Quality Indicators for End-of-Life Care in Vulnerable Elders

Neil S. Wenger, MD, and Kenneth Rosenfeld, MD

Care for vulnerable elders, many of whom may be near the end of life, has come under increasing scrutiny in the past decade. Studies demonstrate inadequate quality of care with regard to symptom control, matching of care with patient preferences, and optimal resource use at the end of life (1). Several expert panels have concluded that end-of-life care requires improvement (2-4). Their recommendations provide a framework for integrating patient preferences into treatment decisions and for delivering high-quality end-of-life care.

The Ethics Committee of the American Geriatrics Society identified areas for improving care at the end of life, including physical and emotional symptoms, support of function and autonomy, advance care planning, aggressiveness of care near death, and patient and family satisfaction (2). The Institute of Medicine Committee on Improving Care at the End of Life designated the following areas as needing improvement (3): overuse of care inconsistent with preferences and prognosis, underuse of care to treat symptoms, untimely referral to hospice, poor technical palliative care, and poor communication about prognosis and treatment preferences. Furthermore, in 1997 a New York State commission identified barriers to providing quality care to dying patients: inadequate professional and public education, legal and regulatory barriers, financial barriers, and underuse of hospice (4). While these panels did not explicitly call for development of measures of quality of end-of-life care, achieving their goals would require such measures.

The quality indicators reported in this paper aim to assess the provision of care to achieve a “good death.” The Institute of Medicine committee defined a good death as “one that is free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards” (3). Emanuel and Emanuel (5) describe a good death in terms of “modifiable dimensions of the patient’s experience,” including symptoms, relationships and support, hopes, expectations, economic demands, caregiving needs, and spiritual and existential beliefs.

Empirical research further describes the components of a good death. A study of 56 deaths identified teamwork, coordination, early nursing involvement, and specification of a key worker as essential for good terminal care (6). Focus groups of chronically ill patients yielded five domains of quality end-of-life care: pain and symptom management, avoiding prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones (7, 8). Another qualitative study added clear decision making, contributing to the well-being of others, and affirmation of the whole person as essential components of a good death (9).

In their framework of a good death, Emanuel and Emanuel postulate that five care-system interventions affect the patient’s dying experience: family and friend interventions, psychosocial interventions, sociofinancial interventions, health care institution interventions, and medical provider interventions (5). The indicators presented here focus on institutional and medical provider interventions. Some measures of care at the end of life have been developed (for example, see the Toolkit of Instruments to Measure End-of-life Care at www.chcr.brown.edu/pcoc/toolkit.htm); however, most have not focused on the processes of end-of-life care.

A major obstacle to developing quality indicators for end-of-life care lies in identifying the population to whom the indicators should apply. Even in an at-risk population such as vulnerable elders, patients with a very low probability of survival are difficult to identify with accuracy (10). Thus, the quality indicators presented here do not rely on stratification by prognosis. Instead, they focus on patient preferences for care (through advance care planning and decisions about aggressiveness of care) and palliation. A second obstacle to developing end-of-life quality indicators is the dearth of clinical trial evidence relevant to end-of-life care (11-13). As a result, most quality-of-care indicators in this
METHODS

The methods for developing these quality indicators, including literature review and expert panel consideration, are detailed in a preceding paper (14). The end-of-life quality indicators adhere to a model in which care is tailored to match a patient’s clinical circumstances and preferences. In this model, a patient must be informed of the clinical situation, including prognosis and treatment alternatives, so that values can be translated into preferences for care. Because these decisions might be needed at times when patients may not be capable of participation, treatment preferences or proxy decision makers might be elicited in advance. Advance directives are one way to formally specify surrogate decision makers and preferences. Preferences would be translated by clinicians into care plans, including decisions about life-sustaining treatments. In turn, such plans would dictate care in the perideath period, including palliative care and bereavement support.

