

# Surrogate Decision Making: Reconciling Ethical Theory and Clinical Practice

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The care of adult patients without decision-making abilities is a routine part of medical practice. Decisions for these patients are typically made by surrogates according to a process governed by a hierarchy of 3 distinct decision-making standards: patients' known wishes, substituted judgments, and best interests. Although this framework offers some guidance, it does not readily incorporate many important considerations of patients and families and does not account for the ways in which many patients and surrogates

prefer to make decisions. In this article, the authors review the research on surrogate decision making, compare it with normative standards, and offer ways in which the 2 can be reconciled for the patient's benefit.

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Surrogates, usually family members, make decisions about health care for cognitively incapacitated patients. The process for making surrogate decisions is widely accepted as following a hierarchy of standards: patients' known wishes, substituted judgments, and patients' best interests (1). This schema, developed several decades ago during an era of rapidly evolving individual and civil rights and rising consumer empowerment, reflects not only a Western notion of personhood, but individual self-determination, which is especially pronounced in the culture of the United States. Over the years, these hierarchical standards have become established as convention in bioethics and interwoven in federal and state law. Although these standards emphasize important values and provide a framework for decision makers, they are at substantial variance with a body of empirical research describing the ways in which patients and families actually make health decisions. This research suggests that many patients want their surrogates to exercise considerable discretion in decision making and finds that families often use a less schematic approach. We outline differences between normative standards for decision making and empirical evidence of practice and offer clinicians ways in which the 2 can be reconciled for the patient's benefit.

## DECISION MAKING AND STANDARDS

The bioethical hierarchy of 3 decision-making standards is endorsed widely by both organized medicine and the law (2–5). It requires surrogates and physicians to attend first and foremost to the explicit wishes of the patient. If such wishes are not available, surrogates are urged to

determine what decision the patient would probably have made on the basis of the patient's values, beliefs, and past decisions, as interpreted by the surrogate. If clinicians are convinced that surrogates are not well-enough informed to do so, then the patients' best interests should guide surrogates' decision making.

Nevertheless, research suggests that patients, surrogates, and even their physicians often operate independently of these standards (6, 7). For example, despite the formal recognition of the primacy of patients' stated wishes, there is growing awareness that patients do not value or even define personal autonomy uniformly (8–10). Moreover, many patients do not necessarily want their surrogates to adhere to their specific treatment preferences or to follow the standards in sequence, but instead wish them to respond dynamically to actual clinical situations in order to maximize their evolving, contemporaneous interests and to make judgments that integrate both medical and nonmedical considerations (11–15). One nonmedical consideration, for example, is that many patients consider placing trust in their surrogates more important than assuring their surrogates' ability to accurately predict the patient's own decisions (16). Some patients modify their preferences to accommodate their family members' concerns, and some give weight to the distress they anticipate their family will experience from unavoidable choices (9, 17).

The substituted judgment standard requires that surrogates strive to produce decisions that the patient would have made. Yet surrogates, even those who patients specifically appoint as health agents, are often inaccurate in representing patients' medical preferences for several reasons (18–21). Surrogates' decisions may reflect considerations that extend beyond narrow medical and solely patient-centered factors (22–25). Although surrogates generally consider the patient's values, such influences as family dynamics, stress associated with the surrogacy role, and the psychology of decision making may affect final treatment decisions (26–28). For example, "status quo bias" may partially account for surrogates' overtreatment relative to patients' preferences (29, 30). The number of surrogates in-

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volved is also important because the dynamics of group decision making influence the way in which information is shared, weighted, and acted on (31, 32). In addition, surrogates often struggle with such issues as recognizing their own needs and values and identifying where these differ from those of the patient.

Despite substantial evidence of surrogate inaccuracy, surrogates' decisions are understandably widely accepted. Less expectedly, many physicians do not require surrogates to adhere to patients' known wishes, and physicians often treat incapacitated patients contrary to expressed preferences (33–40). Perhaps physicians misinterpret their ethical obligations or simply yield to family members' demands in order to avoid stressful encounters (41, 42). More probably, physicians accept surrogates' choices from an unarticulated recognition that treatment decisions are dynamic and situational and that relationships between patient and family are complex. In summary, the preferences and behaviors of many patients, surrogates, and physicians are dissonant from the normative and legally supported hierarchy of decision-making standards.

