



Published in final edited form as:

Ann Intern Med. 2010 August 17; 153(4): 256–261. doi:10.1059/0003-4819-153-4-201008170-00008.

Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD¹ and Terri R. Fried, MD²

¹ Division of Geriatrics, San Francisco Veterans Affairs Medical Center, and University of California, San Francisco

² Clinical Epidemiology Research Center, Veterans Affairs Connecticut Healthcare System and Division of Geriatrics, Yale University School of Medicine

Abstract

The traditional objective of advance care planning has been to have patients make treatment decisions in advance in an attempt to provide care consistent with their goals. We argue that the objective for advance care planning ought to be the preparation of patients and surrogates to participate with clinicians in making the best possible in-the-moment medical decisions. We provide practical steps for clinicians to help patients and surrogate decision makers achieve this objective in the outpatient setting. Preparation for in-the-moment decision making shifts the focus from having patients make premature decisions based on incomplete information to preparing patients and their surrogates for the types of decisions and conflicts they may encounter when they do have to engage in in-the-moment decision making. This approach does not preclude the completion of advance directives, but acknowledges that they are but one piece of information to be used at the time of decision making.

Introduction

The traditional objective of advance care planning has been to have patients make treatment decisions in advance in an attempt to provide care consistent with their goals (1,2). Advance directives and the documentation of values (3-6), have been the method most often used to achieve this objective (2). Although advance directives have, in some cases, shown benefit (7-8), they frequently fail to affect the quality of care received at the end-of-life or improve clinicians' and surrogates' knowledge of patients' preferences (9-13). Substantial improvements have been made to advance directives and advance care planning (6,14-16). Nonetheless, many of these efforts continue to be aimed at, and/or judged to be successful by, obtaining the traditional objective of making advance decisions – an objective which is fundamentally flawed. Based on a synthesis of existing literature, the purpose of this paper is to describe the problems with the traditional objective of advance care planning; provide an alternative objective that focuses on preparing patients and surrogates to make the best possible in-the-moment medical decisions; and outline practical steps that clinicians can take to achieve this new objective in the outpatient setting.

Address correspondence and send reprint requests to: Rebecca Sudore, MD, University of California, San Francisco, VAMC, 4150 Clement Street, Box 181G, San Francisco, CA 94121 USA, Fax: 415-750-6641, Phone: 415-750-6625, rsucsf@yahoo.com.

Current Postal Addresses: Rebecca Sudore, MD, SFVAMC, Division of Geriatrics, 4150 Clement Street, #151R, San Francisco, CA 94121

Terri Fried, MD, Clinical Epidemiology Research Center, 151B, VA Connecticut Healthcare System, 950 Campbell Avenue, West Haven, CT 06516

Problems With the Traditional Objective of Advance Care Planning

Arguments against advance decision making are well documented and based on problems with prediction, adaptation, extrapolation, and on the nature of surrogate decision-making. Individuals have difficulty predicting what they would want in future circumstances because these predictions do not reflect one's current medical, emotional, or social context (17-22). In addition, patients' treatment preferences and values change with changes in health (19, 23-25), at the end-of-life (26-28), and even during periods of stable health (26). One major determinant of changing preferences is adaptability. Patients often cannot envision being able to cope with disability and often report the desire to forgo aggressive treatments in such states (17-18,29). However, once patients experience those health states, they are often more willing to accept even invasive treatments with limited benefits (27,30-33). Conversely, some patients may shift their goals from life-prolongation to comfort (34).

Pre-specifying treatment preferences or broad values statements may be appropriate for patients who can articulate consistent treatment preferences based on long-held beliefs. However, broad values statements, such as wanting to maintain dignity or be free from pain, have been found to be too general to inform individual treatment decisions (2,35-37). Even specific treatment preferences may be difficult to extrapolate to specific clinical situations (2,38-39). For example, advance directives often refer to forgoing an intervention when the patient's condition is "irreversible" or "terminal" (11). However, physicians and surrogates frequently have difficulty determining when patients are in these states (40). Moreover, whereas advance directives may only consider the use of technologically intensive therapies, surrogates often face burdensome decisions about less aggressive therapies (2,38,41-42), such as whether to pursue frequent hospitalizations and repeated intravenous antibiotics for aspiration pneumonia in a patient with dementia. Patients and surrogates may also need to re-evaluate pre-specified wishes in the light of unforeseen clinical contexts (2,13). For example, a patient's decision to forgo mechanical ventilation in the setting of lung cancer may need to be re-evaluated during an acute heart failure episode that could be successfully treated with transient ventilatory support.