This process may be highly iterative, may involve multiple decisions made over time, and may include many clinicians and surrogate decision makers. The process is not necessarily linear, although we present it as such for simplicity (Figure).

Indicators 1 and 2 capture delineation of prognosis and treatment options, along with communication about choices in light of the patient’s values. The first three processes are required for quality indicators 3, 4, and 5. Indicator 6 aims at preserving the information garnered in these efforts. Translation of preferences into care is the focus of indicators 7, 8, and 9. The final five indicators concern provision of care near the time of death.

RESULTS

Of the 21 quality indicators considered by the expert panel, 14 were judged valid (see the quality indicators on pp 653-667) and 7 were not accepted (www.acponline.org/sci-policy/). The literature summaries that support each indicator judged to be valid by the expert panel process are described below.

Quality Indicators 1 and 2

Surrogate Decision Makers and Advance Directives

ALL vulnerable elders should have in their outpatient chart one of the following: 1) an advance directive indicating the patient’s surrogate decision maker, 2) documentation of a discussion about who would be a surrogate decision maker or a search for a surrogate, or 3) indication that there is no identified surrogate. BECAUSE specification of a surrogate decision maker facilitates decision making for a patient who has lost decision-making capacity.
Supporting Evidence. No clinical trials or observational studies have examined designation of surrogate decision makers for patients at risk for losing decision making capacity. This is in part because most studies have not used clinical end points (15). However, many consensus statements promote designation of a surrogate decision maker to improve decision making after incapacity. The Hastings Center guidelines (16) recommend that “when a patient is diagnosed with having a condition that may eventually raise questions about the termination of treatment, the responsible health care professional and patient should begin talking about future options as early as possible.” They suggest completion of an advance directive to designate a proxy (16). The Council on Ethical and Judicial Affairs of the American Medical Association suggests specification of a surrogate as a means of ensuring that an individuals’ interests are promoted in case of future incapacity (17). One prospective study of physicians discussing advance directives with patients revealed that physicians recognized the correct surrogate decision maker 89% of the time after such a discussion (18).

Quality Indicators 3 and 4
Documentation of Care Preferences

IF a vulnerable elder carries a diagnosis of severe dementia, is admitted to the hospital, and survives 48 hours, THEN within 48 hours of admission, the medical record should document that the patient’s prior preferences for care have been considered or that these preferences could not be elicited or are unknown.

IF a vulnerable elder is admitted directly to the intensive care unit (from the outpatient setting or emergency department) and survives 48 hours, THEN within 48 hours of admission, the medical record should document that the patient’s preferences for care have been considered or that these preferences could not be elicited or are unknown BECAUSE patients’ values and preferences should guide life-sustaining care.

Supporting Evidence. No clinical trials or observational studies link elicitation and documentation of preferences to clinical outcomes. However, observational data suggest that physician understanding of patient resuscitation preference is associated with a better match between those preferences and resuscitation attempts (19) and is associated with less end-of-life resource use (20). In a prospective trial of advance directives for nursing home residents, Danis and colleagues (21) showed a high correlation between documented care preferences and life-sustaining treatments. In a randomized, controlled trial, Sulmasy and colleagues (22) showed that an educational intervention caused medical residents to increase the number of potential treatments and “care concerns” considered when writing life-sustaining treatment orders; no effects on patient care or outcome were shown.

Early elicitation of patient preferences and their incorporation in advance directives is widely endorsed (3, 16, 17, 23–25). Despite broad support, no clinical trial evidence indicates that these processes improve clinical outcomes. However, several studies show promising indirect effects. A retrospective study of 182 patients who had undergone hemodialysis and died found that those who had completed advance directives (41%) were more likely to die in a planned, nonemergent fashion, with “greater internal locus of control” (26). A scenario-based study of physicians found that physicians were more likely to follow more specific preferences listed in an advance directive (27). An observational study of a highly developed, community-wide intervention in one midwestern area of the United States shows that advance directives can be widely promulgated, successfully communicated to physicians, and coordinated across health care venues, and they can lead to adherence to nearly all specified end-of-life treatment preferences (28).

