

## Annotated Bibliography

### Health Care Decision Making for Persons without written documents naming a person to provide consent

By Teresa Yao<sup>i</sup>

This annotated bibliography is the product of a comprehensive literature review on the issue of health care decision making for persons who have no document naming a person to make health care decisions. The review of articles and clinical studies covered a multidisciplinary look into the process of surrogate selection for incapacitated patients.

- Berger, Jeffrey T., et al., "Surrogate Decision Making: Reconciling Ethical Theory and Clinical Practice," *Ann. Intern. Med.* 149(1): 48-53 (2008).
  - Surrogate decision making is understood in a bioethical hierarchy of 3 standards: known wishes, substituted judgments, and best interests. Empirical research shows that in practice, surrogates diverge from these standards when making decisions. Patients often want surrogate to respond dynamically to *actual* clinical situations, instead of just following their previously designated treatment preferences. Single standard is inadequate for decision-making. Surrogate decision making is dynamic and nuanced, and thus should account for substantial range of patient's concerns and interests (include both medical and nonmedical concerns) when deciding for patient
  - POV: medical, ethical

#### Table. Recommendations for Decision Making

##### Patients with advance directives

Living wills should indicate what role the content was intended to serve: binding, weighty but not binding, or merely informative.  
Proxy forms should facilitate documentation of wishes to include and exclude other persons from participation in decision making.  
Physicians and others who encourage patients to complete advance directives should elicit these sorts of specifications from patients and document them.

##### Patients without advance directives

Efforts should be made to assist the patient in identifying his or her preferences regarding surrogate decision making—for example, close adherence to medical preference, group versus individual decision making, and degree of latitude in accommodating family concerns.  
Families should be assisted in constructing a narrative for the patient that includes specific treatment preferences, if such were ever known; important medical values; and relevant nonmedical values and considerations.

- Bishop, Mark Stephen, *Crossing the Decisional Abyss: An Evaluation of Surrogate Decision-Making Statutes as a Means of Bridging the Gap Between Post-Quinlan Red Tape and the*

*Realization of an Incompetent Patient's Right to Refuse Life-Sustaining Medical Treatment*, 7 ELDER L.J. 153 (1999).

- This article takes a critical look at the pros and cons of state surrogacy statutes (particularly looks at Illinois, New Mexico and Ohio), and critiques using judicial approach in selecting surrogates/making decisions for the incapacitated patient. Very few people actually complete advance directives, so important to have surrogacy statutes. Although state surrogacy statutes vary, generally have: surrogate priority provisions, limitations on surrogate authority, surrogate decision-making standards, surrogate dispute resolution provisions, and other procedural requirements. Surrogate decision-making statutes must address several parties' interests (patient's interest, family and loved ones' interests, state's interest, health care provider's interest). Study chose to look at Illinois, New Mexico, and Ohio surrogacy statutes because provides a glimpse at the wide variations that states take in addressing decision-making for incapacitated patients. Priority provisions in state surrogacy statutes should account for nontraditional family setting, and must consider scope of surrogate authority (balanced with state interests – often state interests limit surrogate's authority, e.g., requiring guardianship for routine health care treatment decisions). There should be additional procedural safeguards to render accurate decision-making (i.e., requiring concurrence of multiple medical opinions).
- POV: legal
- Brandy, Robin J., et al., "Medical Decision-making During the Guardianship Process for Incapacitated, Hospitalized Adults: A Descriptive Cohort Study," J. Gen. Intern. Med. 25(10) 1009-8 (2010).
  - This is about a study on medical decision-making while patients await appointment of guardians. Participants in the study were 79 patients admitted to Wishard Memorial Hospital (WMH). Important medical decisions were made while patients were awaiting guardian appointment. Unbefriended, incapacitated adults awaiting guardianship appointments may lack surrogate decision maker, in moments where serious treatment decisions must be made
  - POV: medical, clinical study
- Brock, Dan W., "What is the Moral Authority of Family Members to Act as Surrogates for Incompetent Patients?," Milbank Quarterly 74(4): 599-618 (1996).
  - This article questions the moral underpinnings of family members' decision making capacity when choosing surrogates. The analysis is focused on the different grounds in support of selecting family members. Two central moral issues surrounding surrogate authority are who should be selected, and what principles should guide the surrogate's decision. Importantly, this article examines moral (not legal) authority of family members, and acknowledges that these moral arguments may not be easily formed into clear legal standards. The grounds for a family's authority to act as surrogates are: (1) a democratic ground for surrogate authority (based on the pedigree of the process by which the surrogate is appointed, e.g. if there's a law designating who should be surrogate, then fair; obey the law simply because it's the law), (2) a patient-regarding

grounds for surrogate authority (promotes self-determination on behalf of the incapacitated patient, and family members are in position to decide what's best for the patient), (3) a non-patient-regarding grounds for surrogate authority (family members should be surrogates because they will be most affected by the decisions made, and distributive justice requires considering the effects of the decision on others, such as the family; family as independent moral unit with decision-making responsibility for its members). The author suggests taking into account the wide gamut of grounds for surrogate authority, to best fit each case/individual.

- POV: moral
- California Hospital Association, "Health Care Decisions for Unrepresented Patients: Model Policy for General Acute Care Hospitals" (October 2015) (8 pages).
  - This is a model policy detailing the process for decision-making for unrepresented patients as guidance for health care professionals. Details of policy include: uses multidisciplinary team to make decision (important to include someone who will represent patient's interests; lists factors that the multidisciplinary team should consider; provides steps to be taken under different scenarios: agreement on treatment or disagreement on treatment; provides specific considerations for exceptional circumstances (e.g. patient death is likely if withdraw treatment, AND if patient's condition is result of injury that was inflicted by criminal act, was created/aggravated by medical accident, is pregnant, or is parent with sole custody/responsibility of a minor child); requires documentation of deliberation and reasons/findings that served as bases for decision; includes appendix that includes checklist of considerations for hospitals when revising hospital policy/procedure re: decision-making for unrepresented patients
  - POV: policy
- Coppola, Kristen M., et al., "Accuracy of Primary Care and Hospital-Based Physicians' Predictions of Elderly Outpatients' Treatment Preferences With and Without Advance Directives," Arch. Intern. Med. 161: 431-440 (2001).
  - This is a study comparing the accuracy of substituted judgments made by primary care physicians, hospital-based physicians, and family surrogates for elderly patients without advance directives. Family surrogate group of participants served as baseline comparison group. Family surrogates' judgments are more accurate than physicians'. Advance directives did not improve accuracy of substituted judgments made by family surrogate or primary care physicians. However, advance directives did increase accuracy of judgments made by hospital-based physicians (e.g. emergency and critical care doctors who did not have prior experience with the patients). Primary care physician accuracy 66%; hospital-based physician accuracy 64%; family surrogate accuracy 74%. Family surrogate primarily made overtreatment errors, primary care physicians primarily made under treatment errors, and hospital-based physicians made both types of errors. The article breaks down accuracy of judgments for various kinds of treatment decisions (e.g. Alzheimer Disease, Cancer, Coma, Stroke, Emphysema, current health). Since many primary care physicians are withdrawing from hospital care, and since most decisions regarding life-sustaining treatment are made by emergency and critical care physicians,

advance directives can help hospital-based doctors better understand patients' treatment preferences.

