

Advance Care Planning
Selected Abstracts 8/20/05
Sorted by Journal

1. Lahn, M.; Friedman, B.; Bijur, P.; Haughey, M., and Gallagher, E. J. Advance directives in skilled nursing facility residents transferred to emergency departments. *Acad Emerg Med.* 2001 Dec; 8(12):1158-62.

Abstract: OBJECTIVE: Ten years have passed since Congress enacted the Patient Self-Determination Act to promote the use of advance directives (ADs). This study was performed to determine the frequency, type, demographic distribution, and utility of ADs that accompany residents of skilled nursing facilities (SNFs) transferred to emergency departments (EDs). METHODS: This was an observational, cross-sectional cohort of SNF residents, transferred to two urban, academic EDs. Chart review and physician interviews were conducted on consecutive patients arriving during 12-hour data collection shifts. RESULTS: Among 715 patients entered, 315 [44%, 95% confidence interval (95% CI) = 40% to 48%] had an AD. Advance directives were significantly more prevalent among white (50%) than African American (34%) or Hispanic (39%) patients ($p < 0.001$), and varied from 0% to 94% among SNFs. Of the 315 patients with ADs, do-not-resuscitate (DNR) orders were the most prevalent (65%, 95% CI = 58% to 69%). Although 75% (95% CI = 69% to 81%) of the DNR orders addressed cardiopulmonary resuscitation (CPR), only 12% (95% CI = 8% to 16%) addressed intubation. Among 39 patients who required intubation or CPR, 44% had ADs, 82% (95% CI = 57% to 96%) of which were deemed useful. CONCLUSIONS: Despite a decade of legislation promoting their use, ADs are lacking in most SNF residents transferred to EDs for evaluation and in most settings in which a clinical indication exists for intubation or CPR. Variation in their prevalence appears to be associated with both ethnicity and SNF origin. Although about three-fourths of DNR ADs addressed CPR, only about one in ten offered guidance regarding intubation. When available, ADs are used in most instances to guide emergency care.
2. Searight, H. R. and Gafford, J. Cultural diversity at the end of life: issues and guidelines for family physicians. *Am Fam Physician.* 2005 Feb 1; 71(3):515-22.

Abstract: Ethnic minorities currently compose approximately one third of the population of the United States. The U.S. model of health care, which values autonomy in medical decision making, is not easily applied to members of some racial or ethnic groups. Cultural factors strongly influence patients' reactions to serious illness and decisions about end-of-life care. Research has identified three basic dimensions in end-of-life treatment that vary culturally: communication of "bad news"; locus of decision making; and attitudes toward advance directives and end-of-life care. In contrast to the emphasis on "truth telling" in the United States, it is not uncommon for health care professionals outside the United States to conceal serious diagnoses from patients, because disclosure of serious illness may be viewed as disrespectful, impolite, or even harmful to the patient. Similarly, with regard to decision making, the U.S. emphasis on patient autonomy may contrast with preferences for more family-based, physician-based, or shared physician- and family-based decision making among some cultures. Finally, survey data suggest lower rates of advance directive completion among patients of specific ethnic backgrounds, which may reflect distrust of the U.S. health care system, current health care disparities, cultural perspectives on death and suffering, and family dynamics. By paying attention to the patient's values, spirituality, and relationship dynamics, the family physician can elicit and follow cultural preferences.
3. Eiser, A. R. and Weiss, M. D. The underachieving advance directive: recommendations for increasing advance directive completion. *Am J Bioeth.* 2001 Fall; 1(4):W10.

Abstract: Advance directives have failed to achieve a substantial completion rate nationwide despite prior efforts. We hypothesize that the continued low completion rate itself inhibits their utility and application. In this commentary we recommend linking the completion of advance directives to the time when health insurance is initiated or renewed by amending the Patient Self Determination Act. This would relocate the time and locus of their completion from the emotional turmoil of hospital admission and acute illness to a more equanimous time when family and others can be consulted and involved. Moreover actuating increased utilization may require non-coercive incentives as well as

education. Amending the Patient Self Determination Act to require providing advance directive forms at the initiation of healthcare insurance in conjunction with educational and/or incentives could be more effective than the current arrangements.

4. Lo, B. Advance care planning. *Am J Geriatr Cardiol.* 2004 Nov-2004 Dec 31; 13(6):316-20.
Abstract: Advance directives allow patients to have some control over decisions even when they are no longer able to make decisions themselves. All states authorize written advance directives, such as the appointment of a health care proxy, but commonly impose procedural requirements. Some states have restricted the use of oral advance directives, although they are frequently used in everyday practice. Advance directives are limited because they are infrequently used, may not be informed, and may conflict with the patient's current best interests. Moreover, surrogates often cannot state patients' preferences accurately. Furthermore, discussions among physicians and patients about advance directives are flawed. Physicians can improve discussions about advance directives by asking the patient who should serve as proxy and by ascertaining the patient's values and general preferences before discussing specific clinical situations.
5. Rousseau, P. Autonomy, advance directives, and artificial nutrition and hydration. *Am J Hosp Palliat Care.* 2004 Jul-2004 Aug 31; 21(4):254.
6. Crawley, L. M.; Marshall, P. A.; Lo, B., and Koenig, B. A. Strategies for culturally effective end-of-life care. *Ann Intern Med.* 2002 May 7; 136(9):673-9.
Abstract: As a result of profound worldwide demographic change, physicians will increasingly care for patients from cultural backgrounds other than their own. Differences in beliefs, values, and traditional health care practices are of particular relevance at the end of life. Health care providers and patients and families may not have shared understandings of the meaning of illness or death and may not agree on the best strategies to plan for the end of life or to alleviate pain and suffering. Good end-of-life care may be complicated by disagreements between physicians and patients, difficult interactions, or decisions the physician does not understand. Challenges may result from cultural differences between the patient's background and traditional medical practice. Values so ingrained in physicians as to be unquestioned may be alien to patients from different backgrounds. Physicians need to be sensitive to cultural differences and to develop the skills necessary to work with patients from diverse backgrounds. Community and cultural ties provide a source of great comfort as patients and families prepare for death. This paper describes two cases that raise issues about cross-cultural end-of-life practice and suggests strategies for negotiating common problems. Physicians should assess the cultural background of each patient and inquire about values that may affect care at the end of life. They should become aware of the specific beliefs and practices of the populations they serve, always remembering to inquire whether an individual patient adheres to these cultural beliefs. Attention to cultural difference enables the physician to provide comprehensive and compassionate palliative care at the end of life.
7. Lynn, J.; Nolan, K.; Kabcenell, A.; Weissman, D.; Milne, C., and Berwick, D. M. Reforming care for persons near the end of life: the promise of quality improvement. *Ann Intern Med.* 2002 Jul 16; 137(2):117-22.
Abstract: Most people in developed countries will live with a serious, eventually fatal, chronic condition for months or years before dying; yet, the delivery of health care services has only just recently begun adapting to this reality. Quality improvement methods have been effective in helping clinical services to make substantial changes quickly. Quality improvement requires stating an aim, measuring success, and testing possible improvements. The testing of changes requires a clinical team to Plan, Do, Study, and Act on new insights (the "PDSA cycle"). Repeated PDSA cycles generate deep understanding of complex systems and make sustainable improvements rapidly. This paper discusses a composite case study in a nursing home setting, which builds on experience with multisite collaborative efforts and introduces quality improvement methods in the context of end-of-life care.
8. Lynn, J. and Goldstein, N. E. Advance care planning for fatal chronic illness: avoiding commonplace errors and unwarranted suffering. *Ann Intern Med.* 2003 May 20; 138(10):812-8.

Abstract: Patients with eventually fatal illnesses often receive routine treatments in response to health problems rather than treatments arising from planning that incorporates the patient's situation and preferences. This paper considers the case of an elderly man with advanced lung disease who had mechanical ventilation and aggressive intensive care, in part because his nursing home clinicians did not complete an advance care plan and his do-not-resuscitate order did not accompany him to the hospital. The errors that led to his hospitalization and his unwanted treatment there demonstrate how the ordinary lack of advance care planning is deleterious for patients who are nearing the end of life. We discuss serious, recurring, and generally unnoticed errors in planning for care near the end of life and possible steps toward improvement. Repairing these shortcomings will require quality improvement and system redesign efforts, methods familiar from patient safety initiatives. Reliable improvement will also require making it unacceptable for clinicians to fail to plan ahead for care during fatal chronic illness.

9. Teno, J. M. Advance directives: time to move on. *Ann Intern Med.* 2004 Jul 20; 141(2):159-60.
10. Degenholtz, H. B.; Rhee, Y., and Arnold, R. M. Brief communication: the relationship between having a living will and dying in place. *Ann Intern Med.* 2004 Jul 20; 141(2):113-7.

Abstract: **BACKGROUND:** Living wills, a type of advance directive, are promoted as a way for patients to document preferences for life-sustaining treatments should they become incompetent. Previous research, however, has found that these documents do not guide decision making in the hospital. **OBJECTIVE:** To test the hypothesis that people with living wills are less likely to die in a hospital than in their residence before death. **DESIGN:** Secondary analysis of data from a nationally representative longitudinal study. **SETTING:** Publicly available data from the Asset and Health Dynamics Among the Oldest Old (AHEAD) study. **PATIENTS:** People older than 70 years of age living in the community in 1993 who died between 1993 and 1995. **MEASUREMENTS:** Self-report and proxy informant interviews conducted in 1993 and 1995. **RESULTS:** Having a living will was associated with lower probability of dying in a hospital for nursing home residents and people living in the community. For people living in the community, the probability of in-hospital death decreased from 0.65 (95% CI, 0.58 to 0.71) to 0.52 (CI, 0.42 to 0.62). For people living in nursing homes, the probability of in-hospital death decreased from 0.35 (CI, 0.23 to 0.49) to 0.13 (CI, 0.07 to 0.22). **LIMITATIONS:** Retrospective survey data do not contain detailed clinical information on whether the living will was consulted. **CONCLUSION:** Living wills are associated with dying in place rather than in a hospital. This implies that previous research examining only people who died in a hospital suffers from selection bias. During advance care planning, physicians should discuss patients' preferences for location of death.
11. Coppola, K. M.; Ditto, P. H.; Danks, J. H., and Smucker, W. D. Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with and without advance directives. *Arch Intern Med.* 2001 Feb 12; 161(3):431-40.

Abstract: **BACKGROUND:** Past research has documented that primary care physicians and family members are often inaccurate when making substituted judgments for patients without advance directives (ADs). This study compared the accuracy of substituted judgments made by primary care physicians, hospital-based physicians, and family surrogates on behalf of elderly outpatients and examined the effectiveness of ADs in improving the accuracy of these judgments. **PARTICIPANTS AND METHODS:** Participants were 24 primary care physicians of 82 elderly outpatients, 17 emergency and critical care physicians who had no prior experience with the patients, and a baseline comparison group of family surrogates. The primary outcome was accuracy of physicians' predictions of patients' preferences for 4 life-sustaining treatments in 9 hypothetical illness scenarios. Physicians made substituted judgments after being provided with no patient AD, patient's value-based AD, or patient's scenario-based AD. **RESULTS:** Family surrogates' judgments were more accurate than physicians'. Hospital-based physicians making predictions without ADs had the lowest accuracy. Primary care physicians' accuracy was not improved by either AD. Accuracy and confidence in predictions of hospital-based physicians was significantly improved for some scenarios using a scenario-based AD. **CONCLUSIONS:** Although ADs do not improve the accuracy of substituted judgments for primary care physicians or family surrogates, they increase the accuracy of hospital-based physicians. Primary care physicians are withdrawing from hospital-based care in

growing numbers, and emergency medicine and critical care specialists most often are involved in decisions about whether to begin life-sustaining treatments. If ADs can help these physicians better understand patients' preferences, patient autonomy more likely will be preserved when patients become incapacitated.