### SURROGATE DECISIONS AND STANDARDS: AN IMPERFECT FIT

The schema of discrete standards is useful for emphasizing important considerations in surrogate decision making. In the untidy setting of the clinic, however, many decisions do not fit neatly into any single standard. Recasting sequential standards as a continuum better reflects actual practice. For example, although living wills contain patients' explicit statements of preference (corresponding to the patients' known wishes), these statements often are not clinically serviceable (43). Rather, interpretation or qualification is required. To further illustrate this point, a living will template made publicly available by the New York State Bar Association states: "If I am: a) in a terminal condition; b) permanently unconscious; or c) if I am conscious but have irreversible brain damage and will never regain the ability to make decisions and express my wishes . . . I do not want cardiac resuscitation . . . mechanical respiration . . . tube feeding . . . antibiotics" (44). A literal reading of this directive would preclude the use of an oral antibiotic for a simple urinary tract infection if the patient is sufficiently demented to impair decision making, yet enjoys good overall quality of life. Although these boilerplate directives often obscure authentic preferences, many patient-authored, personal expressions of preference also require clarification. For example, the statement "I never want to be fed through tubes" made by a now-incapacitated patient would require an interpretation of the phrase "to be fed." Did the patient mean only ongoing and indefinite support, or time-limited or goal-directed nutritional support as well? Ostensibly clear wishes that, in fact, require interpretation are at a point on the continuum somewhere between known wishes and substituted judg-

#### Key Summary Points

Surrogate decision making is understood to follow a hierarchy of standards: known wishes, substituted judgments, and best interests. However, empirical research on surrogacy finds divergence from these standards in actual practices of patients, families, and physicians.

Many patients do not necessarily want their surrogates to follow their specific treatment preferences, or to follow the standards sequentially, but wish them to respond dynamically to actual clinical situations and to integrate both medical and nonmedical concerns.

A single standard is unlikely to represent the most appropriate decision-making process for all the decisions a surrogate must typically make.

Some patients' primary concerns may be nonmedical and non-patient-centric, such as concerns for minimizing emotional or other burdens on family members. These sorts of concerns are not well accounted for in the normative standards for surrogacy.

Living wills are limited in sensitivity and specificity in that they often fail to capture important preferences of patients, and documented preferences may be inauthentic representations of patients' wishes.

Making surrogate decisions is far more complex, dynamic, and nuanced than is generally understood. Norms for surrogacy should fully account for a robust range of patients' concerns and interests in order to improve the quality of surrogates' decision making.

ments. Where exactly on the continuum a decision falls depends on the degree to which the statement of preference requires explication.

Similarly, a continuum exists between substituted judgments and best interests. Substituted judgments describe decisions that are meaningfully shaped by the patient's values and preferences. As these influences become less clear, weighty, or specific to the individual patient, decisions migrate along the continuum from substituted decisions to decisions governed by the patient's immediately discernible interests.

No single point on the continuum is likely to represent the most appropriate decision-making process for all the decisions required of a surrogate. For example, a surrogate may face decisions about artificial nutrition, cardiopulmonary resuscitation, and ventriculoperitoneal shunting. The patient may have discussed only tube feeding, leaving the surrogate to generate a substituted judgment about cardiopulmonary resuscitation and perhaps simply to rely on his

or her instincts on whether the shunt is in the patient's best interests. Physicians must be mindful that each surrogate is likely to function under multiple standards.

### RESPECTING AUTONOMY IN AN INFLEXIBLE SYSTEM

With respect to decision making, past physician paternalism has been replaced by an inflexible schema for surrogate decision making, supported by a legal framework that assumes that a single correct process for surrogates to follow exists and that patients homogeneously subscribe to this process as well (45, 46). These presuppositions about surrogacy, which are emphasized in medical education, persist despite research identifying substantial heterogeneity among patients. Moreover, physicians are often unaware of the cultural norms that make discussions of advance directives taboo, and for patients agreeable to these discussions, physicians are not taught to elicit patients' preferred mode of surrogate decision making. Undeniably, efforts to record patients' specific preferences have not been successful, and there is now increased emphasis on understanding patients' general values (47–49). Fortunately, these complexities in surrogacy are beginning to be reflected in public policy. In innovative legislation from 2006, Maryland modified its statutory advance directive to present an explicit choice whether “living will” preferences about treatment were meant to be binding or simply as guidance to be applied flexibly (50). This approach encourages a more common-sense consideration of a patient's preferred modes of surrogate decision making.