- POV: medical, clinical
- Connor, Denis M., et al., "The Unbefriended Patient: An Exercise in Ethical Clinical Reasoning" *Journal of General Internal Medicine* 2016; 31(1): 128-132.
  - This is a case study examination of an unbefriended patient. Data on number of unbefriended patients is limited, but estimates range from 5–10% of ICU deaths, to 3–4% of long-term care residents

<b>Decision-Making Type</b>	<b>Decision-Maker</b>
Directed	Patient outlines wishes in advance (living will)
Delegated	Surrogate decision-maker designated by patient
Devolved	Default surrogate (family or friends) as defined by law, varies by state
Displaced	Judicial intervention (guardianship)

<b>Strategies currently in use in the U.S.</b>	<b>Limitations</b>
Public guardianship	<ul style="list-style-type: none"> <li>• Not equipped to handle growing number of unbefriended</li> <li>• Quality, sophistication, and involvement of public guardians vary</li> </ul>
Physicians as surrogates without the need for judicial intervention (often with ethics committee involvement)	<ul style="list-style-type: none"> <li>• Potential for bias and conflicts of interest when only members of a particular institution make decisions for their patients</li> </ul>
Trained volunteers used as surrogates for unbefriended individuals <sup>12</sup>	<ul style="list-style-type: none"> <li>• Typically focused on those with developmental disabilities and psychiatric disease rather than on the elderly</li> <li>• Requires resources for training</li> </ul>
Detailed institutional decisional pathway, e.g. Department of Veterans Affairs: degree of review increases as risk and invasiveness of the proposed treatment increases <sup>15</sup>	<ul style="list-style-type: none"> <li>• Potential for bias and conflict of interest since decisions are made internally (somewhat mitigated by multiple levels of review)</li> <li>• Only suitable for internal medical decisions (i.e. cannot be used to allow long-term placement in a community facility)</li> </ul>
Non-profit organization proactively seeks out adult orphans and encourages documentation of healthcare wishes, and then acts as private conservator when/if clients lose capacity	<ul style="list-style-type: none"> <li>• Requires resources and investment for use on a large scale</li> </ul>

- Courtwright, Andrew, et al., "Who Should Decide for the Unrepresented?" *Bioethics* 2016; 30(3): 173-180.
  - The issue discussed in this article is whether physicians or ethics committees should decide in life support treatment decisions. Pope and White, and other advocates for physicians to be "advisors" rather than "deciders" argue that concerns about doctors being decision makers are either empirically unfounded or apply equally to ethics committees. There are no studies assessing ethics committee's ability to predict patient treatment preferences. Like ethics committees, doctors are not necessarily the best judgment makers for patients either; however, their fiduciary duty obligates them to act as surrogate decision maker (these fiduciary obligations cannot be discharged by third parties like ethics committees). Fiduciary obligation imposes on doctors to make

reasonable efforts in understanding what patient's values are/what patient wants. The authors recommend that physicians should be primary decision makers for their patients, due to their fiduciary obligations. Physicians' treatment decisions must be transparent, and physicians must exhaust efforts to find individuals to serve as reasonable surrogates, ensuring patient's interests are represented as much as possible.

- POV: ethical
- Dayton, Kim, *Standards for Health Care Decision-Making: Legal and Practical Considerations*, 2012 UTAH L. REV. 1329, 1360-1365 (2012).
  - The issue here is the guardian's role in making healthcare decisions, but the article discusses decision making standards that could be applied beyond scope of guardianship. Right of autonomy in health care decisions has constitutional dimensions under both state and federal law. Decision-making using substituted judgment standard is the preferred best practice (articulated by National Guardianship Association, American Bar Association, and American Medical Association). For decision-making using best-interests standard – unless guardian has pre-existing, long-term relationship with patient/ward, it is important to resist imposing personal values on what's "best". Article includes statutory survey on health care decision-making by guardians, in several states (Appendix B). The author recommends that decision-making authority must respect patient's fundamental privacy and liberty interests, in order to assure the greatest degree of personal autonomy.
  - POV: legal
- Edwards, Sarah J.L., et al., "A Qualitative Investigation of Selecting Surrogate Decision-Makers," *J. Med. Ethics* 37(10): 601-605 (2011). – NOTE: this study was done in the UK
  - This article discusses what people look for in selecting surrogates, and also critically examines the assumption that people want surrogates to use substituted judgment. Surprisingly, many people did not indicate that they chose surrogates based on how well the surrogate knew their preferences. Most participants chose surrogates based on characteristics other than those that would be most conducive for substituted judgment, such as general competence (e.g. organized, detailed), caring (e.g. puts others ahead of self), veracity (e.g. honesty, good character), ability to make the "right choice" (e.g. trust surrogate to do the right thing more than others). Some participants did choose surrogate akin to substituted judgment approach: knowledge of the patient, similarity in outlook, reciprocity. Others alluded to concern for others and social norms (e.g. pick surrogate that wouldn't experience too much burden in making the decision; not wanting to offend someone, so pick a family member that would be offended if not chosen). Notably, the participants were undergraduate students, and thus more distant in thinking about being an incapacitated patient. Many people don't select surrogates based on whether the surrogate would make a substituted judgment for the patient.
  - POV: clinical, ethical
- Francis, Leslie P., *The Roles of the Family in Making Health Care Decisions for Incompetent Patients*, 1992 UTAH L. REV. 861 (1992).

- This article discusses the role of family in decision making for incapacitated patients. In different contexts, families should assume different roles (from the law's perspective, families have far less latitude in decision making for young children or infants). There are situations where the burden of decision making on families is especially difficult, such as family survivors of the same accident that incapacitated the patient. If the aim is to ascertain a patient's choice, family members are crucial sources of information. If the aim is to realize patient's best interests, family members may also provide valuable information, but assessment must include understanding medical prognosis and alternatives for care (side note: because decision making in practice involved mixed substituted judgment/best interests standard, explains why physicians are involved in decision making process via application of best interests standard).
- POV: legal
- Frank, Casey, *Surrogate Decision-Making for "Friendless" Patients*, 34 COLO. LAW. 71 (2005).
  - This article looks at the means of substitute decision-making for unbefriended patients (mainly looks at options available in Colorado).

Different Surrogate Roles
<p>The term "surrogate," as used in this article, is a comprehensive term encompassing all substitute decision-makers, including the following:</p> <ul style="list-style-type: none"> <li>● <b>Health Care Agent:</b> Explicitly appointed by a patient, while still competent</li> <li>● <b>Proxy:</b> Chosen by the patient's interested persons only after a patient has lost competency</li> <li>● <b>Guardian:</b> Appointed and supervised by a court</li> <li>● <b>Institutional Guardian:</b> Also appointed and supervised by a court</li> <li>● <b>Special Guardian for Health Care:</b> Only in Veterans Administration facilities; allowed without court supervision.</li> </ul>

- POV: legal
- Geros-Willfond, Kristin N., et al., "Religion and Spirituality in Surrogate Decision

Making for Hospitalized Older Adults," J. Relig. Health 55: 765-777 (2016).