12. Ditto, P. H.; Danks, J. H.; Smucker, W. D.; Bookwala, J.; Coppola, K. M.; Dresser, R.; Fagerlin, A.; Greedy, R. M.; Houts, R. M.; Lockhart, L. K., and Zyzanski, S. Advance directives as acts of communication: a randomized controlled trial. *Arch Intern Med.* 2001 Feb 12; 161(3):421-30.
Abstract: **BACKGROUND:** Instructional advance directives are widely advocated as a means of preserving patient self-determination at the end of life based on the assumption that they improve surrogates' understanding of patients' life-sustaining treatment wishes. However, no research has examined whether instructional directives are effective in improving the accuracy of surrogate decisions. **PARTICIPANTS AND METHODS:** A total of 401 outpatients aged 65 years or older and their self-designated surrogate decision makers (62% spouses, 29% children) were randomized to 1 of 5 experimental conditions. In the control condition, surrogates predicted patients' preferences for 4 life-sustaining medical treatments in 9 illness scenarios without the benefit of a patient-completed advance directive. Accuracy in this condition was compared with that in 4 intervention conditions in which surrogates made predictions after reviewing either a scenario-based or a value-based directive completed by the patient and either discussing or not discussing the contents of the directive with the patient. Perceived benefits of advance directive completion were also measured. **RESULTS:** None of the interventions produced significant improvements in the accuracy of surrogate substituted judgment in any illness scenario or for any medical treatment. Discussion interventions improved perceived surrogate understanding and comfort for patient-surrogate pairs in which the patient had not completed an advance directive prior to study participation. **CONCLUSIONS:** Our results challenge current policy and law advocating instructional advance directives as a means of honoring specific patient wishes at the end of life. Future research should explore other methods of improving surrogate decision making and consider the value of other outcomes in evaluating the effectiveness of advance care planning.
13. Schwartz, C. E.; Wheeler, H. B.; Hammes, B.; Basque, N.; Edmunds, J.; Reed, G.; Ma, Y.; Li, L.; Tabloski, P., and Yanko, J. Early intervention in planning end-of-life care with ambulatory geriatric patients: results of a pilot trial. *Arch Intern Med.* 2002 Jul 22; 162(14):1611-8.
Notes: **CORPORATE NAME:** UMass End-of-Life Working Group.
Abstract: **BACKGROUND:** A large discrepancy exists between the wishes of dying patients and their actual end-of-life care. However, retrospective clinical experience suggests that early advance care planning (ACP) can markedly reduce this discrepancy. This article describes a randomized trial to evaluate the short-term clinical utility of early ACP. We also assessed the feasibility of performing a larger prospective study to document long-term outcomes. **METHODS:** Ambulatory geriatric patients (N = 61) were randomized to either a control group, which received only a Massachusetts Health Care Proxy form to complete, or an intervention group, in which each patient and health care agent discussed ACP with a trained nurse facilitator. The benefits and burdens of life-sustaining treatments were discussed, and patient goals and preferences for these treatments were documented. **RESULTS:** Two-month follow-up revealed that the intervention achieved higher congruence between agents and patients in their understanding of patients' end-of-life care preferences, with 76% (19/25) in complete agreement vs 55% (12/22) of the controls (effect size [ES] = -0.43). There was also a greater increase in patient knowledge about ACP in the intervention group (ES = 0.22). Intervention patients became less willing to undergo life-sustaining treatments for a new serious medical problem (ES = -0.25), more willing to undergo such treatments for an incurable progressive disease (ES = 0.24), and less willing to tolerate poor health states (ES = -0.78). Practical insights were gained about how to conduct a larger study more effectively. **CONCLUSION:** A facilitated discussion about end-of-life care between patients and their health care agents helps define and document the patient's wishes for both patient and agent.
14. Mitchell, S. L.; Kiely, D. K., and Hamel, M. B. Dying with advanced dementia in the nursing home. *Arch Intern Med.* 2004 Feb 9; 164(3):321-6.
Abstract: **BACKGROUND:** Nursing homes are important providers of end-of-life care to persons

with advanced dementia. **METHODS:** We used data from the Minimum Data Set (June 1, 1994, to December 31, 1997) to identify persons 65 years and older who died with advanced dementia (n = 1609) and terminal cancer (n = 883) within 1 year of admission to any New York State nursing home. Variables from the Minimum Data Set assessment completed within 120 days of death were used to describe and compare the end-of-life experiences of these 2 groups. **RESULTS:** At nursing home admission, only 1.1% of residents with advanced dementia were perceived to have a life expectancy of less than 6 months; however, 71.0% died within that period. Before death, 55.1% of demented residents had a do-not-resuscitate order, and 1.4% had a do-not-hospitalize order. Nonpalliative interventions were common among residents dying with advanced dementia: tube feeding, 25.0%; laboratory tests, 49.2%; restraints, 11.2%; and intravenous therapy, 10.1%. Residents with dementia were less likely than those with cancer to have directives limiting care but were more likely to experience burdensome interventions: do-not-resuscitate order (adjusted odds ratio [OR], 0.12; 95% confidence interval [CI], 0.09-0.16), do-not-hospitalize order (adjusted OR, 0.33; 95% CI, 0.16-0.66), tube feeding (adjusted OR, 2.21; 95% CI, 1.51-3.23), laboratory tests (adjusted OR, 2.53; 95% CI, 2.01-3.18), and restraints (adjusted OR, 1.79; 95% CI, 1.23-2.61). Distressing conditions common in advanced dementia included pressure ulcers (14.7%), constipation (13.7%), pain (11.5%), and shortness of breath (8.2%). **CONCLUSIONS:** Nursing home residents dying with advanced dementia are not perceived as having a terminal condition, and most do not receive optimal palliative care. Management and educational strategies are needed to improve end-of-life care in advanced dementia.

15. Lo, B. and Steinbrook, R. Resuscitating advance directives. *Arch Intern Med.* 2004 Jul 26; 164(14):1501-6.
 Abstract: Advance directives have not fulfilled their promise of facilitating decisions about end-of-life care for incompetent patients. Many legal requirements and restrictions concerning advance directives are counterproductive. Requirements for witnessing or notarizing advance directives make it difficult for patients to complete a written directive during a physician visit. State laws that establish a hierarchy of family surrogates for incompetent patients who have not appointed a proxy are inflexible and may not apply to common clinical situations. Advance directives would be more useful if they emphasized discussing end-of-life care with physicians rather than completing a legal document. State laws should be revised to encourage patients to discuss advance directives with physicians and to complete them during an office visit. Such patient-physician discussions about end-of-life care can lead to more informed patient decisions. Procedures for written advance directives should be simplified. Patients should be able to designate health care proxies through oral statements to physicians. These reforms will encourage discussions between patients and physicians about advance directives and may lead to more informed decisions near the end of life.

16. Morrison, R. S. and Meier, D. E. High rates of advance care planning in New York City's elderly population. *Arch Intern Med.* 2004 Dec 13-2004 Dec 27; 164(22):2421-6.
 Abstract: **BACKGROUND:** Previous studies have demonstrated low rates of advance care planning (ACP), particularly among nonwhite populations, raising questions about the generalizability of this decision-making process. **OBJECTIVE:** To explore factors that may influence patients' willingness to engage in ACP. **DESIGN:** Survey. **SETTING:** Thirty-four randomly selected New York City senior centers. **PARTICIPANTS:** A total of 700 African American (n = 239), Hispanic (n = 237), and white (n = 224) adults 60 years and older. **INTERVENTION:** Participants were administered a 51-item survey that assessed attitudes, beliefs, and practices regarding ACP. **MAIN OUTCOME MEASURES:** Attitudes and beliefs about physicians' trustworthiness, fatalism, beliefs about surrogate decision making, and comfort discussing end-of-life medical care; factors associated with health care proxy completion; and health care proxy completion rates. **RESULTS:** More than one third of the participants had completed a health care proxy. There were no significant differences in completion rates across the 3 ethnic groups. Respondents who had a primary care physician (odds ratio [OR], 2.0; 95% confidence interval [CI], 1.3-3.2), were more knowledgeable about advance directives (OR, 2.0; 95% CI, 1.4-2.9), or had seen a friend or family member use a mechanical ventilator (OR, 1.5; 95% CI, 1.02-2.1) were significantly more likely to have designated a health care proxy. Respondents who were only comfortable discussing ACP if the discussion was initiated by the physician (OR, 0.6; 95% CI, 0.0-0.8) were significantly less likely to have completed a health care proxy. **CONCLUSIONS:** African American, Hispanic, and white community-dwelling, older

adults had similarly high rates of advance directive completion. The primary predictors of advance directive completion involved modifiable factors such as established primary care physicians, personal experience with mechanical ventilation, knowledge about the process of ACP, and physicians' willingness to effectively initiate such discussions. Some of the racial/ethnic differences in desire for collective family-based decision making that were observed in this study have implications for the evolution of ACP policy that respects and operationalizes these preferences.

17. Pearlman, R. A.; Starks, H.; Cain, K. C., and Cole, W. G. Improvements in advance care planning in the Veterans Affairs System: results of a multifaceted intervention. *Arch Intern Med.* 2005 Mar 28; 165(6):667-74.
Abstract: **BACKGROUND:** Advance care planning (ACP) aims to guide health care in the event of decisional incapacity. Interventions to promote ACP have had limited effectiveness. We conducted an educational and motivational intervention in Department of Veterans Affairs outpatient clinics to increase ACP use and proxy and health care provider understanding of patients' preferences and values. **METHODS:** We recruited 23 providers and up to 14 of each of their patients; the patients were randomized to the control or intervention group. Eligibility criteria included a preexisting relationship with the provider, age 55 years or older, chronic health condition(s), and no recorded advance directive. The intervention group (n = 119) received an ACP workbook, motivational counseling by social workers, and cues to providers to discuss ACP. The control group (n = 129) received an advance directive booklet. **RESULTS:** The intervention patients reported more ACP discussions with their providers (64% vs 38%; P<.001). Living wills were filed in the medical record twice as often in the intervention group (48% vs 23%; P<.001). Provider-patient dyads in the intervention group had higher agreement scores than the control group for treatment preferences, values, and personal beliefs (58% vs 48%, 57% vs 46%, and 61% vs 47%, respectively; P<.01 for all comparisons). The agreement scores for the proxy-patient dyads did not differ between groups for treatment preferences and values, but were higher in the intervention than the control group for personal beliefs (67% vs 56%). **CONCLUSION:** This intervention demonstrates mixed results and highlights the ongoing challenges of helping health care providers and potential proxy decision makers represent patient preferences and values.
18. Chan, H. M. Sharing death and dying: advance directives, autonomy and the family. *Bioethics.* 2004 Apr; 18(2):87-103.
Abstract: This paper critically examines the liberal model of decision making for the terminally ill and contrasts it with the familial model that can be found in some Asian cultures. The contrast between the two models shows that the liberal model is excessively patient-centered, and misconceives and marginalises the role of the family in the decision making process. The paper argues that the familial model is correct in conceiving the last journey of one's life as a sharing process rather than a process of exercising one's prior or counterfactual choice, and concludes by suggesting a policy framework for the practice of familialism that can answer the liberal challenge that familialism cannot safeguard the patient from abuse and neglect.
19. Pacquiao, D. Addressing cultural incongruities of advance directives. *Bioethics Forum.* 2001 Spring; 17(1):27-31.
Abstract: Shared meanings and socially constructed realities have great significance to individuals and families facing critical illness, pain, suffering, or death. Actions are often based on the context of the professional and dominant societal culture. The concept of Advance Directives is consistent with the dominant value orientation in the American culture of self-reliance and individualism, which places a high premium on self-determination and control of one's own destiny. However, this value is not always consistent with the dominant cultural views of particular sick or dying individuals. Thus, at a time when individuals and their families need the most support, institutionalized care often creates incongruities and meaninglessness.
20. Bomba, P. A. Advance care planning along the continuum. *Case Manager.* 2005 Mar-2005 Apr 30; 16(2):68-72.
21. Mezey, M. D.; Mitty, E. L.; Bottrell, M. M.; Ramsey, G. C., and Fisher, T. Advance directives: older adults

with dementia. *Clin Geriatr Med.* 2000 May; 16(2):255-68.

Abstract: The benefits and risks for older adults with dementia executing advance directives are discussed. Salient issues related to decision-specific capacity and models for advance planning and end-of-life decisions by cognitively impaired older adults are presented.

22. Fischer, G. S.; Arnold, R. M., and Tulskey, J. A. Talking to the older adult about advance directives. *Clin Geriatr Med.* 2000 May; 16(2):239-54.
Abstract: Discussing advance care plans with elderly patients can improve the experience of end-of-life care for patients, families, and health care teams. Specific goals for any particular discussion should be based on patients' particular clinical circumstances. Physicians should focus on patients' overall values and goals and should provide emotional support during the discussion. Decisions made during the advance care planning process should be documented.
23. Kirschner, K. L. When written advance directives are not enough. *Clin Geriatr Med.* 2005 Feb; 21(1):193-209, x.
Abstract: Advance directives have been promoted as being the best device for making decisions on behalf of patients who are unable to speak for themselves. It is believed that an advance directive would tell the health care professionals what to do. Conflicts would dissolve and the course would become clear. Such hopes and expectations probably exceed the capacity of these documents to provide context-based, real-time decisions. This article reviews the research on advance directives, including proxy and instructional documents, and discusses the strengths and limitations of each. Advance directives are often thought of as static, binding documents. Recommendations will be offered on how to use these documents as tools to facilitate patient-centered, dynamic decisions.
24. Dugan, D. O. and Gluck, E. H. Discussing life-sustaining treatments: an overview and communications guide for primary care physicians. *Compr Ther.* 2004 Spring; 30(1):25-36.
Abstract: Physicians must be skilled communicators with patients, families, and multidisciplinary health care teams to meet ethical decision-making challenges arising in end-stage disease care. We offer practical suggestions for collaborative communication in the "perfect storm" of contemporary critical care settings.
25. Prendergast, T. J. Advance care planning: pitfalls, progress, promise. *Crit Care Med.* 2001 Feb; 29(2 Suppl):N34-9.
Abstract: We now have a decade of experience with advance directives since the Patient Self-Determination Act was signed into law in November 1990. With few exceptions, empirical studies have yielded disappointing results. Advance directives are recorded by medical personnel more often but are not completed by patients more frequently. The process of recording them does not enhance patient-physician communication. When available, advance directives do not change care or reduce hospital resources. The most ambitious study of advance care planning, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, failed to show any change in outcomes after an extensive intervention. Investigators have attempted to identify the reasons why the optimism about the Patient Self-Determination Act has not been realized. Many interventions to facilitate advance care planning were focused on specific treatment decisions. Recent research suggests that preferences for care are not fixed but emerge in a clinical context from a process of discussion and feedback within the network of the patient's most important relationships. Clinical trials emphasizing this approach have been successful. The approach that emphasizes communication, building trust over time, and working within the patient's most important relationships offers a hopeful model for clinicians working in intensive care units.
26. Curtis, J. R.; Engelberg, R. A.; Nielsen, E. L.; Au, D. H., and Patrick, D. L. Patient-physician communication about end-of-life care for patients with severe COPD. *Eur Respir J.* 2004 Aug; 24(2):200-5.
Abstract: Since patients with chronic obstructive pulmonary disease (COPD) infrequently discuss treatment preferences about end-of-life care with physicians, the goal of the present study was to identify which specific areas of communication about end-of-life care occur between patients with severe COPD and their physicians, and how patients rate the quality of this communication. A total of 115 patients with oxygen-dependent COPD, identified in pulmonary clinics in three hospitals and

through an oxygen delivery company, were enrolled in this study. A 17-item quality of communication questionnaire (QOC) was administered to patients, along with other measures, including satisfaction with care. The patients reported that most physicians do not discuss how long the patients have to live, what dying might be like or patients' spirituality. Patients rated physicians highly at listening and answering questions. Areas patients rated relatively low included discussing prognosis, what dying might be like and spirituality/religion. Patients' assessments of physicians' overall communication and communication about treatment correlated well with the QOC. Patients' overall satisfaction with care also correlated significantly with the QOC. In conclusion, this study identifies areas of communication that physicians do not address and areas that patients rate poorly, including talking about prognosis, dying and spirituality. These areas may provide targets for interventions to improve communication about end-of-life care for patients with chronic obstructive pulmonary disease. Future studies should determine the responsiveness of these items to interventions, and the effect such interventions have on patient satisfaction and quality of care.