Two clinical trials suggest that advance care planning is not clinically effective. Schneiderman and colleagues (29) conducted a randomized, controlled trial of administering advance directives to 104 sick outpatients and found no differences in health outcomes, medical treatments, or health care costs compared with 100 control patients. The authors concluded that “only if the document stimulates discussion and communication between patients and physicians will the current enthusiasm for advance directives be justified.” The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), a multisite controlled clinical trial, tested interventions to improve end-of-life decision making. The observational phase of the trial documented that physicians often misunderstood patients’ resuscitation preferences, that resuscitation decisions were often made close to death, and that many patients died in substantial discomfort. The intervention
phase of the trial, in which physicians were given patients’ prognostic and preference information and specially trained nurses conducted advance care planning activities, did not affect these clinical outcomes (1).

Although these studies found that the advance care planning interventions did not improve end-of-life care, the interventions did not demonstrate increased communication between patients and physicians about surrogates and care preferences. The proposed indicators aim at these communicative aspects of advance directives; patients (or proxies) must be aware of their situation, prognosis, and treatment alternatives to express preferences.

Chart documentation of care preferences early in the hospital stay is of particular importance—observational studies have shown that even when prior preferences have been expressed through advance directives, their existence and content are often unrecognized by physicians providing inpatient care (21, 30, 31). These indicators focus on patients with advanced dementia and those in the intensive care unit—patients at risk for receiving aggressive care that may be inconsistent with preferences. Many providers and patients believe that treatment of patients with dementia should be guided by a palliative perspective (32, 33). Despite the importance of such discussions, studies have documented poor communication about care preferences for sick patients (34) and patients admitted to an intensive care unit (35). The American College of Physicians–American Society of Internal Medicine (ACP–ASIM) End-of-Life Care Consensus Panel concurs with the recommendation to ask about decision making for all patients admitted to an intensive care unit; although there are no data to substantiate any particular time interval, the panel proposed the same 48-hour window to delineate preferences (36).

Quality Indicator 5

Eliciting Patient Preferences concerning Future Health States

IF a vulnerable elder indicates (during an interview) that he or she would rather die than live permanently comatose, mechanically ventilated, or tube fed, THEN 1) the chart should document a discussion of life-sustaining treatment preferences, 2) the chart should contain an advance directive, or 3) the patient should indicate (during the interview) that he or she discussed this topic with the physician or does not wish to discuss this BECAUSE physicians and surrogate decision makers often do not know patients’ preferences for care and care may not reflect preferences if information is not elicited in advance.

Supporting Evidence. No clinical trials have studied the impact of eliciting patient preferences about future adverse health states on clinical outcomes. Observational studies of patient preferences about future health states show that large proportions of patients would prefer to die than live comatose, mechanically ventilated, or tube fed (33, 37, 38). Observational studies also reveal that physicians and surrogate decision makers often do not know patients’ preferences about life-sustaining treatment (37, 39–41).

As noted above, a randomized clinical trial of administering advance directives did not affect treatments, health outcomes, or costs (29), and the SUPPORT intervention did not improve decision making about care (1). In addition, a prospective, uncontrolled study of advance directives for patients in a nursing home found no increase in concordance between life-sustaining care and patients’ (or surrogate decision makers’) expressed preferences when patients had advance directives (21). However, unlike the proposed indicator, these studies did not elicit and transmit patients’ preferences aimed at less aggressive care in specific health states. Such discussions are consistent with consensus statements from the Hastings Center (17), American Geriatric Society (24), American Medical Association (14), Institute of Medicine (3), and ACP–ASIM End-of-Life Care Consensus Panel (36).