- The article examines the role of religion and spirituality in decision making. The researchers conducted interviews with 46 surrogates for hospitalized older adults. Three themes emerged: (1) religion as guide to decision making, (2) control (God controlling, shared control, or humans controlling), and (3) views on faith, death, and dying. Patient autonomy and substituted judgment are still important for people who are concerned with aligning their decisions with their religion's views. Clinicians should pay attention to religious considerations, because of its impact on decision making.
- POV: clinical
- Isaacs, Eric D., et al., "The Unbefriended Adult Patient: The San Francisco General Hospital Approach to Ethical Dilemmas" San Francisco Medicine 2010; 83(6): 25-26.
  - Ethics committees serve as consultants (provide info and point out nuances in individual cases), but attending physician has primary responsibility for the patient.
  - POV: ethical, medical
- Karp, Naomi & Wood, Erica, *Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly*, Am. Bar Ass'n Comm'n Law & Aging, July 2003.
  - This report discusses decision-making for unbefriended patients. First, it defines "unbefriended elderly" as a (1) patient who doesn't have decisional capacity to give

informed consent to treatment, (2) patient who did not execute advance directive that addresses treatment at hand and has no capacity to do so, (3) patient who has not legally authorized surrogate, and no family/friends to assist in decision-making process. Unbefriended patients tend to have multiple chronic conditions (some of which may have placed them in a position of social isolation), which require decisions on major medical or life support treatment. For unbefriended elderly (no advocate, no track record of preference), health care providers are left in the dark which results in overtreatment or under-treatment. Many states have provided state laws authorizing surrogates to decide on behalf of unbefriended patients (mechanisms for surrogate selection vary across the states). Some healthcare facilities also provide mechanisms for surrogate selection for unbefriended patients. This report also discusses the different kinds of health care decisions, and the varying levels of consent required for each (emergency, routine, major medical, and end-of-life). The goal should be to have a *deliberate process* (both medical and ethical scrutiny) for isolated patients with no advocate and no track record of values/life history (authors provide policy suggestions)

- POV: legal, ethical, sociological
- Kelly, Brenna, et al., "Systematic Review: Individuals' Goals for Surrogate Decision-Making," *J. Am. Geriatr. Soc.* 60: 884-895 (2012).
  - This study examined the extent to which current practice promotes goals of individuals who didn't designate a surrogate through a systematic literature review (studies mostly in US; Data of 22,000 respondents and 36 unique data sets). Majority of individuals wanted close family members to act as their surrogate. Individuals have 3 primary goals with regard to incapacitated decision-making: involve their families, treatment decisions being consistent with their own treatment preferences, and reducing burden on their families. Studies reveal that families often are not able to determine what treatment the patients wanted, and family members often experience significant distress when making such decisions (current practice largely relies on next of kin to make decisions). This shows that current practice does not actually promote individuals' primary goals in incapacitated treatment decision-making. Preferred amounts of leeway for surrogates (how much surrogates can decide based on what they think is best for the patient) vary widely. Perhaps involving the physician in the decision making process would reduce the burden on the family (however, this may undermine the patient's goal of being treated consistently with their own preferences).
  - POV: clinical, literature review
- Kohn, Nina A., *Matched Preferences and Values: A New Approach to Selecting Legal Surrogates*, 52 *SAN DIEGO L. REV.* 399 (2015).
  - This article examines approaches to surrogate selection. The primary purpose of surrogate decision makers is to make decisions that patients would make if they were not incapacitated (substituted judgment principle), thus look at relationship to patient, surrogate's trustworthiness, and willingness to follow patient's directions. However, empirical literature shows that selecting surrogates based on the above criteria is insufficient to protect patients' wishes (surrogates tend to project own preferences).

Currently, surrogate decision making in health care tends to follow next-of-kin approach in selecting surrogates. Social science literature elucidates a congruence problem (“incongruence” means that surrogate’s decision diverges from the decision patient would have made). Studies show inaccuracies of surrogate decisions. The article discusses shortcomings of existing strategies for improving congruence. The author recommends that surrogate decision makers for health care should be selected based on *extent to which they share patients’ treatment preferences*. Surrogates should be selected based on shared values (shared preferences and values approach). This approach would increase likelihood that surrogate’s treatment decision is consistent with patient’s preferences, and this concept should be incorporated into advance planning processes and statutory law for selecting guardians and default surrogate decision makers.

- POV: legal
- Kohn, Nina A., et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111 (2013).
  - This article covers descriptive and normative accounts of supported decision-making. There should be a shift from surrogate decision-making to supported decision-making for persons with intellectual disabilities (supported decision-making is a means of empowering patient by providing help in making decisions rather than just appointing someone to make decisions for them). In supported decision-making, the patient with the cognitive challenges is still the ultimate decision maker. The current approach is surrogate/substitute decision making: appoint surrogate to make decisions for patient (majority of these appointments are guardians). Supported decision-making is an appealing alternative to guardianship. However, there is not enough empirical evidence to show how much it can remedy the problems inherent in surrogate decision-making. The author suggests that we should look at ways supported decision-making can reduce use of guardianship (this is in line with idea of the least restrictive means principle).
  - POV: legal
- Kohn, Nina A. & Blumenthal, Jeremy A., *Designating Health Care Decisionmakers for Patients without Advance Directives: A Psychological Critique*, 42 GA. L. REV. 979 (2008).
  - The issue in this article is whether default surrogate laws have the intended effect of protecting wishes of incapacitated patients, and the analysis grounded in psychological science. Priority lists is surrogate laws often don’t distinguish within a class of surrogates (e.g. which adult child should be the surrogate). Default surrogate statutes aren’t fitting for non-traditional families. Surrogate decisions are frequently inaccurate. There are limitations to these studies because they assume similar decision-making patterns in hypos and in real-life. However, familial surrogates’ choices are overall more accurate than physicians’ choices. For decision making processes, important that the processes are accepted as just and appropriate (even more so than accuracy of the process). Study found that patients were more concerned with *who* the surrogate is than *what* decision making standard was used (actuarial models may be more accurate, but less acceptable because the process is impersonal). Surrogates appointed under default surrogate laws



are likely to make inconsistent decisions with patient's actual wishes. Authors suggest allowing default surrogates to be selected based on personal attributes, rather than familial status (and not simply let treating physician to identify the surrogate). Default surrogates should be given information that will improve accuracy of substantive decisions (i.e. info about inaccuracy of surrogate decision making, info about patient's most common preferences for health care).

- POV: legal, psychological
- Kon, Alexander A., "Difficulties in Judging Patient Preferences for Shared Decision-Making," *J. Med. Ethics* 38(12): 719-720 (December 2012).
  - This is an evaluation of shared decision making. Shared decision-making should be viewed as a continuum: from patient-driven decision making to equal partnership with care providers, to fully physician-driven decision making. Shared decision-making also means sharing responsibility for the decision made. Most people want their doctor to be an active participant in value-laden decision making. Individual-stated preference for a preferred method of decision making is not associated with *actual* decision making preference. The author suggests using informed non-dissent, where physicians first learns patient's values, so that physicians can be an informed active participant when decision-making with the patient/patient's surrogates.
  - POV: medical
- Kwiecinski, Maureen, *To Be or Not To Be, Should Doctors Decide? Ethical and Legal Aspects of Medical Futility Policies*, 7 Marq. Elder's Advisor 313 (2006).
  - The article examines futility decisions, as well as the practicality and legality of futility policies. Professional organizations and individuals advocated for futility policies in late 1990's (policies that address futility situations). Futility policy supporters claimed that health care providers can best determine when continuing treatment is longer worthwhile (because of their expertise and training), whereas futility policy critics claimed that EOL decisions are inherently subjective and value-laden. Futility disputes arose in almost half of EOL treatment cases (2001 study). Futility policies must be cautiously implemented (careful not to give physicians too much latitude, where in some states/institutions, physicians withdrew life support without consent of patients/families).
  - POV: legal, ethical
- Pope, Thaddeus M., "Making Medical Decisions for Patients without Surrogates," *New England Journal of Medicine* 2013; 369(21): 1976-1978.
  - The article discusses decision-making for unrepresented patients without surrogates. In almost every state, court-appointed guardian is the only legally authorized decision maker for unrepresented patients. BUT many problems with guardianship system – often guardians are not available, or assignment of guardian is too slow. Most decisions for unrepresented patients are made by physician alone, without hospital oversight. If cannot prevent patients from becoming unbefriended, then treatment decisions should at least be made by ethics committee that is independent from treating clinician (made

up of physician, nurse, social worker, bioethicist, and community member). Ideally, this multidisciplinary committee would be external to the healthcare facility. Important to balance btw due process and efficiency in decision-making process.