27. Hogstel, M. O.; Curry, L. C.; Walker, C. A., and Burns, P. G. Ethics committees in long-term care facilities. *Geriatr Nurs*. 2004 Nov-2004 Dec 31; 25(6):364-9.
Abstract: Biomedical ethical dilemmas occur in long-term care facilities (LTCFs), particularly in the absence of residents' advance directives. Ethics committees are required in hospitals and long-term care facilities accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), but many LTCFs do not have JCAHO accreditation. A survey of LTCFs in one county in a Southwestern state found that only 29% of those LTCFs responding had an organized ethics committee. This article discusses the purpose, membership, and meetings of an ethics committee in LTCFs. A sample process for resolving a biomedical ethical dilemma is presented. Nurses can initiate the development of an ethics committee using available resources or combining resources with other local LTCFs. The ethics committee should consider the education of all persons involved to facilitate resolution of clinical ethical dilemmas.
28. Gunter-Hunt, G.; Mahoney, J. E., and Sieger, C. E. A comparison of state advance directive documents. *Gerontologist*. 2002 Feb; 42(1):51-60.
Abstract: PURPOSE: Advance directive (AD) documents are based on state-specific statutes and vary in terms of content. These differences can create confusion and inconsistencies resulting in a possible failure to honor the health care wishes of people who execute health care documents for one state and receive health care in another state. The purpose of this study was to compare similarities and differences in the content of state AD documents. DESIGN AND METHODS: AD documents for 50 states and the District of Columbia posted on the Partnership for Caring website were reviewed. States and regions of the country were compared for type or types of documents used and issues included in AD documents. RESULTS: Three states had statutory living will documents only; however, these states did allow for appointment of a health care agent for limited end-of-life decisions. Three states had statutory durable power of attorney for health care documents only, 32 had both statutory living will and durable power of attorney for health care documents, and 13 had statutory forms which combine both types of directive in one document (advance health care directives). Of 8 identified key issues, those addressed by at least 90% of states were designation of a proxy, personal instructions for care, general life-sustaining measures, and terminal illness. When document types were compared, advance health care directive documents included more of the key issues than did living will or durable power of attorney for health care documents ($p < .001$). IMPLICATIONS: This variability suggests a need for national dialogue to standardize some provisions of AD documents.
29. Allen, R. S.; DeLaine, S. R.; Chaplin, W. F.; Marson, D. C.; Bourgeois, M. S.; Dijkstra, K., and Burgio, L. D. Advance care planning in nursing homes: correlates of capacity and possession of advance directives. *Gerontologist*. 2003 Jun; 43(3):309-17.
Abstract: PURPOSE: The identification of nursing home residents who can continue to participate in advance care planning about end-of-life care is a critical clinical and bioethical issue. This study uses high quality observational research to identify correlates of advance care planning in nursing homes, including objective measurement of capacity. DESIGN AND METHODS: The authors used cross-sectional, cohort study between 1997 and 1999. Seventy-eight residents (M age = 83.97, SD = 8.2)

and their proxies (M age = 59.23, SD = 11.77) were included across five nursing homes. The authors obtained data via chart review, proxy interviews, resident assessments, survey completion by certified nursing assistants, and direct observation of residents' daily behaviors. **RESULTS:** Capacity assessments revealed that most residents could state a simple treatment preference (82.4%), but a sizable number did not retain capacity to understand treatment alternatives or appreciate the consequences of their choice. Global cognitive ability (Mini-Mental State Examination score) was related to understanding and appreciation. When the authors removed the effects of global cognitive ability, understanding and appreciation were related to time spent by residents in verbal interaction with others. Residents were more likely to possess advance directives when proxies possessed advance directives, proxies were less religious, and residents were socially engaged. **IMPLICATIONS:** Assessment of proxy beliefs and direct determination of residents' decisional capacity and social engagement may help nursing home staff identify families who may participate in advance planning for end-of-life medical care. Measures of global cognitive ability offer limited information about resident capacity for decision making. Decisional capacity assessments should enhance the verbal ability of individuals with dementia by reducing reliance on memory in the assessment process. Interventions to engage residents and families in structured discussions for end-of-life planning are needed.

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Abstract: **PURPOSE:** This study sought to determine whether nursing homes comply with residents' do-not-hospitalize (DNH) orders prohibiting inpatient hospitalization. **DESIGN AND METHODS:** With the use of data from the nationally representative 1996 Nursing Home Component of the Medical Expenditure Panel Survey, a multivariate logistic regression model was developed. **RESULTS:** Three percent of residents had DNH orders. These residents were half as likely to be hospitalized. Residents in not-for-profit or public facilities were less likely to be hospitalized than those in for-profit homes. Hospitalization was more likely among men, racial or ethnic minorities, those with more diagnosed health conditions, and those in facilities in the South compared with those in the Midwest. Hospitalized residents with DNH orders had no limitations of activities of daily living, were not located in hospital-based nursing homes, were less likely to be in a for-profit facility, and were sicker than nonhospitalized residents with DNH orders. **IMPLICATIONS:** Improved education regarding advance directives, particularly DNH orders, is necessary for health care practitioners and patients. More consistent and rigorous policies should be implemented in nursing facilities.

31. Hawkins, N. A.; Ditto, P. H.; Danks, J. H., and Smucker, W. D. Micromanaging death: process preferences, values, and goals in end-of-life medical decision making. *Gerontologist*. 2005 Feb; 45(1):107-17. **Abstract:** **PURPOSE:** This study examined patients' and surrogates' attitudes about using advance directives to manage end-of-life medical care. It also explored process preferences, or how patients want decisions to be made. **DESIGN AND METHODS:** Data come from the third wave of the Advance Directives, Values Assessment, and Communication Enhancement project, a longitudinal study designed to investigate psychological assumptions underlying the use of advance directives. Three-hundred thirty-seven outpatients aged 65 and older and their designated surrogate decision makers completed interviews and questionnaires. **RESULTS:** Very few individuals wished to document specific medical treatment preferences and mandate that they be followed, without exception, near death. Most desired to express more general preferences, such as values and goals for care, in addition to (or, instead of) specific treatment preferences and to allow surrogate decision makers leeway in decision making. Patient-to-patient variability with regard to process preferences was substantial, as was surrogates' misunderstanding of the patients' process preferences. **IMPLICATIONS:** Very few individuals may desire the standard approach to advance care planning whereby preferences for specific life-sustaining treatments are documented and these requests are strictly followed near death. Instead, patient autonomy may be better served by emphasizing discussion of process preferences and leeway in decision making.

32. Fagerlin, A. and Schneider, C. E. Enough. The failure of the living will. *Hastings Cent Rep*. 2004 Mar-2004 Apr 30; 34(2):30-42.

Abstract: In pursuit of the dream that patients' exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.

33. Hickman, S. E.; Hammes, B. J.; Tolle, S. W., and Moss, A. H. A viable alternative to traditional living wills. *Hastings Cent Rep.* 2004 Sep-2004 Oct 31; 34(5):4-5; author reply 5-6.
Notes: GENERAL NOTE: KIE: KIE Bib: advance directives
34. Emanuel, E. J. Living wills: are durable powers of attorney better? *Hastings Cent Rep.* 2004 Nov-2004 Dec 31; 34(6):5-6; author reply 6-7.
35. Mezey, M.; Teresi, J.; Ramsey, G.; Mitty, E., and Bobrowitz, T. Decision-making capacity to execute a health care proxy: development and testing of guidelines. *J Am Geriatr Soc.* 2000 Feb; 48(2):179-87.
Abstract: OBJECTIVE: To evaluate the reliability and validity of guidelines to determine the capacity of nursing home residents to execute a health care proxy (HCP). DESIGN: A cross-sectional study. SETTING: A 750-bed not-for-profit nursing home located in New York City. PARTICIPANTS: A random sample of 200 nursing home residents: average age, 87; 99% white; 83% female; average length of stay, 3.05 years; mean Mini-Mental State Exam (MMSE) score, 15.9. MEASUREMENTS: Demographic characteristics (Minimum Data Set (MDS)); function and cognitive status (Institutional Comprehensive Assessment and Referral Evaluation (INCARE)); Reisberg Dementia Staging; MMSE; Minimum Data Set-Cognitive Performance Scale (MDS-COGS)); an investigator-developed measure of a nursing home resident's capacity to execute a health care proxy (Health Care Proxy (HCP) Guidelines.) RESULTS: The internal consistency of the decision-making scales in the HCP Guidelines, paraphrased recall and recognition, reached acceptable levels, alphas of .85 and .73, respectively. Interrater reliability estimates were .92 and .94, respectively, for the recall and recognition scales; test-retest reliability estimates were .83 and .90. The discriminant validity of these scales is promising. For example, the MMSE correlation was .51 with the Recall scale and .57 with the Recognition scale. Of residents with severe cognitive impairment (MMSE < 10), 71% completed 50% or more of the scaled items in the HCP guidelines and 95% consistently named a proxy. CONCLUSIONS: Seventy-three percent of testable residents, approximately three-quarters of whom were cognitively impaired, evidenced sufficient capacity to execute an HCP. Of residents with severe cognitive impairment, the HCP guidelines are potentially useful in identifying those with the capacity to execute a HCP. The guidelines are more predictive than the MMSE in identifying residents able to execute a HCP.
36. Covinsky, K. E.; Fuller, J. D.; Yaffe, K.; Johnston, C. B.; Hamel, M. B.; Lynn, J.; Teno, J. M., and Phillips, R. S. Communication and decision-making in seriously ill patients: findings of the SUPPORT project. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *J Am Geriatr Soc.* 2000 May; 48(5 Suppl):S187-93.
Abstract: OBJECTIVES: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) represents one of the largest and most comprehensive efforts to describe patient preferences in seriously ill patients, and to evaluate how effectively patient preferences are communicated. Our objective was to review findings from SUPPORT describing the communication of seriously ill patients' preferences for end-of-life care. METHODS: We identified published reports from SUPPORT describing patient preferences and the communication of those preferences. We abstracted findings that addressed each of the following questions: What patient characteristics predict patient preferences for end of life care? How well do physicians, nurses, and surrogates understand their patients' preferences, and what variables are correlated with this understanding? Does increasing the documentation of existing advance directives result in care more consistent with patients' preferences? RESULTS: Patients who are older, have cancer, are women, believe their prognoses are poor, and are more dependent in ADL function are less likely to want CPR. However, there is considerable variability and geographic variation in these preferences. Physician, nurse, and surrogate understanding of their patient's preferences is only moderately better than chance. Most patients do not discuss their preferences with their physicians, and only about half of patients who do not wish to receive CPR receive DNR orders. Factors other than the patients' preferences and prognoses, including the patient's age, the physician's specialty, and the geographic

site of care were strong determinants of whether DNR orders were written. In SUPPORT patients, there was no evidence that increasing the rates of documentation of advance directives results in care that is more consistent with patients' preferences. CONCLUSIONS: SUPPORT documents that physicians and surrogates are often unaware of seriously ill patients' preferences. The care provided to patients is often not consistent with their preferences and is often associated with factors other than preferences or prognoses. Improving these deficiencies in end-of-life care may require systematic change rather than simple interventions.