### A RICHER AND MORE COMPLEX REPRESENTATION OF INCAPACITATED PATIENTS

Some considerations that are important to patients in decisions by surrogates are not well represented in the normative standards, such as concerns for family (51), and familial roles and influences in decision making are often underappreciated. For example, cultural norms might influence decision-making dynamics by favoring one family member's opinion over another's, by favoring group decision-making over individual decisions, and even by supporting third-party decision making for still-capacitated patients (52, 53). Moreover, the standard hierarchy is based on an atomistic view of autonomy, whereas some patients and families maintain a more inclusive concept of individual personhood. To illustrate, according to a commentator, in Pakistani culture, “you *are* your family and your family is you” (53). Concerns held primary by patients may include minimizing emotional, financial, or other burdens on a spouse or adult children, even if such a decision is not optimal in narrow health objectives (54). Decisions that elevate family concerns may be ethical because, as Mappes and Zembaty state, “When one identifies with the interests of others and acts accordingly, one is *also* acting in one's self interest” (55). Although respecting pa-

tients' deeply held preferences, including those that are not individualistic, can be accommodated within a paradigm that respects individual autonomy, this enriched understanding of self-interest is not yet well integrated into practice (56–58). We note that one challenge is discerning when placing other's needs over one's own is truly autonomous as reflecting deeply held beliefs and when it reflects ethically dubious influences that diminish autonomy (59).

Because patients' lives are more complex than the normative standards allow, many ethically supportable surrogate decisions depart from the conventional hierarchy.

Example 1: *Substituted judgment trumps known wishes*. “I know that my wife wrote in her living will that under no circumstances would she want to be on a ventilator, but our son is returning from Iraq next week, and I believe that she would want to be kept alive to say goodbye.”

Example 2: *Best interests trump substituted judgment*. “We all know that my father is a fighter and would not want to give up no matter what. But he is suffering horribly and there is no end in sight. That is not right. He has suffered enough.”

Example 3: *Off the hierarchy/continuum*. “I know that my wife wrote in her living will that if she had a stroke like this (causing complete unconsciousness and ventilator dependence) that she would not want to be kept alive, but our son is returning from Iraq next week and it is important *to him* to say goodbye.”

### NEEDED SHIFTS IN POLICY

Policy on surrogacy should continue to be guided by respect for individual autonomy, but genuine respect requires a more robust, multidimensional notion of autonomy—one that more deeply accommodates the value and integrity of family. Existing policy should be reexamined for bias and revised to more transparently accommodate patients and families whose beliefs and practices are non-normative and should address the fact that most patients

**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.

will never execute an advance directive. One example of policy based on too narrow a concept of autonomy is found in the laws of Missouri and New York, which limit surrogacy and require clear evidence of the patient's specific wishes in order to forgo life-sustaining measures (60). Other examples include proxy forms that do not accommodate the norms of group decision making and regulations on the use of cardiopulmonary resuscitation that specify a hierarchy of next-of-kin surrogates that is biased by our dominant culture and therefore poorly accommodates other cultures in which, for example, responsibility for health decisions is vested in daughters or the eldest son. Boilerplate living wills that require nothing more than a signature are so often misleading representations of patients' true preferences that elimination of their presumptively binding effect should be considered. Policy should not necessarily abandon advance directives, but should make them more useful and employ them in proper context.