- POV: ethical, legal

Mechanisms and Sources of Authority for Substitute Decision Making.	
Mechanism or Situation	Source of Authority
Emergency	Implied consent
Instructional advance directive (living will)	Decided by the patient
Physician Orders for Life-Sustaining Treatment (POLST) form	Decided by the patient or surrogate
Proxy advance directive (durable power of attorney)	Appointed by the patient
Default surrogate	Appointed by the clinician
Guardian or conservator	Appointed by the court

- Pope, Thaddeus M., “Legal Briefing: Adult Orphans and the Unbefriended: Making Medical Decisions for Unrepresented Patients without Surrogates,” *Journal of Clinical Ethics* 2015; 26(2): 180-188.
  - This article explores decision-making for unrepresented patients without surrogates. One way to prevent having unbefriended patients is to expand default surrogate statutes: some states have broadened the list of default surrogates for unrepresented patients (e.g. some even include “close friend” at the bottom of the list), thus reducing the likelihood that a person lacks a surrogate. If can’t prevent patients from being unbefriended, then need mechanism to authorize treatment decisions. A possible mechanism is to have physician be the decision maker. BUT, problems of personal bias and conflicts of interest (physician’s dual commitment to individual patient and society). Perhaps, physicians can consult with other physicians. Some states propose mechanisms where hospitals are permitted to petition courts to appoint “expedited limited healthcare fiduciary” to make decisions for unbefriended patient (Tennessee amended conservatorship statute to allow this, but mainly for decisions authorizing discharge from acute care setting to more appropriate care setting). Another option is public guardianship, but disadvantages outweigh advantages. However, in most states, guardianship is the sole mechanism for making treatment decisions for unbefriended patients. The author recommends improving the guardianship process – either by establishing completely new guardianship programs where guardians should be assigned as last resort, OR reforming the current guardianship process by addressing key challenges such as delay, lack of available guardians, and limited authority of guardians
  - POV: ethical, sociological
- Pope, Thaddeus M., et al., “Legal Briefing: The Unbefriended: Making Healthcare Decisions for Patients without Proxies (Part 1),” *Journal of Clinical Ethics* 2012; 23(1): 84-96.
  - There is significant disagreement on decision-making mechanisms for the unbefriended. AMA argues that if there is no surrogate, ethics committee should make the decision and judicial intervention should be last resort. AGS argues that patient’s own team of treating physicians should make decision. American College of Physicians argues that court-appointed guardian should be used in every case.

- POV: legal
- Pope, Thaddeus M., et al., “Legal Briefing: The Unbefriended: Making Healthcare Decisions for Patients without Proxies (Part 2),” *Journal of Clinical Ethics* 2012; 23(2): 177-192.
  - This article explores the different mechanisms of decision-making for the unbefriended patient, including guardians, physicians, and committees. Private Guardians are guardians are given legal authority to make decisions for incapacitated individuals (major deficiencies, in terms of speed, cost, competence, and availability). Some states allow volunteer guardians to make up for limited availability of private guardians. Some states have adopted “public guardianship” programs. Most of these programs are publicly funded social services, or funded by county public officials (serious problems in implementation – overburdened, understaffed, and underfunded). Temporary and Emergency Guardians are guardians authorized to make limited number of decisions and don’t have ongoing authority to make decisions for patient (expedited so don’t go through full guardianship hearing. There are significant costs just like traditional guardianship). Some commentators argue that state surrogate statutes should include attending physician on the list to avoid unrepresented patients. Institutional committees are good for offering various viewpoints, and are faster than the court system. However, it can be difficult for a committee to convene for every decision. These committees are often comprised of individuals who are economically dependent upon the healthcare facility. External committees would ensure elimination of economic self-interest that institutional committees might have, but may be too removed from patient to make decision for the patient. The author suggests taking guidance from sliding scale approach, which provides oversight proportionate to the consequences of the decision.
  - POV: legal
- Pope, Thaddeus M., “Legal Fundamentals of Surrogate Decision Making,” *CHEST* 141(4): 1074-81 (2012).
  - This article discusses the importance of surrogate decision making, as well as legal foundations for the process. Decision-making capacity is essential to patient autonomy, but losing capacity does not mean losing autonomy; our society has individualistic norms, and medical decisions should continue to be led by autonomy, even if lose capacity. Author discusses five types of surrogates (in order of priority): patient-designated surrogates (proxies, agents, and attorneys-in-fact), informal and orally patient-designated surrogates, court-designated surrogates (guardians and conservators), physician-designated surrogates (default surrogates), surrogates for unbefriended patients (guardianship is time-consuming and costly; some states developed special mechanism for authorizing treatment decisions for unbefriended patients). The author also discusses shortcomings of surrogate decision making, such as conflict between surrogates/potential surrogates occurs with significant frequency (either surrogates of same class disagree OR potential “lower” surrogates disagree with surrogate’s decision). In many states, physicians are NOT tied strictly to priority list (physician can select someone based on list of factors). AMA and some state laws recommend using ethics committees before resorting to courts. The author proposes

solutions to surrogate problems, e.g. better advance care planning, surrogate education and training, surrogate replacement.

- POV: legal
- Pope, Thaddeus M., *Surrogate Selection: An Increasingly Viable, but Limited, Solution to Intractable Futility Disputes*, 3 ST. LOUIS U. J. HEALTH L. & POL'Y 183 (2010).
  - This article examines disputes between patient's healthcare provider and the patient's surrogate (aka futility disputes). Futility disputes occur when provider wants to stop treatment, but surrogate wants to continue. There is a significant rate of conflict between healthcare providers and surrogates. Most futility disputes are resolved collaboratively (internally and informally; after enough time and explanation, most surrogates agree with physician's recommendation). This article also looks at the role of surrogates. Surrogates are substitute decision makers (includes physician-designated surrogates, i.e. default surrogates), and healthcare provider selects surrogates based on default surrogate statutes. Duties of surrogates include: implement patient's instructions (e.g. advance directive), using substituted judgment to implement patient's preferences, and using best interests to promote patient's welfare. There are two ends to balance in selecting surrogates (quick/easy identification and cumbersome procedural safeguards). Surrogate replacement is proven and viable dispute resolution mechanism, but surrogate selection is still only partial solution to futility disputes. Author recommends that surrogate replacement/selection is a solution to futility disputes, but there is still room to develop dispute resolution mechanisms to handle remaining subsets of futility disputes not covered by surrogate replacement
  - POV: legal
- Prager, Kenneth, "When Physicians and Surrogates Disagree about Futility," *AMA J. ETHICS* 15(12): 1022-26 (December 2013).
  - This article focuses on disagreements in futility treatments. Physicians have a very different POV: by providing aggressive treatments in futile situations, doctors feel that they are violating medical ethical mandate to "first do no harm." Physicians often cite waste of costly medical resources as ethical justifications for withholding life support from ICU patients in futile circumstances. Patients and their surrogates may not share the same values as treating physician (e.g. religious, cultural, personal values). It is difficult to enact legislation because of diverse views/values of Americans on this subject
  - POV: medical, ethical
- Rid, Annette & Wendler, David, "Can We Improve Treatment Decision-Making for Incapacitated Patients?," *The Hastings Center Report*, 40(5): 36-45 (2010).
  - This article explores the current landscape of surrogate decision making, and how it can be improved. Problems with surrogate decision-making are the difficulty processing all the information surrogates know about their loved one to precisely know what the patient would choose. Surrogates assume that they know the preferences of their family and loved ones, and that since the patient is a closed love one, he/she must have similar