37. Cantor, M. D. Improving advance care planning: lessons from POLST. Physician Orders for Life-Sustaining Treatment. *J Am Geriatr Soc.* 2000 Oct; 48(10):1343-4.
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38. Lee, M. A.; Brummel-Smith, K.; Meyer, J.; Drew, N., and London, M. R. Physician orders for life-sustaining treatment (POLST): outcomes in a PACE program. Program of All-Inclusive Care for the Elderly. *J Am Geriatr Soc.* 2000 Oct; 48(10):1219-25.
Abstract: OBJECTIVES: To evaluate whether terminal care was consistent with Physician Orders for Life-Sustaining Treatment (POLST), a preprinted and signed doctor's order specifying treatment instructions in the event of serious illness for CPR, levels of medical intervention, antibiotics, IV fluids, and feeding tubes. DESIGN: Retrospective chart review. SETTING: ElderPlace, a Program of All-Inclusive Care for the Elderly (PACE) site in Portland, Oregon. PARTICIPANTS: All ElderPlace participants who died in 1997 were eligible (n = 58). Reasons for exclusion were no POLST (1), missing POLST (1), and insufficient documentation of care (2). MEASUREMENTS: POLST instructions for each participant and whether or not each of the treatments addressed by the POLST was administered in the final 2 weeks of life. RESULTS: The POLST specified "do not resuscitate" for 50 participants (93%); CPR use was consistent with these instructions for 49 participants (91%). "Comfort care" was the designated level of medical intervention in 13 cases, "limited interventions" in 18, "advanced interventions" in 18, and "full interventions" in 5. Interventions administered were at the level specified in 25 cases (46%); at a less invasive level in 18 (33%), and at a more invasive level in 11 (20%). Antibiotic administration was consistent with POLST instructions for 86% of 28 subjects who had infections in the last 2 weeks of life, and less invasive for 14%. Care matched POLST instructions in 84% of cases for IV fluids and 94% for feeding tubes. CONCLUSIONS: POLST completion in ElderPlace exceeds reported advance directive rates. Care matched POLST instructions for CPR, antibiotics, IV fluids, and feeding tubes more consistently than previously reported for advance directive instructions. Medical intervention level was consistent with POLST instructions for less than half the participants, however. We conclude that the POLST is effective for limiting the use of some life-sustaining interventions, but that the factors that lead physicians to deviate from patients' stated preferences merit further investigation.
39. Kiely, D. K.; Mitchell, S. L.; Marlow, A.; Murphy, K. M., and Morris, J. N. Racial and state differences in the designation of advance directives in nursing home residents. *J Am Geriatr Soc.* 2001 Oct; 49(10):1346-52.
Abstract: OBJECTIVES: To examine racial and state differences in the use of advance directives and surrogate decision-making in a nursing home population. DESIGN: A retrospective cohort study. SETTING: Nursing homes in the states of California (CA), Massachusetts (MA), New York (NY), and Ohio (OH). PARTICIPANTS: Nursing home residents: 130,308 in CA, 59,691 in MA, 112,080 in NY, and 98,954 in OH. MEASUREMENTS: Minimum Data Set information concerning resident race and whether or not residents have a living will (LW), a do not resuscitate (DNR) order, or a surrogate decision-maker (SDM). RESULTS: The proportion of LWs, DNR orders, and SDMs varied significantly ($P < .0001$) by racial categories in each state. In general, whites were distinctly different from other racial categories. Whites were significantly more likely to have a LW (odds ratio (OR) = 1.9 (CA), OR = 2.2 (NY), OR = 4.9 (OH)), a DNR order (OR = 2.4 (CA), OR = 2.4 (MA), OR = 3.3 (NY), OR = 3.2 (OH)), and a SDM (OR = 1.1 (CA), OR = 1.2 (NY), OR = 1.6 (OH)) than were nonwhites, after adjusting for potentially confounding factors. Significant state differences ($P < .0001$) were observed in LWs, DNR orders, and SDMs and were most pronounced in residents of Ohio, who were significantly more likely to have a LW than were residents in other

states (OR = 9.3). CONCLUSIONS: Various resident characteristics explain some of the racial differences, although whites are still more likely to have a LW, a DNR order, or an SDM independent of various resident characteristics included in the adjusted analyses. This pattern is observed in all states, although the ORs varied by state. Some of these differences may be due to distinct cultural approaches to end-of-life care and lack of knowledge and understanding of advance directives. The distinctly higher rates of LWs among all racial groups in Ohio than in other states suggest that states can potentially increase the use of advance directives through intervention.

40. Volicer, L.; Cantor, M. D.; Derse, A. R.; Edwards, D. M.; Prudhomme, A. M.; Gregory, D. C.; Reagan, J. E.; Tulsy, J. A., and Fox, E. Advance care planning by proxy for residents of long-term care facilities who lack decision-making capacity. *J Am Geriatr Soc.* 2002 Apr; 50(4):761-7.
Abstract: This report examines whether long-term care facilities should implement policies and procedures to support advance care planning by proxy for residents who lack decision-making capacity. The report focuses on advance care planning in the Department of Veterans Affairs. After reviewing clinical, legal, and ethical perspectives, the authors conclude that advance proxy planning is ethically sound and can improve patient care. However, because experience with advance proxy planning is still fairly limited, the authors do not recommend that a particular standardized approach be mandated at the national level. Instead, local facilities are advised to develop their own policies and then evaluate their effect. The report contains specific recommendations for the advance proxy planning process.
41. Happ, M. B.; Capezuti, E.; Strumpf, N. E.; Wagner, L.; Cunningham, S.; Evans, L., and Maislin, G. Advance care planning and end-of-life care for hospitalized nursing home residents. *J Am Geriatr Soc.* 2002 May; 50(5):829-35.
Abstract: OBJECTIVES: To describe advance care planning (ACP) and end-of-life care for nursing home residents who are hospitalized in the last 6 weeks of life. DESIGN: Constant comparative analysis of deceased nursing home resident cases. SETTING: A not-for-profit Jewish nursing home. PARTICIPANTS: Forty-three deceased residents hospitalized within the last 6 weeks of life at a tertiary medical center. MEASUREMENTS: Trained nurse reviewers abstracted data from nursing home records and gerontological advanced practice nurse field notes. Clinical and outcome data from the original study were used to describe the sample. Data were analyzed using the constant comparative method and validated in interviews with a gerontological advanced practice nurse and social worker. RESULTS: The analysis revealed distinct characteristics and identifiable transition points in ACP and end-of-life care with frail nursing home residents. ACP was addressed by social workers as part of the nursing home admission process, focused primarily on cardiopulmonary resuscitation preference, and reviewed only after the crisis of acute illness and hospitalization. Advance directive forms specifying preferences or limitations for life-sustaining treatment contained inconsistent language and vague conditions for implementation. ACP review generally resulted in gradual limitation of life-sustaining treatment. Transition points included nursing home admission, acute illness or hospitalization, and decline toward death. Relatively few nursing home residents received hospice services, with most hospice referrals and palliative care treatment delayed until the week before death. Most residents in this sample died without family present and with little documented evidence of pain or symptom management. CONCLUSION: Limiting discussion of advance care plans to cardiopulmonary resuscitation falsely dichotomized and oversimplified the choices about medical treatment and care at end-of-life, especially palliative care alternatives, for these older nursing home residents. Formal hospice services were underutilized, and palliative care efforts by nursing home staff were often inconsistent with accepted standards. These results reinforce the need for research and program initiatives in long-term care to improve and facilitate individualized ACP and palliative care at end of life.
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Abstract: Physicians and families need to interact more meaningfully to clarify the values and preferences at stake in advance care planning. The current use of advance directives fails to respect patient autonomy. This paper proposes using the family covenant as a preventive ethics process designed to improve end-of-life planning by incorporating other family members--as agreed to by

the patient and those family members--into the medical care dialogue. The family covenant formulates advance directives in conversation with family members and with the assistance of a physician, thereby making advance directives more acceptable to the family, and more intelligible to other physicians. It adds the moral force of a promise to the obligation of respecting a patient's preferences about end-of-life care. These negotiations between patient, family, and physician, from early planning phases through implementation, should greatly reduce the incidence of family disagreements on what the patient would have wanted. The family covenant ensures advance directive discussions within the family, promotes and respects the autonomy of other family members, and might even spur others in the family to complete advance directives through additional covenants. The family covenant holds the potential to transform moral quagmires into meaningful moral conversation.

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44. Lorenz, K. A. and Lynn, J. Oregon's lessons for improving advance care planning. *J Am Geriatr Soc.* 2004 Sep; 52(9):1574-5.
45. Schmidt, T. A.; Hickman, S. E.; Tolle, S. W., and Brooks, H. S. The Physician Orders for Life-Sustaining Treatment program: Oregon emergency medical technicians' practical experiences and attitudes. *J Am Geriatr Soc.* 2004 Sep; 52(9):1430-4.
Abstract: OBJECTIVES: To evaluate emergency medical technicians' (EMTs) experiences with the Physician Orders for Life-Sustaining Treatment (POLST) program and learn about attitudes regarding its effectiveness. DESIGN: Anonymous survey mailed to a stratified random sample. SETTING: Tri-County Portland, Oregon, area. PARTICIPANTS: A total of 572 Oregon EMT respondents (out of 1,048 surveys) were included in the analysis. MEASUREMENTS: Survey questions about experiences with the POLST form and opinions about POLST. RESULTS: Respondents were mostly male (76%) and paramedics (66%). Most respondents (73%) had treated a patient with a POLST, and 74% reported receiving education about POLST. EMTs reported that POLST, when present, changed treatment in 45% of cases. Seventy-five percent of the respondents agreed that the POLST form provides clear instructions about patient preferences, and 93% agreed that the POLST form is useful in determining which treatments to provide when the patient is in cardiopulmonary arrest. Fewer (63%) agreed that the form is useful in determining treatments when the patient has a pulse and is breathing. CONCLUSION: Most respondents have experience with the POLST program. EMTs find the POLST form useful and often use it to change treatment decisions for patients.
46. Hickman, S. E.; Tolle, S. W.; Brummel-Smith, K., and Carley, M. M. Use of the Physician Orders for Life-Sustaining Treatment program in Oregon nursing facilities: beyond resuscitation status. *J Am Geriatr Soc.* 2004 Sep; 52(9):1424-9.
Abstract: OBJECTIVES: Program was designed to communicate resident/surrogate treatment preferences in the form of medical orders. To assess statewide nursing facility use of the Physician Orders for Life-Sustaining Treatment (POLST) and to identify the patterns of orders documented on residents' POLST forms. DESIGN: Telephone survey; on-site POLST form review. SETTING: Oregon nursing facilities. PARTICIPANTS: One hundred forty-six nursing facilities in the telephone survey; 356 nursing facility residents aged 65 and older at seven nursing facilities in the POLST form review. MEASUREMENTS: A telephone survey; onsite POLST form reviews. RESULTS: In the telephone survey, 71% of facilities reported using the POLST program for at least half of their residents. In the POLST form review, do-not-resuscitate (DNR) orders were present on 88% of POLST forms. On forms indicating DNR, 77% reflected preferences for more than the lowest level of treatment in at least one other category. On POLST forms indicating orders to resuscitate, 47% reflected preferences for less than the highest level of treatment in at least one other category. The oldest old (> or = 85, n=167) were more likely than the young old (65-74, n=48) to have orders to limit resuscitation, medical treatment, and artificial nutrition and hydration. CONCLUSION: The POLST program is widely used in Oregon nursing facilities. A majority of individuals with DNR orders requested some other form of life-extending treatment, and advanced age was associated with orders to limit treatments.