### DECISION MAKING FOR PATIENTS WITH AND WITHOUT ADVANCE DIRECTIVES

Advance directives create as many challenges for surrogacy as they solve (43, 61). Living wills are particularly problematic because they have limited sensitivity in that they fail to capture important preferences and priorities of patients, and they have limited specificity in that the preferences contained may be inauthentic, either outright (for example, boilerplate documents) or because of the inability of directives to respond to the context of illness. Therefore, we recommend that physicians who assist patients in completing living wills should first objectively assess and communicate prognosis, then encourage patients to develop their broad goals of care and to describe the role they intend all or part of the directive to serve in decisions made by their surrogates: as binding, as weighty but not binding, or as merely informative. Clinicians should ask the following questions when previously executed living wills are being implemented: What burdens did the patient intend to avoid, and what benefits did the patient intend to secure? Who is best positioned to interpret the directive? Is the surrogate's decision, where it diverges from the directive, ethically supportable by patient-referenced considerations? Bioethics consultation may assist in this task.

Because the designation of a single proxy may reflect more the patient's compliance with the format of proxy documents than the intention to exclude intimates from decision making, physicians should inquire about the patient's past pattern of decision making and functioning within the family. Physicians who assist patients in completing proxy documents should clarify whether patients want their proxies to consult with other family members, and to specify whether they wish to exclude all or some other persons from participation in decision making. Physicians should use this opportunity to understand the pa-

tient's preferred mode of family involvement and decision making (Table).

Only a few patients complete advance directives, because of cultural, emotional, and other factors (45). For the persistent majority of patients without directives, physicians will have to work with families to construct a narrative of the patient that includes many of the considerations relevant for patients with directives, such as specific preferences and important medical and nonmedical values, including indications of the patient's preference for modes of surrogate decision making and the patient's concern for family welfare.

### CONCLUSION

A rigidly hierarchical view of surrogate decision making oversimplifies a process that is complex, dynamic, personal, and even idiosyncratic and tends to deemphasize other ethically valid considerations, including morally relevant emotions, and virtues, such as mutual responsibility. Although the normative standards offer a framework for decision making, clinicians should not consider them definitive and patients and families should not be limited by them. Norms for surrogacy should fully account for a robust range of patients' concerns and interests to improve the quality of surrogates' decision making, ensure that clinical decisions more fully respect the patient's own sense of genuine interests, and increase physicians' confidence in caring for incapacitated patients.

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### References

1. Beauchamp JF, Childress TL. Respect for Autonomy. *Principles of Biomedical Ethics*. 4th ed. New York: Oxford Univ Pr; 1994:120-88.
2. National Conference of Commissioners of Uniform State Laws. *Uniform Laws Annotated*. St. Paul, MN: West Publishing; 2005:93-111.
3. Snyder L, Leffler C. Ethics and Human Rights Committee, American College of Physicians. *Ethics manual: fifth edition*. *Ann Intern Med*. 2005;142:560-82. [PMID: 15809467]
4. American Medical Association. *Opinions on Social Policy Issues*. In: *Code of Medical Ethics: Current Opinions with Annotations*. 1996-1997 ed. Chicago: American Med Assoc; 1997:3-62.
5. American Geriatrics Society Ethics Committee. *Legal and Ethics Issues*. *Geriatric Review Syllabus: A Core Curriculum in Geriatric Medicine*. 5th ed. Malden, MA: Blackwell; 2002:19-27.
6. High DM. Why are elderly people not using advance directives? *J Aging Health*. 1993;5:497-515. [PMID: 10129468]
7. Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner M, Mendelssohn DC. Reconceptualizing advance care planning from the patient's perspective. *Arch*