values, so easy for surrogates to exert their own values on decision making. The author suggests finding ways to *supplement* current practice (maintain the benefits of current practice while resolving the gaps), and providing surrogates with information regarding patients in similar circumstances and what those patients prefer (argument that this approach provides more empirically grounded decision-making). Also, author encourages shared decision making between surrogates and clinicians

- POV: medical, ethical
- Roberto, Karen A., "Making Critical Health Care Decisions for Older Adults: Consensus among Family Members," *Family Relations* 48(2): 167-175 (1999).
  - This study analyzed the concordance in decisions made between older adults and their families, on both the extent of concurrence, and also how families came to consensus when there was disagreement about the decisions. 62 older adults and family members responded to 45 hypothetical health care scenarios. Older adults often want a family *group* to participate in decision-making process (instead of a single surrogate), so this study looks at concordance between older adults and a *group* of family members. Many older adults don't necessarily discuss their wishes/health preferences with their families. The study found significant agreement more often where the hypothetical scenarios involved the older adult's current health and when recovery prognosis was lower. When families disagreed, the most common approach to reaching consensus was to discuss/describe the treatment and prognosis for the patient's recovery, and the second most common approach was to refer to interests/wishes of the older adult. Filling out advance directives is not enough, and patients must have conversations with families (e.g., normative affective approach – emotion and value-laden discussions). The author encourages programs for older adults and families that inform on common medical conditions/treatment in later stages of life
  - POV: clinical
- Santa Clara County Medical Association, "Recommendation for Establishing Policy on Health Care Decisions for Incapacitated Patients Without Surrogates," (February 2001) (5 pages).
  - The Association recommends what procedural mechanisms can be used to guide healthcare providers in making decisions for unrepresented patients without surrogates. Statement details include: If no surrogate, should refer to ethics committee (ethics consultant will come from facility's internal ethics committee); for decisions regarding life support withdrawal/treatment, ethics committee will appoint sub-committee as surrogate decision-maker (subcommittee will be multidisciplinary).
  - POV: policy
- Scheunemann, Leslie P., et al., "The Facilitated Values History: Helping Surrogates Make Authentic Decisions for Incapacitated Patients with Advanced Illness," *AM. J. RESPIR. CRIT. CARE MED.* 186(6): 480-86 (September 2012).
  - Current models on medical decision making are: surrogate as expert on patient's values, and physician as expert on technical medical considerations. There is pushback on these models, because knowledge of patient's values and preferences is only *part* of surrogate

decision maker's role. Look at distinction between autonomous decisions vs. authentic decisions: decision can only be autonomous if the patient him/herself made specific choice about medical treatment in advance; otherwise, goal is to make authentic decision (informed by knowledge of patient's values and intention to deliver care that respects patient as a person). Author proposes using facilitated values history (through questions clarifying patient's values for the surrogate).

- POV: medical
- Schwab, Carol A., *Who Holds the Power?*, 45 TENN. B.J. 12 (2009).
  - This article specifically looks at why Tennessee rejected automatic next-of-kin approach for surrogate selection. Physicians play key roles in determining who has legal authority to act on behalf of incapacitated patient. Physician must record their choice of surrogate in patient's medical chart, or else patient is without legal surrogate for health care decisions. The author/Tennessee suggests that there must be actual or apparent authority to act as patient's agent, and simply being next-of-kin does not automatically result in such authority.
  - POV: legal
- Shalowitz, David I., et al., "How Should Treatment Decisions Be Made for Incapacitated Patients, and Why?," *PLoS Medicine* 4(3): 423-428 (2007).
  - This article examines how decisions should be made for incapacitated patients who do not have advance directives, and assesses whether population-based decision aid predicts patient's treatment preferences more accurately than surrogates. The study examines results of the population-based treatment indicator (entering incapacitated patients' circumstances into a computer), and looks at the accuracy of surrogates' decisions ("accuracy" is based in hypothetical scenarios, where patients who were not yet incapacitated indicated their preferences). Surrogate accuracy for treatment preferences is approximately 68%. Two most frequently endorsed methods for improving surrogates' accuracy are ineffective (reliance on surrogates designated by patient rather than next-of-kin, and explicit discussion of patients' treatment preferences), and physicians are even less accurate than surrogates. Population-based treatment indicator predicted just as accurately as surrogates. Perhaps treatment indicator decisions can be used to supplement surrogates' decisions, so family/loved ones don't feel like they're being excluded from the decision-making process. Author suggests that we should reconsider prioritization of *who* should make treatment decisions for incapacitated patients.
  - POV: clinical, ethical
- Shalowitz, David I., et al., "The Accuracy of Surrogate Decision Makers," *Arch. Intern. Med.* 166:493-497 (2006).
  - The article explores the accuracy of surrogate decision making (mainly for next-of-kin surrogates and patient-designated surrogates). Surrogates were instructed to use substituted judgment standard for decision making, and the study method as based on a systematic literature review. Surrogates predicted patient's treatment preferences with

68% accuracy. Patient-designated and next-of-kin surrogates' judgments are not very reliable (incorrectly predict patients' end-of-life preferences in 1/3 of cases), so should explore other mechanisms for predicting patient's treatment preferences.