47. Morrison, R. S.; Chichin, E.; Carter, J.; Burack, O.; Lantz, M., and Meier, D. E. The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *J Am Geriatr Soc.* 2005 Feb; 53(2):290-4.
Abstract: OBJECTIVES: To assess the effect of a multicomponent advance care planning intervention directed at nursing home social workers on identification and documentation of preferences for medical treatments and on patient outcomes. DESIGN: Controlled clinical trial. SETTING: New York City nursing home. PARTICIPANTS: One hundred thirty-nine newly admitted long-term care residents. INTERVENTION: Nursing home social workers were randomized to the intervention or control groups. The intervention consisted of baseline education in advance care planning that incorporated small-group workshops and role play/practice sessions for intervention social workers; structured advance care planning discussions with residents and their proxies at admission, after any change in clinical status, and at yearly intervals; formal structured review of residents' goals of care at preexisting regular team meetings; "flagging" of advance directives on nursing home charts; and feedback to individual healthcare providers of the congruence of care they provided and the preferences specified in the advance care planning process. Control social workers received an educational training session on New York State law regarding advance directives but no additional training or interventions. Subjects were enrolled from January 9, 2001 through May 25, 2003 and followed for 6 months after enrollment. MEASUREMENTS: Nursing home chart documentation of advance directives (healthcare proxies, living wills) and do-not-resuscitate orders; preferences for artificial nutrition and hydration, intravenous antibiotics, and hospitalization; and concordance of treatments received with documented preferences were compared for residents assigned to intervention and control social workers. RESULTS: Intervention residents were significantly more likely than residents in the control group to have their preferences regarding cardiopulmonary resuscitation (40% vs 20%, $P=.005$), artificial nutrition and hydration (47% vs 9%, $P<.01$), intravenous antibiotics (44% vs 9%, $P<.01$), and hospitalization (49% vs 16%, $P<.01$) documented in the nursing home chart. Control residents were significantly more likely than intervention residents to receive treatments discordant with their prior stated wishes. Two of 49 (5%) intervention residents received a treatment in conflict with their prior stated wishes (one hospitalization, one episode of intravenous antibiotics), compared with 17 of 96 (18%) control patients ($P=.04$). CONCLUSION: This generalizable intervention directed at nursing home social workers significantly improved the documentation and identification of patients' wishes regarding common life-sustaining treatments and resulted in a higher concordance between patients' prior stated wishes and treatments received.
48. Winzelberg, G. S.; Hanson, L. C., and Tulsky, J. A. Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. *J Am Geriatr Soc.* 2005 Jun; 53(6):1046-50.
Abstract: Efforts to improve end-of-life decision-making quality have emphasized the principle of individual autonomy to better ensure that patients receive care consistent with their preferences. This principle has primarily been defined through court decisions during the past 3 decades as a patient's right to refuse medical technologies and avoid life-prolonging treatments. However, autonomy as traditionally defined only serves a small segment of dying patients. Patients might not value autonomy or consider autonomy important but define it differently than decision-making self-determination. Some patients also think in terms of their care goals rather than individual treatment preferences. Patients' functional and cognitive abilities, age, racial and ethnic backgrounds, and desire to avoid burdening loved ones may influence attitudes and definitions regarding autonomy. To improve end-of-life decision-making for an increasingly multicultural and aging population, the following priorities should be set: (1) Increase the flexibility of advance care planning and decision-making strategies used with capable patients to encompass diverse perceptions of autonomy; and (2) Improve communication between physicians and patients' families when patients lack decision-making capacity to facilitate decision-making and address families' emotional burdens. The goal of these priorities is to promote understanding of patients' and families' decision-making preferences and goals and to minimize decision-making burdens on families.
49. Cantor, M. D. and Pearlman, R. A. Advance care planning in long-term care facilities. *J Am Med Dir Assoc.* 2003 Mar-2003 Apr 30; 4(2):101-8.
Abstract: Residents of long-term care facilities are at risk of serious medical illnesses and being

unable to express choices when difficult treatment decisions must be made. Advance care planning (ACP) allows residents to consider, make, and communicate their preferences for how medical decisions should be made if they are unable to participate in the decision-making process. This article reviews the three steps in ACP: consideration of options and expression of values, communication of decisions, and documentation of the choices. The article defines and describes the particular value of ACP in long-term care facilities, reviews the literature on successful ACP programs in long-term care, and concludes with practical suggestions on how to develop and implement ACP programs.

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Abstract: Residents of long-term care facilities are at risk of serious medical illnesses and being unable to express choices when difficult treatment decisions must be made. Advance care planning (ACP) allows residents to consider, make, and communicate their preferences for how medical decisions should be made if they are unable to participate in the decision-making process. This article reviews the three steps in ACP: consideration of options and expression of values, communication of decisions, and documentation of the choices. The article defines and describes the particular value of ACP in long-term care facilities, reviews the literature on successful ACP programs in long-term care, and concludes with practical suggestions on how to develop and implement ACP programs.
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52. Oliver, D. P.; Porock, D., and Zweig, S. End-of-life care in U.S. nursing homes: a review of the evidence. *J Am Med Dir Assoc.* 2004 May-2004 Jun 30; 5(3):147-55.
Abstract: OBJECTIVES: The purpose of this study was to systematically review the empiric evidence on end-of-life care in nursing homes in the United States The guiding research question for this review was what is the state of research evidence in end-of-life care in long-term care? DESIGN: We conducted a systematic review of the literature. Data: The review was limited to published and indexed research in peer-reviewed journals in five major databases between 1995 and October 2002. RESULTS: The initial search yielded a total of 395 articles. The search was narrowed, focusing on nursing homes in the United States and empiric research. The result was 43 articles related to research in end-of-life care in American nursing homes. It was categorized into eight foci: prognosis, pain, hospice, hospitalization, advanced care planning, communication, family perceptions, and miscellaneous. CONCLUSION: There is a dearth of research published in end-of-life care in the nursing home setting. What is available is primarily descriptive. The empiric research only documents poor end-of-life care in U.S. nursing homes. Empiric evidence has grown in this area, but there is now a need for research of creative and innovative solutions aimed at improving the quality of end-of-life care in this setting.
53. Berger, J. T. Patients' interests in their family members' well-being: an overlooked, fundamental consideration within substituted judgments. *J Clin Ethics.* 2005 Spring; 16(1):3-10.
54. Patel, R. V.; Sinuff, T., and Cook, D. J. Influencing advance directive completion rates in non-terminally ill patients: a systematic review. *J Crit Care.* 2004 Mar; 19(1):1-9.
Abstract: PURPOSE: To conduct a systematic review of educational advance care planning interventions directed at patients without terminal illness to determine their influence on the completion rate of advance directives (AD). MATERIALS AND METHODS: We searched MEDLINE; Cochrane Library, and reference lists of all pertinent retrieved articles for randomized trials (RCTs), restricted to English language and adults > or =18 years. Two investigators independently and in duplicate determined trial eligibility. We included published RCTs evaluating an educational intervention comprised of at least one of; written, audio, or video materials, or direct counseling, and if an outcome included AD completion rate. RESULTS: Nine RCTs (N=3,206) were included. Overall, methodologic quality and reporting transparency were poor. The median composite quality score was 5 (range, 0-10). The odds ratios for AD completion rates ranged from

0.41 to 106.0 across the trials (test of heterogeneity $P < .001$). The summary odds ratio for these educational interventions was 3.71 (95% C.I. 1.46, 9.40). Trials with greater methodologic rigor and reporting transparency produced a more conservative estimate of effect, 2.42 [0.96, 6.10] versus 28.69 [5.08, 162.06] for less rigorous and poorly reported trials ($P = .013$). **CONCLUSIONS:** Advance directive completion rates documenting patient preferences for end-of-life care may be increased by simple patient-directed educational interventions.

55. Phipps, E. J.; True, G., and Murray, G. F. Community perspectives on advance care planning: report from the Community Ethics Program. *J Cult Divers*. 2003 Winter; 10(4):118-23.
Abstract: The objectives of the Community Ethics Program are to increase community awareness about advance care planning to address patient preferences concerning future care, and to improve hospital-community collaboration around care at end of life in diverse communities. As part of this educational program, community forums and focus groups were held with African-American, Korean-American, and Latino communities in Philadelphia between 2000 and 2001. In this paper, we discuss concerns related to end of life and advance care planning specific to each community, as well as themes that cut across communities. Increasing our understanding of community views and perspectives on potential barriers to advance care planning, particularly through a hospital-community partnership, is an important step toward enhancing the quality of end of life care for all patients.
56. Pauls, M. A.; Singer, P. A., and Dubinsky, I. Communicating advance directives from long-term care facilities to emergency departments. *J Emerg Med*. 2001 Jul; 21(1):83-9.
Abstract: Many residents of long-term care (LTC) facilities are transferred to Emergency Departments without advance directives (AD). The goal of this study was to describe an ideal model for the transfer of AD from LTC facilities to Emergency Departments. Health care providers were asked to describe their ideal model for the completion and transfer of the ADs of LTC residents. A grounded theory methodology was used to identify significant themes. The model we present as a result of this analysis acknowledges the importance of simplifying and standardizing ADs, but focuses more attention on the process of completing and transferring the AD. A key feature of this model is an emphasis on the education of LTC residents and their relatives about ADs and advance-care planning. This education should involve a variety of resources used in creative ways; it should begin as soon as LTC placement is being considered, and the emphasis should be on providing information and discussing options rather than pressuring residents to make a decision.
57. Perkins, H. S.; Geppert, C. M.; Gonzales, A.; Cortez, J. D., and Hazuda, H. P. Cross-cultural similarities and differences in attitudes about advance care planning. *J Gen Intern Med*. 2002 Jan; 17(1):48-57.
Abstract: **OBJECTIVE:** Culture may have an important impact on a patient's decision whether to perform advance care planning. But the cultural attitudes influencing such decisions are poorly defined. This hypothesis-generating study begins to characterize those attitudes in 3 American ethnic cultures. **DESIGN:** Structured, open-ended interviews with blinded content analysis. **SETTING:** Two general medicine wards in San Antonio, Texas. **PATIENTS:** Purposive sampling of 26 Mexican-American, 18 Euro-American, and 14 African-American inpatients. **MEASUREMENTS AND MAIN RESULTS:** The 3 groups shared some views, potentially reflecting elements of an American core culture. For example, majorities of all groups believed "the patient deserves a say in treatment," and "advance directives (ADs) improve the chances a patient's wishes will be followed." But the groups differed on other themes, likely reflecting specific ethnic cultures. For example, most Mexican Americans believed "the health system controls treatment," trusted the system "to serve patients well," believed ADs "help staff know or implement a patient's wishes," and wanted "to die when treatment is futile." Few Euro Americans believed "the system controls treatment," but most trusted the system "to serve patients well," had particular wishes about life support, other care, and acceptable outcomes, and believed ADs "help staff know or implement a patient's wishes." Most African Americans believed "the health system controls treatment," few trusted the system "to serve patients well," and most believed they should "wait until very sick to express treatment wishes." **CONCLUSION:** While grounded in values that may compose part of American core culture, advance care planning may need tailoring to a patient's specific ethnic views.

58. Kolarik, R. C.; Arnold, R. M.; Fischer, G. S., and Hanusa, B. H. Advance care planning. *J Gen Intern Med.* 2002 Aug; 17(8):618-24.
Abstract: **BACKGROUND:** Advance directives (AD) with specific treatment preferences can be difficult to apply in actual clinical situations. As an alternative, advance directives that outline patient goals and values have been advocated. **OBJECTIVE:** To compare patient reactions to values-based and treatment-based advance directive forms. **SETTING:** Two academic general medicine outpatient clinics in Pittsburgh, Pa. **METHODS:** Outpatients age 55 or older who did not have an AD and were not demented were randomly assigned to complete either Emanuel's Medical Directive (EMD) or Pearlman's values history (PVH) form. **MEASUREMENTS:** Length of time to complete and number of questions asked about the AD forms; proportions of patients discussing the AD with family, designating a surrogate, returning the AD by mail, and desiring to have the AD in the medical record; patient ratings of AD by telephone interview; physician report of patient-initiated AD discussions. **RESULTS:** Of the 275 patients approached, 143 refused, 69 already had an AD, 63 patients were enrolled, and 25 in each group completed the telephone interview. A majority of individuals in both groups had conversations with others about the AD (60% EMD, 56% PVH; $P = .77$). All PVH forms designated a surrogate, whereas 79% of EMD forms did so ($P = .02$). One patient in each group initiated a conversation with his or her physician about AD following study completion. Both forms were thought to be a good first step in planning care at the end of life (92% EMD vs 84% PVH totally or mostly agree; $P = .06$). Patients completing the EMD thought it would give them control over the way their doctor cared for them at the end of their lives more than did the PVH group (84% EMD vs 48% PVH totally or mostly agree; $P = .02$). More patients completing the EMD form worried that it would be difficult to change answers on the form if they later changed their minds (20% EMD vs 4% PVH totally or mostly agree; $P = .02$). **CONCLUSIONS:** Both the values-based and treatment-based AD forms were rated favorably overall. Patients thought the treatment-based directive would give them more control over their care. Patients completing the values history form were more likely to designate a surrogate. Patients are likely to discuss both types of AD with family, but neither form alone is likely to lead to AD conversations with physicians.
59. Medvene, L. J.; Wescott, J. V.; Huckstadt, A.; Ludlum, J.; Langel, S.; Mick, K.; Patrick, R., and Base, M. Promoting signing of advance directives in faith communities. *J Gen Intern Med.* 2003 Nov; 18(11):914-20.
Abstract: **OBJECTIVE:** To develop a participatory educational program implemented in faith communities that would increase discussion and signing of two types of advance directives—living will and durable power of attorney for health care decisions. **DESIGN:** Longitudinal study with four annual cycles of program implementation, evaluation, and revision incorporating a program that fostered the discussion, signing, and/or revision of advance directives. The program involved an educational workbook and ongoing support by parish nurses. **SETTING:** Seventeen faith communities in Wichita, Kansas. Faith communities included several predominantly white congregations, as well as several primarily African-American and Hispanic congregations. **PARTICIPANTS:** Seventeen faith communities, their pastors, and 25 parish nurses worked with 361 self-selected residents, living in community settings, to participate in the program as members of their faith communities. Congregations were recruited by the executive director of a local interfaith ministries organization and parish nurses. **MAIN RESULTS:** Two hundred forty-eight (69%) of the congregants who started the program completed it. Of the program completers, 83 (33%) had a directive prior to the program and 140 (56%) had a directive after completion. One hundred eighty-six of the completers discussed directives with family members. Overall, 89 (36%) of the 248 program completers revised an existing directive or signed one for the first time. Age was positively related to having signed/revised a directive prior to the program. Fear that advance directives would be used to deny medical care was negatively related to signing both prior to the program and after program completion, and contributed to participants' reluctance to sign directives. **CONCLUSIONS:** Educational programs implemented by parish nurses in faith communities can be effective in increasing rates of discussion, revision, and/or signing of advance directives.
60. Wissow, L. S.; Belote, A.; Kramer, W.; Compton-Phillips, A.; Kritzer, R., and Weiner, J. P. Promoting advance directives among elderly primary care patients. *J Gen Intern Med.* 2004 Sep; 19(9):944-51.