- Intern Med. 1998;158:879-84. [PMID: 9570174]
8. **Winzelberg GS, Hanson LC, Tulskey JA.** Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. *J Am Geriatr Soc.* 2005;53:1046-50. [PMID: 15935032]
  9. **Berger JT.** Patients' interests in their family members' well-being: an overlooked, fundamental consideration within substituted judgments. *J Clin Ethics.* 2005;16:3-10. [PMID: 15915841]
  10. **Sulmasy DP, Hughes MT, Thompson RE, Astrow AB, Terry PB, Kub J, et al.** How would terminally ill patients have others make decisions for them in the event of decisional incapacity? A longitudinal study. *J Am Geriatr Soc.* 2007; 55:1981-8. [PMID: 18031490]
  11. **Hawkins NA, Ditto PH, Danks JH, Smucker WD.** Micromanaging death: process preferences, values, and goals in end-of-life medical decision making. *Gerontologist.* 2005;45:107-17. [PMID: 15695421]
  12. **Fins JJ, Maltby BS, Friedmann E, Greene MG, Norris K, Adelman R, et al.** Contracts, covenants and advance care planning: an empirical study of the moral obligations of patient and proxy. *J Pain Symptom Manage.* 2005;29:55-68. [PMID: 15652439]
  13. **Puchalski CM, Zhong Z, Jacobs MM, Fox E, Lynn J, Harrold J, et al.** Patients who want their family and physician to make resuscitation decisions for them: observations from SUPPORT and HELP. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Hospitalized Elderly Longitudinal Project. *J Am Geriatr Soc.* 2000;48:S84-90. [PMID: 10809461]
  14. **Sehgal A, Galbraith A, Chesney M, Schoenfeld P, Charles G, Lo B.** How strictly do dialysis patients want their advance directives followed? *JAMA.* 1992; 267:59-63. [PMID: 1489360]
  15. **Moore CD, Sparr J, Sherman S, Avery L.** Surrogate decision-making: judgment standard preferences of older adults. *Soc Work Health Care.* 2003;37:1-16. [PMID: 12959484]
  16. **Terry PB, Vettese M, Song J, Forman J, Haller KB, Miller DJ, et al.** End-of-life decision making: when patients and surrogates disagree. *J Clin Ethics.* 1999;10:286-93. [PMID: 10791278]
  17. **Berger JT, Brody G, Eisenstein L, Pollack S.** Do potential recipients of cardiopulmonary resuscitation want their family members to attend? A survey of public preferences. *J Clin Ethics.* 2004;15:237-42. [PMID: 15630866]
  18. **Shalowitz DI, Garrett-Mayer E, Wendler D.** The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med.* 2006;166:493-7. [PMID: 16534034]
  19. **Danis M, Southerland LI, Garrett JM, Smith JL, Hielema F, Pickard CG, et al.** A prospective study of advance directives for life-sustaining care. *N Engl J Med.* 1991;324:882-8. [PMID: 2000110]
  20. **Sonnenblick M, Friedlander Y, Steinberg A.** Dissociation between the wishes of terminally ill parents and decisions by their offspring. *J Am Geriatr Soc.* 1993;41:599-604. [PMID: 8505455]
  21. **Fried TR, Bradley EH, Towle VR.** Valuing the outcomes of treatment: do patients and their caregivers agree? *Arch Intern Med.* 2003;163:2073-8. [PMID: 14504121]
  22. **Fagerlin A, Ditto PH, Danks JH, Houts RM, Smucker WD.** Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychol.* 2001;20:166-75. [PMID: 11403214]
  23. **Sugarman J, Cain C, Wallace R, Welsh-Bohmer KA.** How proxies make decisions about research for patients with Alzheimer's disease. *J Am Geriatr Soc.* 2001;49:1110-9. [PMID: 11555076]
  24. **Chambers-Evans J, Carnevale FA.** Dawning of awareness: the experience of surrogate decision making at the end of life. *J Clin Ethics.* 2005;16:28-45. [PMID: 15915844]
  25. **Shalowitz DI, Garrett-Mayer E, Wendler D.** How should treatment decisions be made for incapacitated patients, and why? *PLoS Med.* 2007;4:e35. [PMID: 17388655]
  26. **Roberto KA.** Making critical health decisions for older adults: Consensus among family members. *Fam Relat.* 1999;48:167-75.
  27. **Sulmasy DP, Sood JR, Texiera K, McAuley RL, McGugins J, Ury WA.** A prospective trial of a new policy eliminating signed consent for do not resuscitate orders. *J Gen Intern Med.* 2006. [PMID: 16965559]
  28. **Tilden VP, Tolle SW, Nelson CA, Fields J.** Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nurs Res.* 2001; 50:105-15. [PMID: 11302290]
  29. **Anderson CJ.** The psychology of doing nothing: forms of decision avoidance result from reason and emotion. *Psychol Bull.* 2003;129:139-67. [PMID: 12555797]