Quality Indicator 6

Advance Directive Continuity

IF a vulnerable elder has an advance directive in the outpatient, inpatient, or nursing home medical record or the patient reports the existence of an advance directive in an interview, and the patient receives care in a second venue, THEN 1) the advance directive should be present in the medical record at the second venue or 2) documentation should acknowledge its existence, its contents, and the reason that it is not in the medical record BECAUSE advance directives can guide care only...
if their existence is recognized and their content is known.

Supporting Evidence. Five observational studies have documented that even when advance directives are completed, patients’ physicians often do not know that they exist (21, 30, 31), and the directives are not always documented in the patients’ charts (42) or transferred from outpatient to inpatient settings (43).

For advance directives to have an effect, they must come to the attention of surrogate decision makers and the medical care team. The Hastings Center cited the importance of the advance care planning process “to help ensure consistent treatment for the patient as he or she comes under the care of different health care professionals in various institutional settings” (16). Yet, one observational study found that do-not-resuscitate orders may not be carried over between hospital admissions, even to the same facility (44). It is a goal of advance care planning to preserve elicited preferences so that they may be reviewed, revisited, updated, and ultimately affect care when needed. Continuity of an advance directive across venues can stimulate reconsideration of care goals and assessment of whether the patient’s clinical condition or prognosis has changed.

Quality Indicator 7
Patient Preferences for Mechanical Ventilation

IF a vulnerable elder requires mechanical ventilation during a hospitalization (except short-term and postoperative mechanical ventilation), THEN within 48 hours of the initiation of mechanical ventilation the medical record should document the goals of care and the patient’s preference for mechanical ventilation or why this information is unavailable BECAUSE mechanical ventilation should be performed only when it is consistent with a patient’s goals and because early consideration of prognosis and preferences will guide care to be consistent with the patient’s values.

Supporting Evidence. Practices concerning withdrawal of care for patients receiving mechanical ventilation vary widely. One study of 308 critical care physicians showed that 15% almost never withdrew ventilation, and 37% did so for fewer than half of patients forgoing life-sustaining treatment (45). Withholding practices among surveyed physicians also varied greatly (45). Data from SUPPORT confirm that ventilator-withdrawal patterns vary widely among care sites, even after adjustment for patient prognosis and characteristics (46). This study showed that a main predictor of whether a ventilator was withdrawn was the existence of communication about care preferences.

Quality Indicator 8
Patient Participation in Life-Sustaining Care Decisions

IF a vulnerable elder with decision-making capacity has orders written in the hospital or the nursing home to withhold or withdraw a particular treatment (for example, a do-not-resuscitate order or an order not to initiate dialysis), THEN the medical record should document 1) patient participation in the decision or 2) why the patient did not participate in the decision BECAUSE patients with decision-making capacity who wish to participate should have their values guide important care decisions.

Supporting Evidence. Patients with decision-making capacity and desire to participate in end-of-life decisions should be allowed to do so (16, 17, 24, 25). The American College of Physicians Ethics Manual states that “The crux of the issue is that the patient’s (rather than the physician’s) assessment of the benefits and burdens of treatment should determine what treatment is administered or withheld” (25). The American Medical Association Code of Medical Ethics (17) adds:

The physician has an ethical obligation to honor the resuscitation preferences expressed by the patient. Physicians should not permit their personal value judgments about quality of life to obstruct the implementation of a patient’s preferences regarding the use of CPR [cardiopulmonary resuscitation].

On the basis of these principles, hospitals have policies guiding physicians to include patients’ values and preferences in resuscitation (and other life-sustaining treatment) decisions and to document the decisions leading to resuscitation orders. A small study comparing chart documentation to patient recall about life-sustaining treatment decisions showed that medical record documentation reflected patient understanding of these decisions (47).