In addition to the clinical context, surrogates may also use their own hopes, desires and needs to inform their decisions (13,39,43-45). Therefore, surrogates decisions may contradict patients' pre-specified wishes. Surrogates' consideration of factors in addition to patients' advance treatment preferences may lead to better decisions and improved patient care (46). Perhaps because of an inherent understanding of the need for surrogates to base their decisions on multiple considerations, the majority of patients want their loved ones to have the leeway in decision making (4,47-49).

A New Objective of Advance Care Planning Focused on Preparation for in-the-Moment Decision-Making

Given the problems with the pre-specification of treatment preferences, we propose that the main objective of advance care planning be to prepare patients and surrogates to participate with clinicians in making the best possible in-the-moment decisions. A preparation for in-the-moment decision-making approach shifts the focus away from asking patients to make what are often premature treatment decisions based on incomplete or hypothetical information. Rather, this approach seeks to ensure that complex healthcare decisions are based on a more comprehensive set of considerations including the current clinical context, shifting and evolving goals, and patients' and surrogates' needs. These factors must be synthesized by clinicians who, depending upon the patient and surrogates' desire to be involved in decision making, can provide specific recommendations and/or help patients and surrogates decide among available alternatives (13-14,39,50). This approach does not preclude the completion

of an advance directive, but recognizes that it is but one piece of information to be used during in-the-moment decision making (51-52).

The complexities of in-the-moment decision making for patients with advanced illness have been well recognized and have led to efforts focused on preparing clinicians to help patients and surrogates navigate in-the-moment decisions (14-16,53-54). Furthermore, system-level constraints on the care received at the end-of-life, including bed availability and access to palliative care trained clinicians (55-56), have led to efforts focused on increasing the palliative care workforce and providing care options better suited to patients' needs (57-59). Both clinician- and system-level changes are necessary to improve care for patients with advanced illness. What remains less clear, however, is whether, in addition to these efforts, patients and surrogates can and/or should receive preparation for in-the-moment decision-making. There are a number of substantial barriers to patients' and surrogates' meaningful participation in preparation for in-the-moment decision making. First, it can be difficult, if not impossible, for patients and surrogates to consider all of the implications that in-the-moment treatment decisions entail, including the substantial logistic, financial, and caregiver burdens that may arise (56). Second, many patients and surrogates do not want to think about issues related to illness, death, and dying, and they may not want to participate in decision making (47,60-62). Finally, clinicians do not have time to have lengthy advance care planning discussions.

Why then, with all of these barriers, should efforts aimed at preparation for in-the-moment decision making include patients and surrogates? The inclusion of patients and surrogates is not meant to shift the burdens and complexities of medical decision making to them. Rather, clinicians cannot make high-quality in-the-moment treatment recommendations or guide patients and surrogates through the decision-making process without incorporating patients' and surrogates' values and needs. Because these perspectives are highly individual, they can only be provided by the patient and/or surrogate. Given the extreme stress experienced by patients and/or surrogates (13) and the frequent absence of a prior relationship with the clinician at the time a decision must be made (63), it is unlikely that patients and surrogates will be able to communicate effectively without some form of preparation (2,13).

A consideration of the specific challenges of in-the-moment decision making and how these challenges contribute to stress, conflict, and decision-making burden for patients and surrogates can help to identify essential preparatory steps. Up to 76% of patients will be unable to participate in some or all of their own decisions at the end-of-life (8,63-65). Surrogates who have made medical decisions for others report being unprepared (34), and describe the process as highly stressful (42,66-68). Despite the limitations of advance statements of preference, surrogates find decision making more difficult if they do not have any sense of what the patient may have wanted and, in fact, frequently lack this sense (34,37,68).

A major challenge is to help patients identify and articulate their values in a way that can guide decisions. Although it is impossible to know with certainty what a patient would have wanted, and although advance statements of preference should not be the sole consideration on which in-the-moment decisions are based, it is nonetheless possible for surrogates to have a fundamental understanding of the patient's values as one of the multiple considerations informing in-the-moment decisions (2,13,50). In contrast to eliciting preferences for specific interventions, what matters most to patients when thinking about healthcare decisions is the potential outcomes of treatment (33,69-72). Therefore, asking patients to consider what outcomes they most hope for or fear can be an effective means of identifying their values in a way that can inform decision making (72-75). Asking patients to do this over time can help patients, surrogates, and clinicians recognize whether and how patients are adapting to their illness or reaching a point when the burdens involved in fighting their illness become too great.