  30. **Samuelson W, Zeckhauser R.** Status quo bias in decision making. *J Risk Uncertain.* 1988;1:7-59.
  31. **Loewenstein GF, Thompson L, Bazerman MH.** Social utility and decision making in interpersonal contexts. *J Pers Soc Psychol.* 1989;57:426-41.
  32. **Hollingshead A.** Information suppression and status persistence in group decision making: the effects of communication media. *Hum Commun Res.* 1996;23:193-219.
  33. **Danis M, Southerland LI, Garrett JM, Smith JL, Hielema F, Pickard CG, et al.** A prospective study of advance directives for life-sustaining care. *N Engl J Med.* 1991;324:882-8. [PMID: 2000110]
  34. **Alpert HR, Emanuel L.** Comparing utilization of life-sustaining treatments with patient and public preferences. *J Gen Intern Med.* 1998;13:175-81. [PMID: 9541374]
  35. **Hardin SB, Yusufaly YA.** Difficult end-of-life treatment decisions: do other factors trump advance directives? *Arch Intern Med.* 2004;164:1531-3. [PMID: 15277284]
  36. **Thompson T, Barbour R, Schwartz L.** Adherence to advance directives in critical care decision making: vignette study. *BMJ.* 2003;327:1011. [PMID: 14593032]
  37. **Teno JM, Licks S, Lynn J, Wenger N, Connors AF Jr, Phillips RS, et al.** Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc.* 1997;45:508-12. [PMID: 9100722]
  38. **Asch DA, Hansen-Flaschen J, Lanken PN.** Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: conflicts between physicians' practices and patients' wishes. *Am J Respir Crit Care Med.* 1995;151:288-92. [PMID: 7842181]
  39. **Farber NJ, Simpson P, Salam T, Collier VU, Weiner J, Boyer EG.** Physicians' decisions to withhold and withdraw life-sustaining treatment. *Arch Intern Med.* 2006;166:560-4. [PMID: 16534044]
  40. **Goodman MD, Tarnoff M, Slotman GJ.** Effect of advance directives on the management of elderly critically ill patients. *Crit Care Med.* 1998;26:701-4. [PMID: 9559607]
  41. **Helton MR, van der Steen JT, Daaleman TP, Gamble GR, Ribbe MW.** A cross-cultural study of physician treatment decisions for demented nursing home patients who develop pneumonia. *Ann Fam Med.* 2006;4:221-7. [PMID: 16735523]
  42. **Swanson JW, McCrary SV.** Medical futility decisions and physicians' legal defensiveness: the impact of anticipated conflict on thresholds for end-of-life treatment. *Soc Sci Med.* 1996;42:125-32. [PMID: 8745113]
  43. **Fagerlin A, Schneider CE.** Enough. The failure of the living will. *Hastings Cent Rep.* 2004;34:30-42. [PMID: 15156835]
  44. **New York State Bar Association.** New York Living Will. Internet. 2007. Accessed at [www.nysba.org/Content/NavigationMenu/PublicResources/LivingWillHealthCareProxyForms/LivingWillEnglish.pdf](http://www.nysba.org/Content/NavigationMenu/PublicResources/LivingWillHealthCareProxyForms/LivingWillEnglish.pdf) on 12 May 2008.
  45. **Berger JT.** Cultural discrimination in mechanisms for health decisions: a view from New York. *J Clin Ethics.* 1998;9:127-31. [PMID: 9750984]
  46. **Giger JN, Davidhizar RE, Fordham P.** Multi-cultural and multi-ethnic considerations and advanced directives: developing cultural competency. *J Cult Divers.* 2006;13:3-9. [PMID: 16696539]
  47. **Young AJ, Rodriguez KL.** The role of narrative in discussing end-of-life care: eliciting values and goals from text, context, and subtext. *Health Commun.* 2006; 19:49-59. [PMID: 16519592]
  48. **Shrank WH, Kutner JS, Richardson T, Mularski RA, Fischer S, Kagawa-Singer M.** Focus group findings about the influence of culture on communication preferences in end-of-life care. *J Gen Intern Med.* 2005;20:703-9. [PMID: 16050878]
  49. **Seymour J, Gott M, Bellamy G, Ahmedzai SH, Clark D.** Planning for the end of life: the views of older people about advance care statements. *Soc Sci Med.* 2004;59:57-68. [PMID: 15087143]
  50. **Laws of Maryland.** Chapter 522. Annapolis, MD: Department of Legislative Services; 2006: 2583-95. Md. Health-Gen. Code Ann. § 5-603 (2005, 2007 Supp.).
  51. **Chan HM.** Sharing death and dying: advance directives, autonomy and the family. *Bioethics.* 2004;18:87-103. [PMID: 15146852]
  52. **Matsumura S, Bito S, Liu H, Kahn K, Fukuhara S, Kagawa-Singer M, et al.** Acculturation of attitudes toward end-of-life care: a cross-cultural survey of Japanese Americans and Japanese. *J Gen Intern Med.* 2002;17:531-9. [PMID: 12133143]
  53. **Moazzam F.** Families, patients, and physicians in medical decisionmaking: a