Unless preferences have been elicited in advance, a patient’s meaningful participation in treatment decisions requires that he or she have decision-making capacity. While the level of cognition and reasoning required de-
pends on the gravity of the decision (48), decision-making capacity requires that a patient can appreciate the information relevant to the decision, can reason a choice that is consistent with his or her goals and values, and can communicate this decision (49). The caregiving physician usually determines whether a patient has decision-making capacity, although consultation with a specialist may be valuable at times.

Studies of communication between physicians and patients about important medical decisions show that patients desire to be informed and that some patients desire to participate in the decision-making process (50–52). No clinical trials have tested whether documentation of patient input into life-sustaining treatment decisions affects outcomes.

Quality Indicator 9
Care Consistency with Documented Care Preferences

If a vulnerable elder has specific treatment preferences (for example, a do-not-resuscitate order, no tube feeding, or no hospital transfer) documented in a medical record, THEN these treatment preferences should be followed BECAUSE medical care should aim to be consistent with a patient’s preferences.

Supporting Evidence. As noted in the evidence for indicator 7, there are a strong theoretical basis and expert consensus that patient preferences should drive care. In the nursing home, Danis and colleagues (21) showed a high correlation between documented care preferences and life-sustaining treatments. Similar work has not been performed in the outpatient or hospital settings. No trials have studied whether documentation improves the concordance of care with values and preferences. This indicator directs that if care preferences are documented, these preferences (unless reversed) should be reflected in the care that the patient receives. The exception to this might be disagreement over care that will sustain patients in extremely poor health states (53).

Quality Indicator 10
Management of Ventilator Withdrawal

If a noncomatose vulnerable elder is not expected to survive and a mechanical ventilator is withdrawn or intubation is withheld, THEN the patient should receive (or have orders available for) an opiate or benzodiazepine or barbiturate infusion to reduce dyspnea, and the chart should document whether the patient has dyspnea, BECAUSE dyspnea can be controlled in the setting of comfort care when mechanical ventilation is withdrawn or withheld.

Supporting Evidence. Withdrawal of patients from ventilators with the expectation that the patient will not survive is not uncommon (54). However, how often this occurs varies widely across providers and hospitals (45, 46). Management of the patient withdrawn from a ventilator can be difficult because the clinician must avoid producing excess suffering without unnecessarily promoting death. "Best practices” for withdrawal of mechanical ventilation have been published (55), including several treatment options (56). These have been integrated into hospital policies (57) and are endorsed by the ACP–ASIM End-of-Life Care Consensus Panel (36). No clinical trials have studied the effectiveness of these strategies.

Quality Indicators 11, 12, 13, and 14: Care of the Dying Patient

Treatment of Dyspnea

If a vulnerable elder who had dyspnea in the last 7 days of life died an expected death, THEN the chart should document how the dyspnea was treated and follow-up should be documented about the dyspnea BECAUSE dyspnea can be effectively treated with oxygen and pharmacologic agents.

Treatment of Pain

If a vulnerable elder who was conscious during the last 3 days of life died an expected death, THEN the medical record should contain documentation about pain or lack of pain during the last 3 days of life BECAUSE pain is common at the end of life and can be effectively treated.

Attention to Spiritual Issues

If a vulnerable elder who was conscious during the last 3 days of life died an expected death, THEN the medical record should contain documentation about spirituality or how the patient was dealing with death or religious feelings BECAUSE spiritual issues play a prominent role at the end of life and can be addressed by a variety of interventions.
Searching for Next of Kin

If a vulnerable elder without known family or next of kin died in the hospital, then the chart should document a search for next of kin because it is critical to inform family of the death of a loved one in a timely fashion and because the next of kin may provide information about patient’s desires for after-death arrangements.