However, understanding patients' preferences is not sufficient. Surrogates may still need to make decisions that conflict with this understanding. This conflict greatly contributes to surrogate stress, especially if surrogates were not given leeway in decision-making (34,68). For example, surrogates report guilt when they are unable to honor a patient's wish to die at home, generally because they cannot provide the care necessary to ensure sufficient palliation (34,68). These experiences suggest that surrogate burden may be eased by establishing leeway in decision making prior to a medical crisis in order to address potential conflicts between patients' desires and other factors relevant during in-the-moment decision making (14,34,37, 68,76).

Steps to Prepare Patients and Surrogates for in-the-Moment Decision Making

Three key steps address patients' and surrogates' needs for preparation for in-the-moment decision making: 1) choosing an appropriate surrogate decision maker; 2) clarifying and articulating patients' values over time; and 3) establishing leeway in surrogate decision making. These steps are included in other, more comprehensive and successful advance care planning programs (6,77-78). However, these programs require the efforts of either a specially trained facilitator or highly motivated patients and surrogates who can engage in advance care planning on their own. Because the majority of primary-care patients want their clinicians to initiate these discussions (79-80), for preparation to have a broad reach, clinicians will need to engage their patients. To be feasible, these interactions must be brief. The efficiency of these interactions can be enhanced by assessing patients' readiness for engagement followed by a tailored response (62). For patients who are not ready to engage in preparation, the most efficient use of the clinician's time is to educate, motivate, and address barriers to participation (81). For patients who are ready and unlikely to engage in preparation outside the clinicians' office, clinicians can guide them through the preparatory steps over one or more visits. The steps also provide highly motivated patients and surrogates to continue preparation on their own.

Assessing and Addressing Patients' Lack of Readiness to Engage in Preparation

Readiness can be assessed by asking: "If you were to get very sick, is there anyone you trust to make medical decisions for you and have you talked with this person about what is important to you? Can we talk about this today?" Patients may respond in a number of ways indicating they are not ready to engage in preparation; e.g., "I do not plan to get sick" or "I don't want to burden my family" (60,62,82-83). Patients can be motivated to engage in preparation by appealing to the benefits of the process including reducing surrogate burden, maintaining control, and achieving peace of mind (82-86). Clinicians can also address barriers to participation as an additional means of promoting readiness (60,62,81). (Table 1)

Step1: Choosing an Appropriate Surrogate Decision Maker

In this step, clinicians ask patients to identify an appropriate surrogate and also ensure that the surrogate has been asked to play this role. (Table 2) Ideally a surrogate should accompany the patient to an appointment so that clinicians can assess their understanding and acceptance of the surrogate role: "If your loved one were to become really sick, are you willing to make medical decisions for him/her?"

Step 2: Clarifying and Articulating Patients' Values Over Time

A useful technique to help patients articulate their values is to have them discuss how they feel about the health states they have either personally experienced or seen others experience (73). Patients who do not have personal experiences with illness can reflect on stories presented in the media or on healthcare experiences of family or friends (73,87). (Table 2) Clinicians can ask, "If you were in this situation, what you would you hope for?" or "What would you be

most worried about (73,88)?” Clinicians can also ask patients to reflect on whether they consider any of these health states worse than death (72,74-75) or whether, in such a state, they would prefer treatment to focus on comfort rather than life extension. As patients progress along their disease trajectory, these discussions can move from general considerations to specific personal experiences e.g., “When you were in the hospital with heart failure... (82)” (Table 2) Clinicians can also help patients reflect on whether they are changing or adapting to serious illness – a technique shown to help patients better predict their preferences (90). “You told me in the past that (e.g., not being able to leave the house independently) would not be acceptable to you. Now that this has happened to you, have you changed your opinion about the ways of being that would be unacceptable?” (Table 2)

Step 3: Establishing Leeway in Surrogate Decision making

In this step, patients and surrogates think about factors, other than patients' preferences, that may be relevant to in-the-moment decisions and patients consider providing surrogates leeway in decision making (13,39,50). Studies of surrogate decision-making suggest there are two common scenarios that should be addressed. For patients who value life extension and express a desire to undergo treatment regardless of its outcomes, clinicians can ask: “What if your health changes and your doctors recommend against further treatment?” For patients who express a desire to be cared for at home, clinicians can ask: “What if it is too hard for loved ones to provide care for you/help you die at home?” It is important to include surrogates in these discussions to improve patient-surrogate understanding, help surrogates realize whether they have permission to make decisions based on considerations other than the patient's stated preferences, and to identify irreconcilable differences necessitating the need to appoint a different surrogate (45).