- POV: medical, literature review
- Snead, O. Carter, *The (Surprising) Truth About Schiavo: A Defeat for the Cause of Autonomy*, 22 CONST. COMMENT. 383 (2005).
  - The Terry Schiavo case is not actually a victory for the cause of autonomy/self-determination, because the Florida courts actually focused on the conditions/benefits of different treatments for Schiavo, and less on her actual subjective intentions. Although the positive law in place was actually built towards promoting autonomy, the adjudication of the Schiavo case used more of a best interests approach, rather than substituted judgment (thus actually under-prioritizing autonomy). Principle of autonomy and self-determination predominates in bioethics, and informed consent is extension of personal autonomy.
  - POV: legal
- Su, Christopher T., et al., "Family Matters: Effects of Birth Order, Culture, and Family Dynamics on Surrogate Decision-Making," *J. Am. Geriatr. Soc.* 62(1): 175-182 (2014).
  - This study looks at filial expectations and family dynamics in the context of surrogate decision-making. The mean age of participants in this study was 69. There are different cultural influences on surrogate selection and decision making (some cultures place a lot more emphasis on the oldest child being the decision maker/having the most responsibility; and some cultures discuss death as a taboo). Because firstborn children are the crucial surrogate decision makers in different cultures, this causes conflict with younger siblings who may be the actual primary day-to-day caregivers. Clinicians should be aware of the cultural differences, and particularly of the filial expectations placed on the eldest child. Being aware, clinicians can facilitate communication among the family members and reduce overall stress for the surrogates.
  - POV: clinical, psychological
- Torke, Alexia M., et al., "Physicians' Experience with Surrogate Decision-Making for Hospitalized Adults," *J. Gen. Intern. Med.* 24(9): 1023-8 (2009).
  - This study looks at physicians' approaches to surrogate decision-making, using 281 physicians who recently cared for adult in-patients. Key features in physicians' surrogate decision-making experience included nature of the decision, physician's reaction, physician-surrogate communication, and physician-surrogate agreement regarding best course of action. Physicians reported trouble contacting the surrogate in 21% of the cases; conflict between the physician and surrogate was rare (5%), and the majority of physicians agreed with surrogates about best course of action (65%). Agreement about best course of action was more common among surrogates for older patients.
  - POV: clinical, medical
- Torke, Alexia M., "Physicians' Views on the Importance of Patient Preferences in Surrogate Decision Making," *J. Am. Geriatr. Soc.* 58(3): 533-38 (2010).

- This study looks at the extent to which physicians report relying on patient preferences when making medical decisions for incapacitated patients, using 281 physicians who recently cared for hospitalized adults. 73% physicians reported using a standard of decision making that related to patient preferences. Of this 73%, 82% reported that patient preferences were highly important (HOWEVER, only 29% reported that patient preferences was the most importance factor in the decision). Physicians were more likely to based decision on patient preferences for ICU patients. Presence of living will, prior discussions with patients, and physician’s beliefs about ethical guidelines did not significantly predict physicians’ reliance on patient preferences. Physicians who selected “what was best for patient overall” may be making a global assessment, using both best interest and patient preferences standards. There was a decreased reliance on patient preferences with an increasing age of patient. Physicians relied on a variety of decision-making factors, and the most important factor may vary from case to case.
  - POV: ethical, clinical
- Torke, Alexia M., et al., “Scope and Outcomes of Surrogate Decision Making Among Hospitalized Older Adults,” JAMA Intern. Med. 174(3): 370-77 (2014).
  - This study looks at decision making for incapacitated patients, outside of ICU and EOL settings, using 1083 hospitalized older adults requiring major medical decisions. 47.4% (nearly half) of older adults required some surrogate involvement (23% required all decisions to be made by surrogate). Patients who required a surrogate experienced more complicated hospital care, with greater use of ventilators, artificial nutrition, and greater length of stay (over treatment). Decisions are most often made by daughters (note: perhaps because this is incapacitated *older* adults, so spouses are no longer available). Hospital structures/routines must include focus on incapacitated patients and must explicitly address the role of surrogate decision makers.
  - POV: medical, clinical
- Torke, Alexia M., et al., “Substituted Judgment: The Limitations of Autonomy in Surrogate Decision Making,” J. Gen. Intern. Med. 23(9): 1514-7 (2008).
  - This is a criticism of the substituted judgment approach. Substituted judgment approach is primarily based on principle of autonomy. There is empirical evidence against substituted judgment. In spite of empirical evidence, physicians still turn to substituted judgment (because autonomy is intensely valued in American society). An alternative model for decision-making is using best-interest standard based on community norms (objective standards for best interest based on community norms). Substituted judgment has many shortcomings, and other approaches should be considered. Patient’s dignity may be just as important (if not more important) than autonomy.
- Varma, Sumeeta & Wendler, David, “Medical Decision Making for Patients Without Surrogates,” Arch. Intern. Med. 167(16): 1711-1715 (2007).
  - This article covers standards of decision-making, particularly for patients without surrogates. Alternative approach to predicting patients’ preferences is the population-based treatment approach. This works by inputting patient characteristics, and looking



at preferences of other individuals who share patient's demographic characteristics. Analysis shows that population-based treatment predicted patient preferences just as accurately as patient-appointed or next-of-kin surrogates. However, more data is needed on individuals' treatment preferences to create the database needed for this approach. The authors recommend using population-based treatment indicator in decision-making for unbefriended patients.

- POV: sociological
- Veterans Health Administration, "Informed Consent for Clinical Treatments and Procedures," VHA Handbook 1004.01 (August 2009) (31 pages).
  - This is a policy on informed consent for clinical treatments and procedures. Practitioners make determinations of decision-making capacity, through appropriate clinical evaluation. When patients lack decision-making capacity and there is no advance directive, physician should make reasonable inquiry into availability of possible surrogates. Priority of surrogates is: health care agent, legal guardian, next-of-kin, close friend. If there is disagreement between surrogates at the same priority level, practitioner/physician should try to reach consensus. If can't reach consensus, then physician has to choose which surrogate is best able to represent patient's values. If have surrogate, surrogate takes on same authority and responsibilities as patient in informed consent process. If don't have surrogate, practitioner can contact Regional Counsel to obtain guardian for health care decisions, OR follow process for different kinds of treatments: treatments that DON'T require signature consent; treatments that DO require signature consent (there is list of treatments that do require signature consent); withholding or withdrawal of life support. There is implied consent in emergency situations.
  - POV: policy
- Vig, Elizabeth K., et al., "Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision-Making," J. Am. Geriatr. Soc. 54:1688-1693 (2006).
  - This study looks at how surrogates make decisions. Surrogates were interviewed by phone (surrogate decision makers for older, chronically ill veterans). Surrogates revealed 5 bases for decision making: conversations with the patient, relying on documents, shared experiences with the patient, surrogates' own values and preferences, surrogates' network (enlist help from others to make decision). One way to improve the accuracy of surrogate judgments is to inform them of the limitations of advance directive documents (study found that surrogates tend to have overconfidence in advance care planning documents).
  - POV: medical, clinical
- Vig, Elizabeth K., et al., "Surviving Surrogate Decision-Making: What Helps and Hampers the Experience of Making Medical Decisions for Others," Soc'y Gen. Intern. Med . 22: 1274-1279 (2007).
  - This study addresses the challenges of EOL treatment decision making for surrogates. Four factors that affect surrogate decision making: surrogate characteristics and life

circumstances (e.g. different coping strategies), surrogates' social networks (e.g. intrafamily support or conflict), surrogate-patient relationship and communication, surrogate-clinician relationship and communication.