Supporting Evidence. These indicators are based on the definitions and constituents of a “good death” described above. These studies demonstrate that aspects of care near death should focus on symptoms, mood, spirituality and completion, bereavement, and the needs of survivors. There is consensus among many bodies that these aspects of care for dying patients must be improved (3, 13, 23, 36, 58–60). This subgroup of quality indicators targets in the final week of life—patients who are expected to die. One of the challenges of using medical records to measure care provided to dying patients is the difficulty in using chart documentation to prospectively identify patients who will die. For a patient dying an “expected death,” the medical record contains explicit documentation more than 1 day before death that the patient is expected to die in a short period or that the patient is not expected to survive to hospital discharge. Physician, nurse, social worker, and pastoral care notes may contain such documentation, which also includes information about bereavement counseling, religious rites, and postmortem arrangements.

Several studies have described the prevalence of uncontrolled symptoms at the end of life. Lynn and colleagues (61) found that in the final 3 days of life, 40% of SUPPORT patients experienced moderate or severe pain and 50% had severe dyspnea. In afterdeath interviews with 103 family members in Oregon, 54% reported that their loved one experienced moderate or severe pain in the final week of life (62). However, little research has evaluated interventions attempting to improve the experience of dying. The SUPPORT intervention, in which patients’ pain reports were passively fed back to physicians, did not change family members’ judgments of patients’ terminal pain (63). Despite the lack of clinical trials of symptom control for dying patients, substantial literature demonstrates the efficacy of pharmacologic treatments for pain, dyspnea, nausea, and other symptoms.

No controlled trials have assessed the impact of addressing spiritual or religious concerns in dying patients. However, the consensus statements and qualitative studies cited above endorse supporting a patient’s spirituality as an important component of a good death. In a survey of 177 ambulatory patients in which 51% described themselves as religious, 94% of religious patients and 45% of nonreligious patients believed that physicians should ask about religious beliefs that would influence the patients’ medical decisions if they became gravely ill (64).

Similarly, no studies have assessed the impact of next-of-kin notification on family members’ emotional well-being or bereavement. One study of a protocol for notifying next of kin about death and supporting survivors demonstrated that family members reported satisfaction with more thorough and timely information about the events of death (65).

Discussion

Communication about prognosis, elicitation of preferences, and translation of preferences into care are recognized as essential to quality medical care. However, as pointed out by this paper, few clinical trials provide evidence to support the end-of-life care processes deemed valid by the ACOVE expert panel for measurement of the quality of care for vulnerable elders. Thus, the quality indicators we present are based on clinical judgment and opinion. A paucity of data—nearly all observational—support these quality indicators. A major finding of this effort is the deficiency of clinical trials of end-of-life care processes.

This project investigated the relationship between processes and outcomes of care and sought to develop explicit criteria to evaluate the quality of end-of-life care of vulnerable elders. Fourteen indicators were judged sufficiently valid for use as measures of the quality of care for vulnerable elders. These indicators might serve as a basis with which to compare the care provided by different health care delivery systems and as a method to evaluate change over time or in response to intervention.

From University of California, Los Angeles, Los Angeles, California; and Veterans Affairs Greater Los Angeles Healthcare System, West Los Angeles, California.

Acknowledgments: The authors thank Laura Hanson, MD, for her review of an earlier version of the monograph containing the full set of
proposed quality indicators and Patricia Smith and Victor Gonzalez for technical assistance.

Grant Support: By a contract from Pfizer Inc. to RAND, Dr. Wenger was a Soros Foundation Project on Death in America Faculty Scholar during this project, and Dr. Rosenfeld was supported by a Veterans Affairs Health Services Research and Development Career Development Award.

Requests for Single Reprints: Neil S. Wenger, MD, Department of Medicine, Division of General Internal Medicine and Health Services Research, University of California, Los Angeles, CA 90095-1736; e-mail, nwenger@mednet.ucla.edu.

Current Author Addresses: Dr. Wenger: Department of Medicine, Division of General Internal Medicine and Health Services Research, University of California, Los Angeles, CA 90095-1736. Dr. Rosenfeld: Department of General Medicine, West Los Angeles/Veterans Affairs Medical Center, 11301 Wilshire Boulevard, Building 111G, Los Angeles, CA 90012.