Abstract: OBJECTIVE: To determine efficient ways of promoting advance directives among heterogeneous populations of elderly ambulatory patients. DESIGN: One-year quasi-experimental trial. SETTING: Five suburban and urban health centers in one region of a large managed care organization. One additional suburban center served as a control site. PARTICIPANTS: Individuals ages 65 and older (N= 2,120) who were continuously enrolled and had a health maintenance visit with their primary care provider during the study year. INTERVENTION: Physician education (oral and written) and physician and patient prompts to discuss advance directives. MAIN RESULTS: Sixty-six (7.8%) of patients at the intervention centers completed new advance directives, versus 9 of 1,277 (<1%) at the comparison center (P <.001). Patients 75 and older were twice as likely (odds ratio [OR], 2.0; 95% confidence limits [CL], 1.2 to 3.3) as those 65 to 74 to file a new advance directive, and the odds were twice as great (OR, 2.6; 95% CL, 1.4 to 4.6) at centers serving communities with median household income over the state median. Gender, recent hospitalization, emergency room visits, and number of chronic conditions were not related to making new directives nor was predominant ethnicity of the center community (African-American versus white). Adjusted for these factors, the intervention resulted in a 20-fold increase (95% CL, 10.4 to 47.8) in the odds of creating a new advance directive. Doctors reported barriers of time and unwillingness to press discussions with patients. CONCLUSIONS: A replicable intervention largely targeting doctors achieved a modest increase in advance directives among elderly ambulatory patients. Future interventions may need to target lower-income patients, "younger" elderly, and more specifically address doctors' attitudes and comfort discussing advance directives.

61. Meyers, J. L.; Moore, C.; McGrory, A.; Sparr, J., and Ahern, M. Physician orders for life-sustaining treatment form: honoring end-of-life directives for nursing home residents. *J Gerontol Nurs.* 2004 Sep; 30(9):37-46.

Abstract: Physician Orders for Life-Sustaining Treatment (POLST) form provides choices about end-of-life care and gives these choices the power of physician orders. The POLST form assures end-of-life choices can be implemented in all settings, from the home through the health-care continuum. The use of the POLST form was evaluated in a pilot study in nursing homes in two eastern Washington counties. Chart reviews and template analysis of interviews revealed the POLST form accurately conveyed end-of-life wishes in 19 of 21 cases. An informed consent process was evidenced in 16 of 21 cases, and the POLST form was congruent with residents' existing advance directives for health care. The findings support the continued use, development, and evaluation of this promising tool for improving end-of-life care.

62. Nolde, D. The New York State Health Care Proxy Law and the issue of artificial hydration and nutrition. *J N Y State Nurses Assoc.* 2003 Fall-2004 Winter; 34(2):22-7.

Abstract: The New York State Health Care Proxy (HCP) Law allows a surrogate to make medical decisions for an individual when he or she loses the capacity to make them. In the area of artificial hydration and nutrition, however, this law dictates that if the agent is not aware of the patient's wishes regarding hydration and nutrition, the agent cannot decide about this treatment.

63. Fins, J. J.; Maltby, B. S.; Friedmann, E.; Greene, M. G.; Norris, K.; Adelman, R., and Byock, I. Contracts, covenants and advance care planning: an empirical study of the moral obligations of patient and proxy. *J Pain Symptom Manage.* 2005 Jan; 29(1):55-68.

Abstract: Previously we had speculated that the patient-proxy relationship existed on a contractual to covenantal continuum. In order to assess this hypothesis, and to better understand the moral obligations of the patient-proxy relationship, we surveyed 50 patient-proxy pairs as well as 52 individuals who had acted as proxies for someone who had died. Using structured vignettes representative of three distinct disease trajectories (cancer, acute stroke, and congestive heart failure), we assessed whether respondents believed that proxies should follow explicit instructions regarding life-sustaining therapy and act contractually or whether more discretionary or covenantal judgments were ethically permissible. Additional variables included the valence of initial patient instructions--for example, "to do nothing" or "to do everything"--as well as the quality of information available to the proxy. Responses were graded on a contractual to covenantal continuum using a modified Likert scale employing a prospectively scored survey instrument. Our data indicate that the patient-proxy relationship exists on a contractual to covenantal continuum and that variables

such as disease trajectory, the clarity of prognosis, instructional valence, and the quality of patient instructions result in statistically significant differences in response. The use of interpretative or covenantal judgment was desired by patients and proxies when the prognosis was grim, even if initial instructions were to pursue more aggressive care. Nonetheless, there was a valence effect: patients and proxies intended that negative instructions to be left alone be heeded. These data suggest that the delegation of patient self-determination is morally complex. Advance care planning should take into account both the exercise of autonomy and the interpretative burdens assumed by the proxy. Patients and proxies think inductively and contextually. Neither group viewed deviation from patient instructions as a violation of the principal's autonomy. Instead of adhering to narrow notions of patient self-determination, respondents made nuanced and contextually informed moral judgments. These findings have implications for patient education as well as the legal norms that guide advance care planning.

64. Hines, S. C.; Glover, J. J.; Babrow, A. S.; Holley, J. L.; Badzek, L. A., and Moss, A. H. Improving advance care planning by accommodating family preferences. *J Palliat Med.* 2001 Winter; 4(4):481-9.
Abstract: CONTEXT: Family members often lack the knowledge of patients' values and preferences needed to function well as surrogate decision-makers. OBJECTIVE: To determine whether differences in values and preferences for the advance care planning process may be reasons family members are inadequately informed to act as surrogates. DESIGN: Face-to-face and telephone surveys using structured questionnaires. PARTICIPANTS: Two hundred forty-two pairs of dialysis patients and their designated surrogates. MAIN OUTCOME MEASURES: Content and number of end-of-life care discussions; patient and surrogate attitudes toward having patients express preferences explicitly; factors most important to surrogates in decision making; and within-pair agreement about the values of suffering and certainty. RESULTS: Ninety percent of patients designated a family member as their surrogate. In most cases, having more conversations about end-of-life issues did not increase surrogate knowledge of patients' values or preferences. Surrogates wanted written and oral instructions more often than patients wanted to provide them (62% vs. 39%, $p < 0.001$). Knowing the patient's wish to stop treatment in the present condition was more important to most surrogates than the physician's recommendation to stop treatment (62% vs. 45%, $p < 0.001$). Compared to patients, surrogates were less likely to want to prolong the patient's life if it entailed suffering (12% vs. 23%, $p < 0.01$) and were more concerned about being certain before stopping life-sustaining treatments (85% vs. 77%, $p < 0.02$). CONCLUSIONS: Differences in preferences for the advance care planning process between patients and their surrogates and failure to discuss specific end-of-life values and preferences may explain why surrogates often lack information needed to serve as surrogate decision-makers.
65. Hammes, B. J. What does it take to help adults successfully plan for future medical decisions? *J Palliat Med.* 2001 Winter; 4(4):453-6.
66. Tolle, S. W. and Tilden, V. P. Changing end-of-life planning: the Oregon experience. *J Palliat Med.* 2002 Apr; 5(2):311-7.
Abstract: Large state-by-state variations exist in location of dying and level of aggressive treatment during the final phase of life. This paper describes Oregon's incremental gains toward improving advance planning for end-of-life care in a state with the lowest rate of in-hospital deaths. Action strategies have required data gathering and reporting, and coalition building with a focus on systems change. Also, public education through the news media has proved to be a vital component of Oregon's process of change. The impact of media coverage is complemented by continuing education for health professionals. Special efforts are still needed to improve access to the Physician's Orders for Life-Sustaining Treatment program (POLST) for some rural, minority, and pediatric populations and for persons living at home with a diagnosis other than cancer. However, with enough time, a sustained effort, and a broad coalition of partners, profound change is possible.
67. Kolarik, R. C.; Arnold, R. M.; Fischer, G. S., and Tulsky, J. A. Objectives for advance care planning. *J Palliat Med.* 2002 Oct; 5(5):697-704.
Abstract: Identifying objectives for advance care planning (ACP) is an important step toward improving care at the end of life. Previous studies of ACP have used many different measures of

success. However, there has been no consensus on what should be the objectives for ACP. Lack of attention to specific objectives for ACP may lead to ineffective communication and research. The first step to improving outcomes in ACP is to acknowledge the diversity of objectives that ACP may achieve. Health care providers, patients, and surrogates should identify and agree on common objectives for particular conversations. Various methods, conversations, and forms may be used to achieve these objectives over time. Clarifying objectives from various perspectives is an important step toward achieving the level of understanding necessary to make these difficult decisions. It is time for physicians to reconsider the way in which they think about and discuss ACP with patients. If we are to improve care at the end of life, future patient care, research, and education about ACP should proceed with specific objectives in mind.

68. Parker-Oliver, D.; Porock, D.; Zweig, S.; Rantz, M., and Petroski, G. F. Hospice and nonhospice nursing home residents. *J Palliat Med.* 2003 Feb; 6(1):69-75.
Abstract: OBJECTIVE: To compare hospice residents in nursing homes with residents who are noted as end-stage, but not in hospice programs. DESIGN: Descriptive comparison of the outcomes reported on Minimum Data Set (MDS) for all residents admitted to Missouri nursing homes in 1999. SETTING: Nursing homes. PARTICIPANTS: Residents of nursing homes designated as either hospice or end-stage on admission MDS. MEASUREMENTS: Percentage of hospice residents having various conditions as compared with other end-stage residents. RESULTS/CONCLUSIONS: Overall the clinical conditions of both hospice and nonhospice end-stage residents were similar. A greater percentage of hospice residents were found to have living wills, DNR orders, and cancer, and to be in moderate or severe pain. Hospice and nonhospice residents experienced similar time from admission to death or discharge (20 and 36 days, respectively). Based on the clinical condition of the two groups, it would appear that there are limited clinical reasons for the low utilization of the hospice benefit in nursing homes. The increased prevalence of advance care planning may lead toward use of hospice or may result from hospice enrollment. Hospice services seem to be thought of more frequently for residents with cancer and residents experiencing pain. Nursing homes must recognize their role as caregivers to the dying before palliative care is seen as a need for nursing home residents. Nursing homes need education in determining when a patient is appropriate for palliative care as only 4% are designated as end of life, and only 2% are shown to be receiving hospice care in hospice-contracted facilities.
69. Bricker, L. J.; Lambing, A., and Markey, C. Enhancing communication for end-of-life care: an electronic advance directive process. *J Palliat Med.* 2003 Jun; 6(3):511-9.
Abstract: An advance directive, a description of one's future preferences for medical treatment, must be easily available to care providers to ensure that one's treatment preferences are honored. The transition of our health care system to an electronic medical record complicated the availability of a patient's written advance directive. This paper describes the development of an electronic advance directive to facilitate access to a patient's treatment wishes at any site in our health care system. The successes and challenges encountered in the development process are discussed.
70. Stuart, B.; D'Onofrio, C. N.; Boatman, S., and Feigelman, G. CHOICES: promoting early access to end-of-life care through home-based transition management. *J Palliat Med.* 2003 Aug; 6(4):671-83.
Abstract: CHOICES is a comprehensive home-based care coordination program designed to bridge the gap between home health and hospice for Medicare + Choice enrollees with advanced chronic illness in San Francisco's East Bay region. Key elements of the program include physician education, enrollment of patients with high disease burden who may not be terminally ill, co-management of care with the primary physician, and an advanced practice clinical team that provides comprehensive in-home assessments, a flexible mix of life-prolonging and palliative care that evolves with disease progression, focused education and advance planning, and caregiver support. During a 42-month demonstration, 208 patients were enrolled in the program. Eighty percent had a non-cancer diagnosis; 40% were people of color. After an 8-month follow-up, 44% of the study cohort had died in the program or after transfer to hospice, 51% had been discharged, and 5% remained active. Median length of stay for decedents was 260 days. Preliminary evidence supports the program's feasibility and acceptability to patients, families, physicians, and agency partners. However, the uncertain future of Medicare + Choice and of managed care may jeopardize

the program's sustainability. Policymakers and taxpayers will need to determine how to care for the growing number of chronically ill elderly who wish to remain at home as illness advances. The care needs of these patients and their families may overwhelm a health system organized around hospital treatment of acute illness.