- POV: clinical
- Visser, Mieke, et al., "Physician-related Barriers to Communication and Patient- and Family-centered Decision-making towards the End of Life in Intensive Care: A Systematic Review," *Critical Care* 18:604-623 (2014).
  - This study examines how to improve communication to facilitate decision-making (NOTE: included both English and Dutch studies). The research method was to use studies across different research platforms (list of studies used is in the article, on pp. 6-9), and to examine barriers in physician knowledge and physician practice. Physicians' attitudes demonstrate that physicians often see their job as more about saving lives, rather than letting patients die in the best possible way. Physicians tend to favor their own judgment/ideas on withholding/withdrawing life support treatment (focus on physiological and clinical parameters, rather than asking about patient's or family's preferences). ICU physicians should be trained to use a more holistic approach in treating patients in EOL cases. Particularly, training should be in communication (with colleagues and patients/families) and understanding the legal framework surrounding EOL.
  - POV: clinical, medical, ethical
- Volpe, Rebecca L. & Steinman, Deborah, *Peeking Inside the Black Box: One Institution's Experience Developing Policy for Unrepresented Patients*, 36 *HAMLIN L. REV.* 265 (2013).
  - This is a study on decision making options for unbefriended patients (specifically, application in local Penn State area). There are 3 broad options: physician consensus, internal committee, emergency guardianship. For physician consensus, advantages are fast and convenient (useful for urgent treatment decisions), but disadvantages are ignoring the fact that treatment decisions are personal (there are social and ethical ramifications). For internal committees, advantages are offering multidisciplinary perspectives and faster than court process, but disadvantages are that it could be slow/inconvenient to convene to make decision (also, same disadvantages as physician consensus approach). For emergency guardianship, advantages are that it avoids the problem of healthcare providers serving role of surrogate (who may have different values/motives), but disadvantages are that it's slow, costly, and time-intensive. In Penn State area, emergency guardianship had the most benefits (relatively quick and guardians had appropriate training).
  - POV: legal
- Weiss, Barry D., et al., "Medical Decision-Making for Older Adults without Family," *Journal of the American Geriatrics Society* 2012; 60(11): 2144-2150.
  - This article looks at decision making for unrepresented older adult patients. As age increases, it becomes more difficult to find surrogates. Friends of older adults are also less likely to be capable of acting as surrogates. Currently used approaches are:

physicians making decisions, hospital ethics committees, statutory rules and court-appointed surrogate agents, population-based treatment indicators (computer based system that predicts individual patient's preferences based on known preferences of large sample of individuals who have similar demographic characteristics as the patient). Authors recommend having health fiduciaries as a new type of professional, trained and certified to act as surrogate decision-maker for unbefriended patients. The health fiduciary's tasks would be to perform initial and follow-up conversations with patient regarding end-of-life preferences, to actively serve as healthcare decision maker when patient loses capacity, and to possibly take on post-death tasks. Decisions by health fiduciaries would have same weight of authority as the patient themselves or family members of patients.

- POV: sociological
- Weyrauch, Samantha, *Decision Making for Incompetent Patients: Who Decides and By What Standards?*, 35 Tulsa L.J. 765 (2000).
  - This article focuses on capacity (definitions of capacity, as well as roles/tests in health care decision making). Decision making is a balancing between autonomy and beneficence (physicians may inject subjective values in deciding what's best for the patient, but this may take away from patient autonomy if contradict patient's desires). Author distinguishes capacity/competency and autonomy: autonomy is self-governance, whereas capacity is the ability to perform a task (so losing capacity does not mean losing autonomy), which gets us into the realm of decision making for incapacitated patients.
  - POV: legal, moral
- White, Douglas B., et al., "Are Physicians' Recommendations to Limit Life Support Beneficial or Burdensome?," *Am. J. Respir. Crit. Care Med.* 180:320-325 (2009).
  - Many professional medical societies have recommended that doctors routinely provide recommendations to surrogates about whether to limit life support. This study explores the actual value/helpfulness of these recommendations. Surrogates viewed 2 videos of simulated physician-surrogate discussions regarding whether to limit life support (only difference in the 2 videos is whether physician gave recommendation). 56% surrogates preferred to receive recommendation, 42% preferred not to have recommendation, 2% felt both approaches were acceptable. There were 4 main themes that explain surrogates' preferences: surrogates' perceptions of physicians' appropriate role, perceptions of positive/negative consequences of physicians' recommendations on the physician-surrogate relationship, consequences on the decision-making process, and consequences on long-term regret for the family. There is no consensus on whether physicians should routinely provide recommendations in life support decisions, and physicians should first ask the surrogates whether they would like to receive the recommendation.
  - POV: medical, clinical

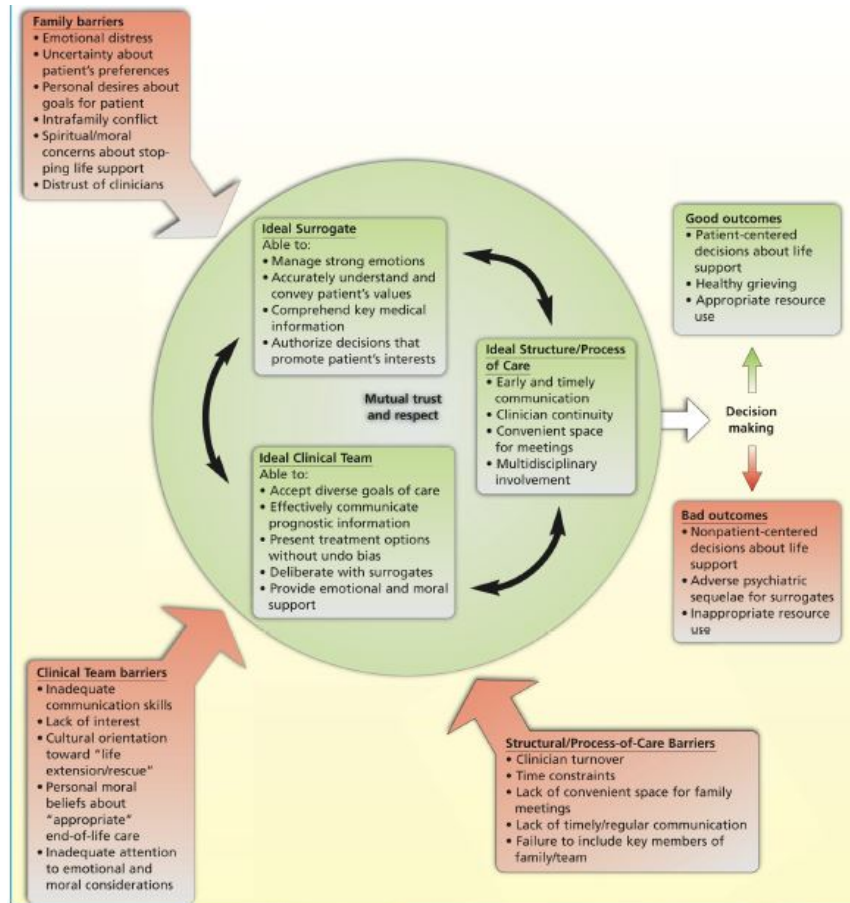
- White, Douglas B., et al., “Decisions to Limit Life-Sustaining Treatment for Critically Ill Patients who Lack Both Decision-Making Capacity and Surrogate Decision-Makers,” *Crit. Care Med.* 34(8): 2053-59 (2006).
  - This article examines how often unbefriended patients are admitted to ICU of a metropolitan hospital, and how end-of-life decisions are made for these patients. For each unbefriended patient, attending physicians completed questionnaire about the decision-making process regarding life support treatment. 16% (49 out of 303) of admitted patients during the study were incapacitated and unbefriended; 37% (18 out of 49) of these patients had physicians consider withdrawing/withholding treatment; 56% (10 out of 18) of these cases, attending physician obtained opinion of another attending physician; 33% (6 out of 18) of these cases, physicians made the decision independently; 11% (2 out of 18) of these cases, input from courts or ethics committees were obtained. For decisions to limit life support, physicians usually made these decisions without judicial or institutional review.
  - POV: medical, clinical
- White, Douglas B., et al., “Ethical Challenge: When Clinicians Act as Surrogates for Unrepresented Patients” *American Journal of Critical Care* 2012; 21(3): 202-207.
  - The article examines the “clinician as decision maker” approach, with a focus on life support decisions. The author highlights the principle of American bioethics to promote patient self-determination (e.g. norm of American medicine is that clinicians do not have authority to administer treatment without patient consent; patient or surrogate has final authority). It’s important to remember that life support decisions require more than just biomedical judgments – also includes social, ethical, and individual values determinations. Physicians have professional responsibilities to both individual patient and society to use resources in cost-conscious manner. This dual commitment may influence clinicians’ recommendations (may not necessarily be in patient’s best interest). There is a lack of procedural fairness (e.g. transparency, dialogue, oversight) when physicians decide. The author acknowledges treating clinicians’ expertise and obligation to act for patient’s interests; however, if physicians are decision-makers, ethical problems arise. Clinicians should play role of “advisers” rather than “deciders” for unrepresented patients
  - POV: ethical, sociological
- White, Douglas B., et al., “Expanding the Paradigm of the Physician’s Role in Surrogate Decision-Making: An Empirically Derived Framework,” *Crit. Care Med.* 38(3): 743-750 (2010).
  - This study looks at the role of physicians in the decision making process for life support treatment in ICUs. Data were audio tapes of clinician-family conferences at select hospitals in Seattle and San Francisco. Physicians took 1 of 4 distinctive roles: informative role, facilitative role, collaborative role, directive role. Physicians frequently refused to provide treatment recommendations (in 20 conferences where surrogates requested recommendation, physicians refused to provide one in 10 of such conferences). As a middle ground between physicians who are reluctant to provide