Patients who complete the preparatory steps can be encouraged to complete a durable power of attorney form and prepare family/friends, e.g., “To avoid conflict, it is important to tell your other family and friends that you chose your loved one to make medical decisions for you/ have given them flexibility in decision making (13,91).” For patients who have severe illness, stable preferences, and the desire, documenting their wishes may then be appropriate (92).

Conclusion

The main objective of advance care planning, rather than advance treatment decisions, should be to prepare patients and surrogates to work with their clinicians to make the best possible in-the-moment medical decisions. Clinicians can help to prepare patients and surrogates in the outpatient setting to communicate their values and needs at the time a decision must be made and to establish leeway in surrogate decision making. Future efforts will need to determine whether the preparatory steps result in increased engagement in and quality of medical decision making and whether medical treatments obtained are the result of informed choices that take into consideration the patients' goals, patients' and surrogates' needs, and the specific clinical circumstances.

Acknowledgments

Financial support: Dr. Sudore was supported by a Veterans Affairs Career Development Award and a Pfizer Fellowship in Clear Health Communication. This manuscript was written in the course of employment by the United States Government and it is not subject to copyright in the United States. Dr. Fried is supported by K24 AG028443.

References

1. Emanuel LL, von Gunten CF, Ferris FD. Advance care planning. *Arch Fam Med* Nov-Dec;2000 9(10): 1181–1187. [PubMed: 11115227]

2. Gillick MR. Advance care planning. *N Engl J Med* Jan 1;2004 350(1):7–8. [PubMed: 14702421]
3. Doukas DJ, McCullough LB. The values history. The evaluation of the patient's values and advance directives. *J Fam Pract* Feb;1991 32(2):145–153. [PubMed: 1990042]
4. Hawkins NA, Ditto PH, Danks JH, Smucker WD. Micromanaging death: process preferences, values, and goals in end-of-life medical decision making. *Gerontologist* Feb;2005 45(1):107–117. [PubMed: 15695421]
5. Schonwetter RS, Walker RM, Solomon M, Indurkha A, Robinson BE. Life values, resuscitation preferences, and the applicability of living wills in an older population. *J Am Geriatr Soc* Aug;1996 44(8):954–958. [PubMed: 8708307]
6. Pearlman RA, Starks H, Cain KC, Cole WG. Improvements in advance care planning in the Veterans Affairs System: results of a multifaceted intervention. *Arch Intern Med* Mar 28;2005 165(6):667–674. [PubMed: 15795344]
7. Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T. Association between advance directives and quality of end-of-life care: a national study. *J Am Geriatr Soc* Feb;2007 55(2):189–194. [PubMed: 17302654]
8. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* Apr 1;2010 362(13):1211–1218. [PubMed: 20357283]
9. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA* Nov 22–29;1995 274(20):1591–1598. [PubMed: 7474243]
10. Danis M, Mutran E, Garrett JM, et al. A prospective study of the impact of patient preferences on life-sustaining treatment and hospital cost. *Crit Care Med* Nov;1996 24(11):1811–1817. [PubMed: 8917030]
11. Teno JM, Licks S, Lynn J, 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* Apr;1997 45(4):508–512. [PubMed: 9100722]
12. Fagerlin A, Schneider CE. Enough. The failure of the living will. *Hastings Cent Rep* Mar-Apr;2004 34(2):30–42. [PubMed: 15156835]
13. Perkins HS. Controlling death: the false promise of advance directives. *Ann Intern Med* Jul 3;2007 147(1):51–57. [PubMed: 17606961]
14. Back AL, Arnold RM, Baile WF, et al. Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Arch Intern Med* Mar 12;2007 167(5):453–460. [PubMed: 17353492]
15. Tulsky JA. Interventions to enhance communication among patients, providers, and families. *J Palliat Med* 2005;8 1:S95–102. [PubMed: 16499474]
16. Briggs L. Shifting the focus of advance care planning: using an in-depth interview to build and strengthen relationships. *J Palliat Med* Apr;2004 7(2):341–349. [PubMed: 15130215]
17. Halpern J, Arnold RM. Affective forecasting: an unrecognized challenge in making serious health decisions. *J Gen Intern Med* Oct;2008 23(10):1708–1712. [PubMed: 18665428]
18. Loewenstein G. Projection bias in medical decision making. *Med Decis Making* Jan-Feb;2005 25(1):96–105. [PubMed: 15673587]
19. Ditto PH, Jacobson JA, Smucker WD, Danks JH, Fagerlin A. Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Med Decis Making* Jul-Aug;2006 26(4):313–322. [PubMed: 16855121]
20. Ubel PA. Emotions, decisions, and the limits of rationality: symposium introduction. *Med Decis Making* Jan-Feb;2005 25(1):95–96. [PubMed: 15673586]
21. Forrow L. The green eggs and ham phenomena. *Hastings Cent Rep* Nov-Dec;1994 24(6):S29–32. [PubMed: 7860277]
22. Koch T. Future states: the axioms underlying prospective, future-oriented, health planning instruments. *Soc Sci Med* Feb;2001 52(3):453–465. [PubMed: 11330779]
23. Danis M, Garrett J, Harris R, Patrick DL. Stability of choices about life-sustaining treatments. *Ann Intern Med* Apr 1;1994 120(7):567–573. [PubMed: 8116994]

