⁵⁶ Weiss and his colleagues propose a new type of professional called ‘health fiduciaries,’ who would have post-Bachelor’s degree training and certification to act as a surrogate decision-maker.⁵⁷

The ABA suggests an informal surrogate relationship between skilled nursing facility staff members and patients, so that, when the patient becomes acutely ill, the staff member can serve in the role as surrogate. Additionally, many patients still do not have an advance directive—increasing completion rates is likely to help decision-making for unrepresented patients. The bottom line: ultimately, prevention is the cure.⁵⁸ In the meantime, however, institutions ought to seriously explore whether emergency guardianship could be right for them.

⁵⁴ These details and timelines are region-specific, and likely to change depending upon geographic location.

⁵⁵ Kapp, *supra* note 4, at 46 (stating some of the alternative approaches).

⁵⁶ Varma & Wendler, *supra* note 8, at 1712–15 (explaining an alternative approach to predicting patients’ preferences).

⁵⁷ B.D. Weiss et al., *Medical Decision-Making for Older Adults Without Family*, 60 J. AM. GERIATRICS SOC’Y 2144 (2012).

⁵⁸ See Pope & Sellers, *supra* note 3, at 87.