recommendations, but whom also want to provide more than just medical facts (aka informative role), the facilitative role is a happy medium. Physician coaches families through the decision making process and guides their focus, but does not make recommendation. But, caution that facilitative role is not ideal in all circumstances, because needs vary by individual families

- POV: medical, clinical
- White, Douglas B., et al., "Life Support for Patients without a Surrogate Decision Maker: Who Decides?" *Annals of Internal Medicine* 2007; 147(1): 34-40.
  - This is a medical/public health study on physician decision-making for unrepresented critically ill patients. The study looks at the frequency in which life support withdrawal decisions are made in ICUs for unrepresented patients who lacked decision-making capacity. Without surrogates, physicians are more hesitant to limit life support, perhaps to avoid legal ramifications. For incapacitated patients without surrogate or advance directive, physicians had to make decisions such as writing DNR orders and life support withdrawals. Out of 3011 critically ill patients, only 37 were incapacitated and unrepresented (small sample size). Physicians varied on whether to include another physician to make the decision, but vast majority DID include another physician in making decision to limit life support. Researchers examined hospital policies at the 7 health institutions that participated in the study: 2 hospitals didn't address how to make decisions for patients without surrogates or advance directives, remaining hospitals varied in recommended approaches (none required judicial review). Note that physicians can make largely variable decisions regarding life support due to personal characteristics. No *normative* consensus on life support decisions for incapacitated patients. Hospitals should have multidisciplinary consultation regarding DNR orders and life support withdrawals.
  - POV: medical/scientific, public health
- White, Douglas B., "Rethinking Interventions to Improve Surrogate Decision Making in Intensive Care Units," *Am. J. Crit. Care* 20(3): 252-57 (May 2011).

- This article looks at physician-level barriers to high quality surrogate decision making in ICUs. The author suggests incorporating clinical nurses into interventions to improve surrogate decision making in ICUs (nurses can prepare family for role of surrogate, organize meetings btw family and multidisciplinary teams, prepare family before each intensive care unit family meeting, provide emotional support/”nudges” during meetings, and be present if families want to meet after the intensive care unit meeting).

- **Whitton, Frolik, A., Decision-Theory for Reality, L. REV. (2012).**



- **POV: medical Linda S. & Lawrence Surrogate Making Standards Guardians: and 2012 UTAH 1491**

- This article looks at how guardians should make decisions for

incapacitated patients. The article details which standards are in each state's guardianship statutes. There is a spectrum of viewpoints: strict substituted judgment (decision based on incapacitated person's prior directions/expressed wishes), expanded substituted judgment (decision based on incapacitated person's prior statements, actions, values, preferences), strict best interest (decision based on comparison of benefits/burdens from viewpoint of reasonable person in incapacitated person's circumstances), expanded best interest (decision based on comparison of benefits/burdens from viewpoint of reasonable person in incapacitated person's circumstances, and include consideration of consequences for significant others if reasonable person might ordinarily consider such consequences), hybrid substituted judgment/best interest (two kinds of hybrid: 1. Decision based on substituted judgment; if not, then decision based on person's best interest; 2. Decision based on substituted judgment if there's evidence of what the person would've wanted and decision also

promotes best interest; if no evidence, then decision based on best interest). Nearly all guardians try to consider both standards when making decision.

- POV: legal
- Winter, Laraine, "Patient Values and Preferences for End-of-Life Treatments: Are Values Better Predictors Than a Living Will?," *J. Palliative Med.* 16(4): 362-368 (2013).
  - This study is a comparison of accuracy between using patient values and relying on living wills, in terms of predicting treatment preferences. The study recruited 304 participants in Philadelphia area. Knowledge about patient's religiosity, wishes for longevity, and wishes for following family preferences provide better guidance than a living will. However, wishes for dignity, pain management, and reluctance to burden others don't offer better guidance than a living will. Knowing individual's values on religion, longevity, and desire to follow family wishes may be helpful in predicting preferences for EOL care.
  - POV: clinical
- Yuen, Michele, *Letting Daddy Die: Adopting New Standards for Surrogate Decisionmaking*, 38 *UCLA L. REV.* 581 (1992).
  - This article discusses surrogate decision-making pertaining to life-support withholding/withdrawal treatment decisions. Part of the article examines "Who is the Appropriate Surrogate Decisionmaker?" (pp. 600-610). One option is the judicial system as decisionmaker: decreasing requirement of judicial intervention for surrogate decision making (this article was written in early 1990's). A second option is the family as decisionmaker: family members are usually most familiar with patient's life, goals, preferences, and values (substituted judgment), and family is usually more concerned about the patient's welfare (best interests); however, shortcomings are that family members may have differing religious/ethical views and also may not want to see a loved one suffer (family's "self-interests"). A third option is the physician as decisionmaker: very few people believe that doctors should have unilateral decision making power. Doctors may have ulterior motives regarding limited medical resources and financial costs of maintaining unconscious patients. Author thinks family is best candidate for surrogate decisionmaker (as compared with judicial system and physicians). However, families are also influenced by external factors, so there should still be a check on their decision making. If there's conflict between family's choice and doctor's choice, third party should decide (ex. ethics committees, arbitrators, etc.). If there's no conflict, then doctor and family's consensus for patient's best interests should govern.
  - POV: legal
- Zweibel, Nancy R. & Cassel, Christine K., "Treatment Choices at the End of Life: A Comparison of Decisions by Older Patients and Their Physician-Selected Proxies," *Geron. Soc'y America* 29(5): 615-621 (1989).
  - This study looks at whether physician-selected proxies (particularly middle-generation proxies) can choose as the patient would have chosen (i.e., engage in substituted judgment). Using physician-selected proxies is the most commonly used approach (despite its shortcomings). Physician-selected proxies often make decisions that go against what patient

would have chosen for themselves. These middle-generation proxies tend to underestimate the patient's preference for resuscitation (proxies are mostly children of patients in this study).

- POV: clinical

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