24. Rosenfeld KE, Wenger NS, Phillips RS, et al. Factors associated with change in resuscitation preference of seriously ill patients. The SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Arch Intern Med* Jul 22;1996 156(14):1558–1564. [PubMed: 8687264]
25. Lockhart LK, Ditto PH, Danks JH, Coppola KM, Smucker WD. The stability of older adults' judgments of fates better and worse than death. *Death Stud* Jun;2001 25(4):299–317. [PubMed: 11803982]
26. Fried TR, O'Leary J, Van Ness P, Fraenkel L. Inconsistency over time in the preferences of older persons with advanced illness for life-sustaining treatment. *J Am Geriatr Soc* Jul;2007 55(7):1007–1014. [PubMed: 17608872]
27. Fried TR, Byers AL, Gallo WT, et al. Prospective study of health status preferences and changes in preferences over time in older adults. *Arch Intern Med* Apr 24;2006 166(8):890–895. [PubMed: 16636215]
28. Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. *Lancet* Sep 4;1999 354(9181):816–819. [PubMed: 10485723]
29. Ubel PA, Loewenstein G, Schwarz N, Smith D. Misimagining the unimaginable: the disability paradox and health care decision making. *Health Psychol* Jul;2005 24(4 Suppl):S57–62. [PubMed: 16045420]
30. Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Soc Sci Med* Jun;1999 48(11):1507–1515. [PubMed: 10400253]
31. Winter L, Lawton MP, Ruckdeschel K. Preferences for prolonging life: a prospect theory approach. *Int J Aging Hum Dev* 2003;56(2):155–170. [PubMed: 14533855]
32. Straton JB, Wang NY, Meoni LA, et al. Physical functioning, depression, and preferences for treatment at the end of life: the Johns Hopkins Precursors Study. *J Am Geriatr Soc* Apr;2004 52(4):577–582. [PubMed: 15066074]
33. Fried TR, Bradley EH. What matters to seriously ill older persons making end-of-life treatment decisions?: A qualitative study. *J Palliat Med* Apr;2003 6(2):237–244. [PubMed: 12854940]
34. Fried TR, O'Leary JR. Using the experiences of bereaved caregivers to inform patient- and caregiver-centered advance care planning. *J Gen Intern Med* Oct;2008 23(10):1602–1607. [PubMed: 18665427]
35. Coppola KM, Ditto PH, Danks JH, Smucker WD. Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with and without advance directives. *Arch Intern Med* Feb 12;2001 161(3):431–440. [PubMed: 11176769]
36. Ditto PH, Danks JH, Smucker WD, et al. Advance directives as acts of communication: a randomized controlled trial. *Arch Intern Med* Feb 12;2001 161(3):421–430. [PubMed: 11176768]
37. Lo B, Steinbrook R. Resuscitating advance directives. *Arch Intern Med* Jul 26;2004 164(14):1501–1506. [PubMed: 15277279]
38. Brett AS. Limitations of listing specific medical interventions in advance directives. *Jama* Aug 14;1991 266(6):825–828. [PubMed: 1865521]
39. Vig EK, Taylor JS, Starks H, Hopley EK, Fryer-Edwards K. Beyond substituted judgment: How surrogates navigate end-of-life decision-making. *J Am Geriatr Soc* Nov;2006 54(11):1688–1693. [PubMed: 17087695]
40. Teno JM, Stevens M, Spornak S, Lynn J. Role of written advance directives in decision making: insights from qualitative and quantitative data. *J Gen Intern Med* Jul;1998 13(7):439–446. [PubMed: 9686709]
41. Ditto PH, Hawkins NA. Advance directives and cancer decision making near the end of life. *Health Psychol* Jul;2005 24(4 Suppl):S63–70. [PubMed: 16045421]
42. Tilden VP, Tolle SW, Nelson CA, Fields J. Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nurs Res* Mar-Apr;2001 50(2):105–115. [PubMed: 11302290]
43. Berger JT, DeRenzo EG, Schwartz J. Surrogate decision making: reconciling ethical theory and clinical practice. *Ann Intern Med* Jul 1;2008 149(1):48–53. [PubMed: 18591637]
44. Fagerlin A, Ditto PH, Danks JH, Houts RM, Smucker WD. Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychol* May;2001 20(3):166–175. [PubMed: 11403214]