71. Gillick, M. R. Adapting advance medical planning for the nursing home. *J Palliat Med.* 2004 Apr; 7(2):357-61.
72. Maltby, B. S. and Fins, J. J. Informing the patient-proxy covenant: an educational approach for advance care planning. *J Palliat Med.* 2004 Apr; 7(2):351-5.
73. Briggs, L. Shifting the focus of advance care planning: using an in-depth interview to build and strengthen relationships. *J Palliat Med.* 2004 Apr; 7(2):341-9.
74. Romer, A. L. and Hammes, B. J. Communication, trust, and making choices: advance care planning four years on. *J Palliat Med.* 2004 Apr; 7(2):335-40.
75. Schwartz, C. E.; Merriman, M. P.; Reed, G. W., and Hammes, B. J. Measuring patient treatment preferences in end-of-life care research: applications for advance care planning interventions and response shift research. *J Palliat Med.* 2004 Apr; 7(2):233-45.
Abstract: Understanding the dynamics of patient treatment preferences can be important for end-of-life care research, and has particular salience not only to guide a process of advance care planning (ACP) but also as an outcome measure. Ascertaining the reliability and responsiveness of preferences for life-sustaining treatments within and between patients is a necessary foundation for utilizing patient-agent congruence as an outcome for ACP interventions. This study validated a modified version of the Emanuel and Emanuel Medical Directive for use in both research and clinical applications. Seriously ill patients (n = 168) were asked at baseline and 21 days to consider four common end-of-life health state scenarios, to indicate their goals for treatment, and to state their preferences for six specific treatments. We investigated the reliability and validity of this tool. We found that preferences for life-sustaining treatments were highly intercorrelated, and internally consistent across treatments by scenario and across scenarios by treatment. Preferences for pain medications were, however, distinct from preferences for other treatments. Preference scores exhibited stability over follow-up, and demonstrated both concurrent and discriminant validity. We detected a small effect size for change in preferences as a function of health state change, suggesting that re-prioritization response shifts do occur but are small in magnitude in these patient samples over this time frame. We conclude that this measure is reliable and valid for use in clinical settings and for evaluating interventions designed to improve patient-agent congruence about patient preferences for life-sustaining treatments. Clinical applications of the tool are discussed.
76. Buchanan, R. J.; Choi, M.; Wang, S., and Ju, H. End-of-life care in nursing homes: residents in hospice compared to other end-stage residents. *J Palliat Med.* 2004 Apr; 7(2):221-32.
Abstract: OBJECTIVE: To compare residents in hospice care at admission to the nursing facility to end stage residents not in hospice at admission. DESIGN AND METHODS: We analyzed 18,211 admission assessments recorded in the Minimum Data Set (MDS) during the year 2000 throughout the United States for residents classified as having an end-stage disease (6 or fewer months to live). Fifty-nine percent (n = 10,656) of these residents were in hospice care at the time of their admission assessment. We used these MDS admission assessments to compare residents in hospice care to other end-stage residents not in hospice for demographic characteristics, health status, and treatments. RESULTS: Hospice residents at admission were significantly more likely to be female, older, white, and widowed than other end-stage residents at admission. There were significant differences between hospice residents and other residents at end stage in the use of advanced directives at admission. Hospice residents at admission experienced significantly more frequent and more intense pain than other end-stage residents at admission, while these hospice residents also showed greater impairment in cognitive ability and physical function. While cancer was the most common disease among these end-stage residents, it was significantly more prevalent among hospice residents. IMPLICATIONS: Many end-stage residents may not be receiving adequate palliative care

in nursing facilities; further study of this is warranted. The MDS should be revised to record minimum standards for palliative care with or without the use of hospice to improve end-of life care in nursing facilities.

77. Weiner, J. S. and Cole, S. A. Three principles to improve clinician communication for advance care planning: overcoming emotional, cognitive, and skill barriers. *J Palliat Med.* 2004 Dec; 7(6):817-29.
Abstract: BACKGROUND: Medical care of patients with life limiting illness remains fraught with serious deficiencies, including inadequate advance care planning, delayed hospice referral, and continued delivery of aggressive treatment that is overtly counter to patients' preferences. OBJECTIVE: This paper describes clinicians' emotional, cognitive, and skill barriers to shared decision-making with seriously ill patients and their loved ones. DESIGN: Thematic literature review. RESULTS: Based on a literature review, as well as clinical and educational experience, we articulate three principles to address these barriers and guide future professional communication training for advance care planning. CONCLUSIONS: We argue that these barriers must be overcome before deficiencies in end-of-life care can be fully ameliorated.
78. Mitchell, S. L.; Morris, J. N.; Park, P. S., and Fries, B. E. Terminal care for persons with advanced dementia in the nursing home and home care settings. *J Palliat Med.* 2004 Dec; 7(6):808-16.
Abstract: BACKGROUND: Many older persons with advanced dementia receive terminal care in nursing homes, others remain in the community with home care services. OBJECTIVES: To describe and compare the end-of-life experience of persons dying with advanced dementia in the nursing home and home care settings. DESIGN: Retrospective cohort study. Setting/Subjects: Persons 65 years or older with advanced dementia who died within 1 year of admission to either a nursing home in Michigan between July 1, 1998 until December 31, 2000 (n = 2730), or the state's publicly funded home and community-based services from October 1, 1998 until December 31, 2001 (n = 290). MEASUREMENTS: Data were derived from the Minimum Data Set (MDS)-Nursing home Version 2.0 for the institutionalized sample, and the MDS-Home Care for the community-based sample. Variables from the MDS assessment completed within 180 days of death were used to describe the end-of-life experiences of these two groups. RESULTS: Nursing home residents dying with advanced dementia were older, had greater functional impairment, and more behavior problems compared to home care clients. Few subjects in the nursing home (10.3%) and home care (15.6%) cohorts were perceived to have less than 6 months to live. Only 5.7% of nursing home residents and 10.7% home care clients were referred to hospice. Hospitalizations were frequent: nursing home, 43.7%; home care, 31.5%. Pain and shortness of breath were common in both settings. End-of-life variables independently associated with nursing home versus home care included: hospice (adjusted odds ratio [AOR] 0.26, 95% confidence interval [CI], 0.16-0.43), life expectancy less than 6 months (AOR 0.31; 95% CI, 0.20-0.48), advance directives (AOR, 1.48; 95% CI, 1.11-1.96), pain (AOR, 0.38; 95% CI, 0.29-0.50), shortness of breath (AOR 0.20; 95% CI (0.13-0.28), and oxygen therapy (AOR, 2.47; 95% CI, 1.51-4.05). CONCLUSIONS: Persons dying with advanced dementia admitted to nursing homes have different characteristics compared to those admitted to home care services. Their end-of-life experiences also differ in these two sites of care. However, palliative care was not optimal in either setting.
79. Chong, K.; Olson, E. M.; Banc, T. E.; Cohen, S.; Anderson-Malico, R., and Penrod, J. D. Types and rate of implementation of palliative care team recommendations for care of hospitalized veterans. *J Palliat Med.* 2004 Dec; 7(6):784-90.
Abstract: BACKGROUND: Hospital-based interdisciplinary palliative care teams (PCTs) are increasingly being established to meet the growing demand for high quality care for patients with life-limiting illnesses in which the goal is comfort rather than cure. Two recent studies suggest that PCTs teams are highly effective in influencing care of patients within large academic medical centers. The current study examines whether the previously demonstrated success of palliative care teams within subspecialty academic health centers could be replicated in an urban Veterans Affairs medical center (VAMC). OBJECTIVE: To describe the characteristics of patients referred to, recommendations made by, and implementation rate of an interdisciplinary PCT in an urban VAMC. DESIGN: Retrospective, observational study. SETTING/SUBJECTS: One hundred patients referred by inpatient doctor to the PCT between October 1999 and March 2002 in a 214-bed VA hospital in

the New York City area. MEASUREMENTS: Patient demographics, prevalence of five types of recommendations by the PCT and implementation rate by primary physician: (1) advance directives; (2) discharge planning; (3) pain management; (4) symptom management of dyspnea, delirium, constipation, nausea, anxiety, and depression; and (5) consultation orders for other services. RESULTS: The average number of recommendations per patient was 2.84 and 84.2% were implemented. The most frequent recommendations concerned discharge plans. The reasons recommendations were not implemented included: (1) patient or family refusal noted in the medical record, (2) the patient's clinical status changed, including patient death, and (3) the attending physician chose a different dose, medication, or route of administration than was recommended. CONCLUSIONS: Overall, most recommendations were implemented by the referring physicians. This finding is consistent with several prior studies demonstrating that PCTs in acute care can and do influence processes of care for hospitalized patients. Well-designed observational studies and randomized controlled trials of specific palliative care interventions and their effect on patient, family, and health care system outcomes are needed.

80. Braun, K. L.; Zir, A.; Crocker, J., and Seely, M. R. Kokua Mau: a statewide effort to improve end-of-life care. *J Palliat Med.* 2005 Apr; 8(2):313-23.
Abstract: BACKGROUND: Many Americans die in pain, without hospice, and without regard to advance directives, suggesting a need to improve end-of-life (EOL) awareness and services. OBJECTIVE: This paper describes Kokua Mau, a community-state partnership to improve EOL in Hawaii funded by The Robert Wood Johnson Foundation (RWJF). Coalition activities were guided by innovation-diffusion theory, targeting "innovators" and "change agents" within communities and organizations willing to learn about and facilitate improvements to EOL care. DESIGN: Evaluation of a community-wide intervention to improve EOL care. SETTING/SUBJECTS: Honolulu, Hawaii. MEASUREMENTS: We tracked dissemination of campaign messages by counting numbers of coalition members (including innovators and change agents to carry on the work), individuals reached through awareness and educational offerings, and new EOL projects initiated during and after the initial 3-year RWJF funding. To measure change, we counted the number of legislative policies that were modified by the coalition as well as indicators of hospice utilization, advance directive (AD) completion, support for physician-assisted death, and place of death. RESULTS: In the first 3 years of the project: coalition membership grew to 350 members; EOL care curricula were developed and offered to various target audiences; 17,000 individuals attended educational events; policy changes were facilitated; decreases were seen in proportions of residents supporting physician-assisted suicide; and increases were seen in advance directive completion rates and hospice utilization. Most importantly, after the grant period, coalition members went on to develop and implement new programs to improve care to the dying. CONCLUSIONS: Although it will take several years to effect comprehensive and sustained changes in the way death is perceived and the dying process is facilitated, findings suggest that programs based on innovation-diffusion theory can increase EOL awareness and help develop the change agents and role models needed to affect community-wide change over the long term.
81. Briggs, L. A.; Kirchoff, K. T.; Hammes, B. J.; Song, M. K., and Colvin, E. R. Patient-centered advance care planning in special patient populations: a pilot study. *J Prof Nurs.* 2004 Jan-2004 Feb 28; 20(1):47-58.
Abstract: The purpose of this study was to assess the feasibility of a patient-centered advance care planning (PC-ACP) approach to patients with chronic illnesses and their surrogates with respect to promotion of shared decision-making outcomes-congruence between patient and surrogate, patient's decisional conflict, and knowledge of advance care planning. An experimental design was used. The settings were the heart failure, renal dialysis, and cardiovascular surgery clinics at Gundersen Lutheran Medical Center in La Crosse, WI. Twenty-seven patient-surrogate pairs participated. A 1-hour PC-ACP interview was provided to the experimental group. Only usual care was delivered to participants in the control group. Comparison of the composite scores of a Statement of Treatment Preferences indicated that congruence in decision-making for future medical treatment in patient-surrogate pairs in the treatment group was significantly higher than in the control group. Greater satisfaction with the decision-making process and less decisional conflict were demonstrated in the treatment group. The PC-ACP interview can be effective in promoting shared decision-making

between patients and their surrogates and in producing greater satisfaction with the process of decision-making and less decisional conflict.

82. Molloy, D. W.; Guyatt, G. H.; Russo, R.; Goeree, R.; O'Brien, B. J.; Bedard, M.; Willan, A.; Watson, J.; Patterson, C.; Harrison, C.; Standish, T.; Strang, D.; Darzins, P. J.; Smith, S., and Dubois, S. Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. *JAMA*. 2000 Mar 15; 283(11):1437-44.
Abstract: CONTEXT: Although advance directives are commonly used in the community, little is known about the effects of their systematic implementation. OBJECTIVES: To examine the effect of systematically implementing an advance directive in nursing homes on patient and family satisfaction with involvement in decision making and on health care costs. DESIGN: Randomized controlled trial conducted June 1, 1994, to August 31, 1998. SETTING AND PARTICIPANTS: A total of 1292 residents in 6 Ontario nursing homes with more than 100 residents each. INTERVENTION: The Let Me Decide advance directive program included educating staff in local hospitals and nursing homes, residents, and families about advance directives and offering competent residents or next-of-kin of mentally incompetent residents an advance directive that provided a range of health care choices for life-threatening illness, cardiac arrest, and nutrition. The 6 nursing homes were pair-matched on key characteristics, and 1 home per pair was randomized to take part in the program. Control nursing homes continued with prior policies concerning advance directives. MAIN OUTCOME MEASURES: Residents' and families' satisfaction with health care and health care services utilization over 18 months, compared between intervention and control nursing homes. RESULTS: Of 527 participating residents in intervention nursing homes, 49% of competent residents and 78% of families of incompetent residents completed advance directives. Satisfaction was not significantly different in intervention and control nursing homes. The mean difference (scale, 1-7) between intervention and control homes was -0.16 (95 % confidence interval [CI], -0.41 to 0.10) for competent residents and 0.07 (95% CI, -0.08 to 0.23) for families of incompetent residents. Intervention nursing homes reported fewer hospitalizations per resident (mean, 0.27 vs 0.48; $P = .001$) and less resource use (average total cost per patient, Can \$3490 vs Can \$5239; $P = .01$) than control nursing homes. Proportion of deaths in intervention (24%) and control (28%) nursing homes were similar ($P = .20$). CONCLUSION: Our data suggest that systematic implementation of a program to increase use of advance directives reduces health care services utilization without affecting satisfaction or mortality.
83. Pantilat, S. Z. and Steimle, A. E. Palliative care for patients with heart failure. *JAMA*. 2004 May 26; 291(20):2476-82.
Abstract: Heart failure accounts for more hospitalizations among Medicare beneficiaries than any other condition. Its symptoms, including shortness of breath, fatigue, and edema, can be frightening and diminish quality of life. Although treatment advances have allowed patients to live longer with a better quality of life, heart failure remains a leading cause of death in the United States. Half of heart failure patients die within 5 years of diagnosis, and for many patients, death is sudden. Given the availability of effective treatments, the prevalence of distressing symptoms, and a persistent high risk of death that may occur suddenly, physicians must simultaneously treat the underlying condition while helping patients plan for future needs and complete advance directives. Using the case of Mr R, a 74-year-old man with heart failure, we illustrate ways that physicians can address these issues to improve the care of patients with heart failure, including symptom management and discussing advance directives, prognosis, and hospice care. By combining optimal medical management with palliative care, physicians can best care for heart failure patients and their families.
84. Weissman, D. E. Decision making at a time of crisis near the end of life. *JAMA*. 2004 Oct 13; 292(14):1738-43.
Abstract: As patients approach the end of life, their disease process may create an immediate life-threatening emergency, yet invasive interventions may be less likely to provide benefit while carrying the same or greater risks. Knowing when it is time to shift from life-prolonging to more palliative approaches, focused on quality of life and comfort, is emotionally and clinically challenging for patients, families, and physicians. Key factors in the decision process include prognosis, risk-benefit analysis of the proposed intervention, current symptom burden, temporal