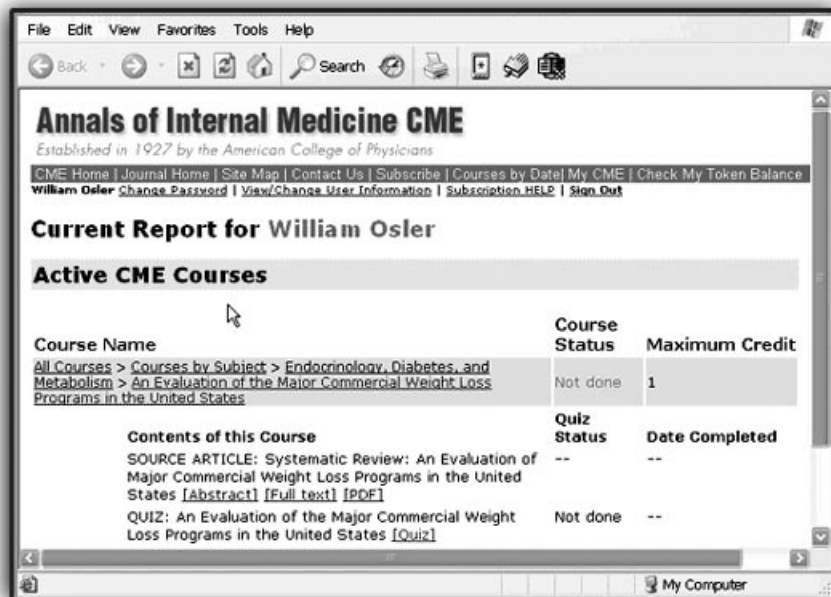
Pakistani perspective. *Hastings Cent Rep.* 2000;30:28-37. [PMID: 11475993]  
 54. **Lynn J.** Why I don't have a living will. *Law Med Health Care.* 1991;19:101-4. [PMID: 1895759]  
 55. **Mappes TA, Zembaty JS.** Patient choices, family interests, and physician obligations. *Kennedy Inst Ethics J.* 1994;4:27-46. [PMID: 11645254]  
 56. **Jecker NS.** Being a burden on others. *J Clin Ethics.* 1993;4:16-20. [PMID: 8490213]  
 57. **Nelson JL.** Taking families seriously. *Hastings Cent Rep.* 1992;22:6-12. [PMID: 1506187]

58. **Hyun I.** Conceptions of family-centered medical decision making and their difficulties. *Camb Q Healthc Ethics.* 2003;12:196-200. [PMID: 12764886]  
 59. **Ho A.** Relational autonomy or undue pressure? Family's role in medical decision-making. *Scand J Caring Sci.* 2008;22:128-35. [PMID: 18269432]  
 60. **Gasner MR.** Cruzan v Harmon, and In the Matter of O'Connor. Two anomalies. *J Am Geriatr Soc.* 1990;38:594-9. [PMID: 2332578]  
 61. **Perkins HS.** Controlling death: the false promise of advance directives. *Ann Intern Med.* 2007;147:51-7. [PMID: 17606961]

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