45. Sudore RL. A piece of my mind. Can we agree to disagree? *JAMA* Oct 21;2009 302(15):1629–1630. [PubMed: 19843890]
46. High DM. Families' roles in advance directives. *Hastings Cent Rep* Nov-Dec;1994 24(6):S16–18. [PubMed: 7860271]
47. Winzelberg GS, Hanson LC, Tulsy JA. Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. *J Am Geriatr Soc* Jun;2005 53(6):1046–1050. [PubMed: 15935032]
48. Sehgal A, Galbraith A, Chesney M, Schoenfeld P, Charles G, Lo B. How strictly do dialysis patients want their advance directives followed? *Jama* Jan 1;1992 267(1):59–63. [PubMed: 1489360]
49. Prendergast TJ. Advance care planning: pitfalls, progress, promise. *Crit Care Med* Feb;2001 29(2 Suppl):N34–39. [PubMed: 11228571]
50. Gillick MR. A broader role for advance medical planning. *Ann Intern Med* Oct 15;1995 123(8):621–624. [PubMed: 7677304]
51. Tulsy JA. Beyond advance directives: importance of communication skills at the end of life. *Jama* Jul 20;2005 294(3):359–365. [PubMed: 16030281]
52. Torke AM, Moloney R, Siegler M, Abalos A, Alexander GC. Physicians' Views on the Importance of Patient Preferences in Surrogate Decision-Making. *J Am Geriatr Soc*. Feb 11;2010
53. Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *Lancet* Feb 23;2002 359(9307):650–656. [PubMed: 11879860]
54. Skinner CS, Pollak KI, Farrell D, Olsen MK, Jeffreys AS, Tulsy JA. Use of and reactions to a tailored CD-ROM designed to enhance oncologist-patient communication: the SCOPE trial intervention. *Patient Educ Couns* Oct;2009 77(1):90–96. [PubMed: 19321287]
55. Pritchard RS, Fisher ES, Teno JM, et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. *J Am Geriatr Soc* Oct;1998 46(10):1242–1250. [PubMed: 9777906]
56. Meier DE, Morrison RS. Autonomy reconsidered. *N Engl J Med* Apr 4;2002 346(14):1087–1089. [PubMed: 11932479]
57. Lynn, J. *Sick to death and not going to take it anymore! Reforming health care for the last years of life*. Berkeley, California: University of California Press; 2004.
58. Gillick MR. Choosing appropriate medical care for the elderly. *J Am Med Dir Assoc* Nov-Dec;2001 2(6):305–309. [PubMed: 12812536]
59. Meier DE, Beresford L. Palliative care seeks its home in national health care reform. *J Palliat Med* Jul;2009 12(7):593–597. [PubMed: 19594342]
60. Schickedanz AD, Schillinger D, Landefeld CS, Knight SJ, Williams BA, Sudore RL. A clinical framework for improving the advance care planning process: start with patients' self-identified barriers. *J Am Geriatr Soc* Jan;2009 57(1):31–39. [PubMed: 19170789]
61. Knight SJ, Emanuel L. Processes of adjustment to end-of-life losses: a reintegration model. *J Palliat Med* Oct;2007 10(5):1190–1198. [PubMed: 17985975]
62. Fried TR, Bullock K, Iannone L, O'Leary JR. Understanding Advance Care Planning as a Process of Health Behavior Change. *J Am Geriatr Soc*. Aug 4;2009
63. Torke AM, Siegler M, Abalos A, Moloney RM, Alexander GC. Physicians' experience with surrogate decision making for hospitalized adults. *J Gen Intern Med* Sep;2009 24(9):1023–1028. [PubMed: 19633896]
64. Guidelines for the appropriate use of do-not-resuscitate orders. Council on Ethical and Judicial Affairs, American Medical Association. *JAMA* Apr 10;1991 265(14):1868–1871. [PubMed: 2005737]
65. Kim SY, Karlawish JH, Caine ED. Current state of research on decision-making competence of cognitively impaired elderly persons. *Am J Geriatr Psychiatry* Mar-Apr;2002 10(2):151–165. [PubMed: 11925276]
66. Anderson WG, Arnold RM, Angus DC, Bryce CL. Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. *J Gen Intern Med* Nov;2008 23(11):1871–1876. [PubMed: 18780129]