pattern of the illness, patient's age and life stage, and the patient's goals of care. A structured approach to decision making includes assessing the patient's physical, psychological, and spiritual needs; assessing the patient's support system; discussing prognosis; and assessing patient-specific goals. Physicians can best help patients decide which treatments are appropriate by taking the necessary time to explore all curative and palliative care options, providing honest and timely prognostic information, making clear recommendations, facilitating patient-family discussions, and affirming patient choices.

85. Tulskey, J. A. Beyond advance directives: importance of communication skills at the end of life. *JAMA*. 2005 Jul 20; 294(3):359-65.
Abstract: Patients and their families struggle with myriad choices concerning medical treatments that frequently precede death. Advance directives have been proposed as a tool to facilitate end-of-life decision making, yet frequently fail to achieve this goal. In the context of the case of a man with metastatic cancer for whom an advance directive was unable to prevent a traumatic death, I review the challenges in creating and implementing advance directives, discuss factors that can affect clear decision making; including trust, uncertainty, emotion, hope, and the presence of multiple medical providers; and offer practical suggestions for physicians. Advance care planning remains a useful tool for approaching conversations with patients about the end of life. However, such planning should occur within a framework that emphasizes responding to patient and family emotions and focuses more on goals for care and less on specific treatments.
86. Guglielmo, W. J. How to discuss end-of-life care. Here's a guide to making advance care planning a part of your practice. *Med Econ*. 2004 Apr 9; 81(7):27-30.
87. Welie, J. V. Living wills and substituted judgments: a critical analysis. *Med Health Care Philos*. 2001; 4(2):169-83.
Abstract: In the literature three mechanisms are commonly distinguished to make decisions about the care of incompetent patients: A living will, a substituted judgment by a surrogate (who may or may not hold the "power of attorney"), and a best interest judgment. Almost universally, the third mechanism is deemed the worst possible of the three, to be invoked only when the former two are unavailable. In this article, I argue in favor of best interest judgments. The ever more common aversion of best interest judgments entails a risk that health care providers withdraw from the decision-making process, abandoning patients (or their family members) to these most difficult of decisions about life and death. My approach in this article is primarily negative, that is, I criticize the alleged superiority of the living will and substituted judgment. The latter two mechanisms gain their alleged superiority because they are supposedly morally neutral, whereas the best interest judgment entails a value judgment on behalf of the patient. I argue that on closer inspection living wills and substituted judgments are not morally neutral; indeed, they generally rely on best interest judgments, even if those are not made explicit.
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Abstract: Three-fourths of those who die in America are 65 or older. In all but the cases where death is sudden and unexpected, decisions frequently must be made about whether to limit treatment. In this paper, we provide a framework and specific tools that may help physicians in talking to older patients and their family members about end-of-life care. After briefly reviewing the demography of dying and methods of advance care planning, we propose a four-step process for deciding about end-of-life care: 1. Identifying patient preferences. 2. Communicating about medical prognosis. 3. Defining goals of care. 4. Implementing a management plan consistent with those goals. The paper concludes with special considerations about four common experiences of dying as an older person: chronic diseases with acute exacerbations (e.g. congestive heart failure or chronic obstructive lung disease), cancer, end stage dementia, and unexpected catastrophic decline.
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91. Gillick, M. R. Advance care planning. *N Engl J Med.* 2004 Jan 1; 350(1):7-8.
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93. Hanchett, J. M. Advance care planning. *N Engl J Med.* 2004 Apr 1; 350(14):1470-1; author reply 1470-1.
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 Abstract: The substituted judgement principle is often recommended as a means of promoting the self-determination of an incompetent individual when proxy decision makers are faced with having to make decisions about health care. This article represents a critical ethical analysis of this decision-making principle and describes practical impediments that serve to undermine its fundamental purpose. These impediments predominantly stem from the informality associated with the application of the substituted judgement principle. It is recommended that the principles upon which decisions are made about health care for another person should be transparent to all those involved in the process. Furthermore, the substituted judgement principle requires greater rigour in its practical application than currently tends to be the case. It may be that this principle should be subsumed as a component of advance directives in order that it fulfils its aim of serving to respect the self-determination of incompetent individuals.
99. Salmond, S. W. and David, E. Attitudes toward advance directives and advance directive completion rates. *Orthop Nurs.* 2005 Mar-2005 Apr 30; 24(2):117-27; quiz 128-9.
 Abstract: **BACKGROUND:** The Patient Self-Determination Act (PSDA) (part of the) requires that all healthcare institutions receiving Medicare and Medicaid funds inform patients about their right to participate in healthcare decisions, including their right to have an advance directive. Advance directives (ADs) allow an individual to participate indirectly in future medical care decisions if he or she becomes decisionally incapacitated. Despite passage of this bill and mechanisms within most healthcare institutions to provide this information, the AD completion rate remains low. **PURPOSE:** The purpose of this study was to identify the significant attitudes and factors that influence the completion of ADs among adult hospitalized patients admitted to medical/surgical units. **DESIGN:** Descriptive correlational survey design. **METHODS:** A convenience sample of patients admitted to medical-surgical units during a 2-month period completed face-to-face interviews and completion of the Advance Directive Attitude Survey. **FINDINGS:** Eighty-two percent of the sample identified having received information on ADs, although hospital policy had it distributed to all patients on admission. Eighteen percent of the sample had completed an AD, and an additional 8% completed an AD after the interview and accompanying education during the interview for a 26% completion rate. The mean attitude toward ADs was slightly positive, and there was no difference in attitude score between those with an AD and those without. **IMPLICATIONS:** Low completion rates of ADs among the majority of the population and even lower among ethnically diverse individuals despite favorable attitudes toward ADs suggest that there are factors beyond access to information that may influence the decision not to complete an AD. Results of this study are congruent with other research

raising the question of whether ADs as currently designed are appropriate for all groups.

100. Buchanan, R. J.; Choi, M.; Wang, S., and Huang, C. Analyses of nursing home residents in hospice care using the minimum data set. *Palliat Med.* 2002 Nov; 16(6):465-80.
Abstract: OBJECTIVE: To present comprehensive profiles of residents in hospice care at admission to the nursing home using the Minimum Data Set (MDS). DESIGN AND SETTING: We analysed 40,622 MDS admission assessments for nursing home residents in hospice care. The MDS contains resident-focused data on pain, cognitive patterns, physical function, disease diagnoses, medications, nutrition, and specific treatments received. RESULTS: About four in five recently admitted hospice residents had 'do not resuscitate' orders and only 27% had a living will. Over 70% of recently admitted hospice residents experienced pain, with almost one half experiencing daily pain. Over one half of those hospice residents in pain experienced moderate pain and almost one third experienced horrible or excruciating pain. About 57% of recently admitted hospice patients had cancer, 21 % had congestive heart failure, 20% had emphysema/chronic obstructive pulmonary disease, and 18% had depression. About one in two recently admitted hospice residents exhibited at least moderate impairment in cognitive function. CONCLUSIONS: There is a need to improve pain management, advanced directives, and mental health services for residents dying in nursing homes.
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Abstract: BACKGROUND: Heart failure is increasing in prevalence and incidence, with considerable mortality among the elderly. AIM: To determine preferences concerning cardiopulmonary-resuscitation (CPR) and end-of-life care in elderly patients hospitalized for heart failure. DESIGN: Prospective interview-based survey. METHODS: Patients >64 years old admitted for acute heart failure were interviewed to address their preferences regarding end-of-life care and cardio-pulmonary resuscitation (CPR) when facing the last stages of their disease. RESULTS: We interviewed 80 patients (mean age 79 years; 58% women). Thirty-two (40%) expressed a wish not to have CPR. Only two had previously discussed their CPR preferences with their physicians. When recovery from the illness was considered unlikely, 40 (50%) participants preferred to receive treatment at home, 32 (40%) preferred in-hospital management, and 8 (10%) were unsure. Thirty-three patients (41%) expressed a desire for spiritual support, 38 (48%) said not and the remaining 9 (11%) were indifferent. DISCUSSION: Advance planning of end-of-life procedures and doctor-patient communication regarding these items remains poor and must be improved.
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Abstract: Proscriptive planning exercises are critical to and generally accepted as integral to health planning at varying scales. These require specific instruments designed to predict future actions on the basis of present knowledge. At the macro-level of health economics, for example, a number of future-oriented Quality of Life Instruments (QL) are commonly employed. At the level of individual decision making, on the other hand, Advance Directives (AD's) are advanced as a means by which healthy individuals can assure their wishes will be carried out if at some future point they are incapacitated. As proscriptive tools, both instrument classes appear to share an axiomatic set whose individual parts have not been rigorously considered. This paper attempts to first identify and then consider a set of five axioms underlying future oriented health planning instruments. These axioms are then critiqued using data from a pre-test survey designed specifically to address their assumptions. Results appear to challenge the validity of the axioms underlying the proscriptive planning instruments.
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Abstract: Advance directives (ADs) are documents that allow competent individuals to set forth their medical treatment wishes and/or to name a proxy in the event that they lose the capacity to communicate these decisions in the future. Despite the benefits of and support for such documents, very few people have completed an AD. This posttest-only experimental study examined whether an individualized intervention given to half of the older adults who attended an educational session

increased the discussion and/or completion of ADs. Of the 74 participants, 25.7% (n = 19) completed an AD. There were no significant differences between control and intervention groups on the discussion and/or completion of ADs. Multivariate analysis indicated that perceived barriers were significantly associated with the discussion and completion of ADs. Content analysis revealed that major barriers to discussion and completion include procrastination and a reluctance to think about deteriorating health status and/or death.

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Abstract: The purpose of this survey was to explore how adults communicate their end-of-life preferences. Face-to-face interviews were conducted with 119 community-dwelling adults who had previously engaged in conversations about their end-of-life preferences. Factors that made it easier to initiate the discussion included having personal experience with illness or death (24.4%), being straightforward (24.4%), or having someone else facilitate the discussion (11.8%). Most described vague end-of-life preferences such as not wanting any machines (41.2%) or heroics (34.5%). Although 22.7% reported using a living will to make their preferences clear, only 5.9% mentioned repeating or reinforcing their preferences. In all, 21% had discussed their end-of-life preferences with their physicians. These findings show discussions about end-of-life preferences frequently lack the clarity and detail needed by significant others and health care providers to honor the preferences. Routine dialogue with health care providers and significant others about end-of-life preferences might provide greater clarity and comfort.
105. Rich, B. A. Current legal status of advance directives in the United States. *Wien Klin Wochenschr.* 2004 Jul 15; 116(13):420-6.
Abstract: Advance directive legislation has been in place throughout much of the United States for nearly 3 decades. The right to give an informed consent to or refusal of medical treatment has been recognized by state and federal courts, and that right has been determined to survive the loss of decisional capacity and may be exercised through the execution of instructional or proxy directives. Despite these developments, the percentage of the adult population with a formal advance directive of any type has never exceeded 15%. Moreover, a remarkable number of these directives are ambiguous and/or their existence is unknown to the physicians who are expected to rely upon them. Even unambiguous directives may not be followed at the critical stage in the trajectory of a patient's illness, and the accountability for such disregard by health care institutions or professionals is negligible to nonexistent. Nevertheless, there is real potential for advance directives, as a key element to sound advance care planning, to fulfill their initial promise as instruments of the prospective autonomy of patients. In order for that potential to be realized, primary care physicians must embrace advance care planning as a part of their professional responsibility to patients.