67. Azoulay E, Pochard F, Kentish-Barnes N, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med* May 1;2005 171(9):987–994. [PubMed: 15665319]
68. Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K. Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J Gen Intern Med* Sep;2007 22(9):1274–1279. [PubMed: 17619223]
69. Rosenfeld KE, Wenger NS, Kagawa-Singer M. End-of-life decision making: a qualitative study of elderly individuals. *J Gen Intern Med* Sep;2000 15(9):620–625. [PubMed: 11029675]
70. Fried TR, Bradley EH, Towle VR, Allore H. Understanding the treatment preferences of seriously ill patients. *N Engl J Med* Apr 4;2002 346(14):1061–1066. [PubMed: 11932474]
71. Coppola KM, Bookwala J, Ditto PH, Lockhart LK, Danks JH, Smucker WD. Elderly adults' preferences for life-sustaining treatments: the role of impairment, prognosis, and pain. *Death Stud* Oct-Nov;1999 23(7):617–634. [PubMed: 10915454]
72. Ditto PH, Druley JA, Moore KA, Danks JH, Smucker WD. Fates worse than death: the role of valued life activities in health-state evaluations. *Health Psychol* Sep;1996 15(5):332–343. [PubMed: 8891712]
73. Quill TE. Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: addressing the “elephant in the room”. *JAMA* Nov 15;2000 284(19):2502–2507. [PubMed: 11074781]
74. Pearlman RA, Cain KC, Patrick DL, et al. Insights pertaining to patient assessments of states worse than death. *J Clin Ethics* Spring;1993 4(1):33–41. [PubMed: 8490217]
75. Patrick DL, Pearlman RA, Starks HE, Cain KC, Cole WG, Uhlmann RF. Validation of preferences for life-sustaining treatment: implications for advance care planning. *Ann Intern Med* Oct 1;1997 127(7):509–517. [PubMed: 9313018]
76. Torke AM, Alexander GC, Lantos J, Siegler M. The physician-surrogate relationship. *Arch Intern Med* Jun 11;2007 167(11):1117–1121. [PubMed: 17563018]
77. Hammes BJ, Rooney BL. Death and end-of-life planning in one midwestern community. *Arch Intern Med* Feb 23;1998 158(4):383–390. [PubMed: 9487236]
78. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010;340:c1345. [PubMed: 20332506]
79. Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care--a case for greater use. *N Engl J Med* Mar 28;1991 324(13):889–895. [PubMed: 2000111]
80. Johnston SC, Pfeifer MP, McNutt R. The discussion about advance directives. Patient and physician opinions regarding when and how it should be conducted. End of Life Study Group. *Arch Intern Med* May 22;1995 155(10):1025–1030. [PubMed: 7748044]
81. Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. *Am J Health Promot* Sep-Oct;1997 12(1):38–48. [PubMed: 10170434]
82. Jezewski MA, Finnell DS, Wu YW, Meeker MA, Sessanna L, Lee J. Psychometric testing of four transtheoretical model questionnaires for the behavior, completing health care proxies. *Res Nurs Health* Dec;2009 32(6):606–620. [PubMed: 19777500]
83. Medvene LJ, Base M, Patrick R, Wescott JV. Advance Directives: Assessing Stage of Change and Decisional Balance in a Community-Based Educational Program. *Journal of Applied Social Psychology* 2007;37(10):2298–2318.
84. Steinhauser KE, Christakis NA, Clipp EC, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage* Sep;2001 22(3):727–737. [PubMed: 11532586]
85. Hauser JM, Chang CH, Alpert H, Baldwin D, Emanuel EJ, Emanuel L. Who's caring for whom? Differing perspectives between seriously ill patients and their family caregivers. *Am J Hosp Palliat Care* Mar-Apr;2006 23(2):105–112. [PubMed: 16572748]
86. Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner M, Mendelssohn DC. Reconceptualizing advance care planning from the patient's perspective. *Arch Intern Med* Apr 27;1998 158(8):879–884. [PubMed: 9570174]

87. Sudore RL, Landefeld CS, Pantilat SZ, Noyes KM, Schillinger D. Reach and impact of a mass media event among vulnerable patients: the Terri Schiavo story. *J Gen Intern Med* Nov;2008 23(11):1854–1857. [PubMed: 18716849]
88. Pantilat SZ, Steimle AE. Palliative care for patients with heart failure. *JAMA* May 26;2004 291(20):2476–2482. [PubMed: 15161899]
89. Goldstein NE, Back AL, Morrison RS. Titrating guidance: a model to guide physicians in assisting patients and family members who are facing complex decisions. *Arch Intern Med* Sep 8;2008 168(16):1733–1739. [PubMed: 18779459]
90. Ubel PA, Loewenstein G, Jepson C. Disability and sunshine: can hedonic predictions be improved by drawing attention to focusing illusions or emotional adaptation? *J Exp Psychol Appl* Jun;2005 11(2):111–123. [PubMed: 15998183]
91. Drazen JM, Desai NR, Green P. Fighting on. *N Engl J Med* Jan 29;2009 360(5):444–445. [PubMed: 19179313]
92. Meier DE, Beresford L. POLST offers next stage in honoring patient preferences. *J Palliat Med* Apr; 2009 12(4):291–295. [PubMed: 19327064]

Table 1
Assessing and Addressing Lack of Readiness to Engage in Preparation for in-the-Moment Decision Making

Assessing Readiness:

“If you were to get very sick, is there anyone you trust to make medical decisions for you, and have you talked with this person about what is important to you? Can we talk about this today?”

Educating and Motivating:

“Because of illness or an accident, most patients will be unable to make their own decisions at some time in their life.”

“Because making decisions for someone is very stressful, you could help to take the burden off of your family/friends by starting to think about what would be important to you if you were to become very sick.”

“When patients talk with me and their loved ones about what would be important to them if they were to become very sick it helps them to keep a sense of control about their medical care and to have peace of mind.”

Addressing Barriers:

“Are there things that you worry about when you think about your loved one making decisions for you?”

“Are there reasons it is difficult to talk about such things with me or your loved ones?”

Table 2

Steps to Prepare Patients for in-the-Moment Decision Making***Step 1: Choosing an Appropriate Surrogate Decision Maker**

Opening: As your clinician, it would be helpful to know who to contact if you were to become really sick.

Choosing a Surrogate

If you were to become really sick, is there anyone that you trust to make medical decisions for you?

Does this person know that you have chosen them for this role? It is important to ask them if they are willing to do it.

Step 2: Clarifying and Articulating Patients' Values Over Time

Opening: Patients are often deeply affected by their past medical experiences.

Clarifying Patients' Values:

Have you seen someone on television/had someone close to you/had your own experience with serious illness or death?(73)

If you were in this situation (again), what you would you hope for? What would you be most worried about?(73,88)

Did this situation make you think of ways of being that would be so unacceptable that you would consider it worse than death?(72-73)

Some patients say that if they became so sick that they could not recognize or talk to their loved ones, for example if they had dementia or were in a coma, they would want all possible treatments to prolong their life. Other patients say they would rather have care focused on comfort. Which kind of person are you?

Exploring Changes:

Your health has/will change over time. Sometimes patients can get used to these changes and sometimes they cannot. In the past you told me that (e.g., staying out of the hospital) was important to you.

When you were (e.g., in the hospital with your heart failure...when your brother died), did this situation change your opinion about the ways of being that would be unacceptable or a state worse than death?

If you went through this situation again, would it be worth it to you?

Step 3: Establishing Leeway in Surrogate Decision Making

Opening: If your loved ones have to make medical decisions for you, they have to think about what you said in the past, but also about what the doctors are telling them about your medical condition and what they are able to do for you. If these differ from one another, this can be very stressful for your loved one.

Establishing Leeway:

Having told me what is important to you, what if your surrogate finds it difficult to provide this for you? What if it is too hard for loved ones to provide care for you/help you die at home?

What if, based on changes in your health, the doctors recommend something different from what you have told your loved one?

Will you give your loved one/s permission to work with your doctors to make the best decision they can for you even if it may differ from what you said you wanted in the past?

Are there certain decisions about your health that you would never want your loved one to change under any circumstances?

* This table includes a broad range of example statements/questions that clinicians can use in order to meet the individual preferences of the clinician and the individual needs of patients and surrogates. These statements/questions can and should be modified as needed.