References
1. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). The SUPPORT Principal Investigators. JAMA. 1995; 274:1591-8. [PMID: 7474243]
2. The care of dying patients: a position statement from the American Geriatrics Society, AGS Ethics Committee. J Am Geriatr Soc. 1995;43:577-8. [PMID: 7537290]
3. Field MJ, Cassel CK, eds. Approaching Death: Improving Care at the End of Life. Washington, DC: National Academy Pr; 1997.
4. Dennis C. Vaico’s Commission on quality of care at the end of life. Final Report of the Attorney General. July 1998.
5. Emanuel EJ, Emanuel LL. The promise of a good death. Lancet. 1998;351 Suppl 2:SI21-9. [PMID: 9606363]
6. Robinson L, Stacy R. Palliative care in the community: setting practice guidelines for primary care teams. Br J Gen Pract. 1994;44:461-4. [PMID: 7538315]
7. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients’ perspectives. JAMA. 1999;281:163-8. [PMID: 9917120]
8. Martin DK, Thid EC, Singer PA. A new model of advance care planning: observations from people with HIV. Arch Intern Med. 1999;159:86-92. [PMID: 9829336]
9. Steinhauser KE, Clipp EC, McNelly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. Ann Intern Med. 2000;132:825-32. [PMID: 10819070]
10. Fox E, Landrum-McNiff K, Zhong Z, Dawson NV, Wu AW, Lynn J. Evaluation of prognostic criteria for determining hospice eligibility in patients with advanced lung, heart, or liver disease. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. JAMA. 1999;282:1638-45. [PMID: 10553790]
11. Teno JM, Nelson HL, Lynn J. Advance care planning. Priorities for ethical and empirical research. Hastings Cent Rep. 1994;24:S32-6. [PMID: 7860278]
12. Key TJ, Fredman L, Taler GA, Datta S, Levenson SA. Indicators of quality medical care for the terminally ill in nursing homes. J Am Geriatr Soc. 1994;42:853-60. [PMID: 8046195]
13. Good care of the dying patient. Council on Scientific Affairs, American Medical Association. JAMA. 1996;275:474-8. [PMID: 8627970]
14. Shekelle PG, MacLean CH, Morton SC, Wenger NS. Assessing care of vulnerable elders: methods for developing quality indicators. Ann Intern Med. 2001;135:647-52.
15. Hanson LC, Tulsky JA, Danis M. Can clinical interventions change care at the end of life? Ann Intern Med. 1997;126:381-8. [PMID: 9054283]
16. Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying. Briardcliff Manor, NY: Hastings Center; 1987.
17. Code of Medical Ethics Reports of the AMA Council on Ethical and Judicial Affairs. Report 34—Decisions to Forgo Life-Sustaining Treatment for Incompetent Patients. Chicago: American Medical Assoc; 1991.
18. Fischer GS, Tulsky JA, Rose MR, Siminoff LA, Arnold RM. Patient knowledge and physician predictions of treatment preferences after discussion of advance directives. J Gen Intern Med. 1998;13:447-54. [PMID: 9686710]
19. Wenger NS, Phillips RS, Teno JM, Oye RK, Dawson NV, Liu H, et al. Physician understanding of patient resuscitation preferences: insights and clinical implications. J Am Geriatr Soc. 2000;48:854-51. [PMID: 10809456]
20. Teno JM, Hakim RB, Knaus WA, Wenger NS, Phillips RS, Wu AW, et al. Preferences for cardiopulmonary resuscitation: physician-patient agreement and hospital resource use. The SUPPORT Investigators. J Gen Intern Med. 1995;10:179-86. [PMID: 7790978]
21. Dansis M, Southerland LJ, Garrett JM, Smith JL, Hilema F, Pickard CG, et al. A prospective study of advance directives for life-sustaining care. N Engl J Med. 1991;324:882-8. [PMID: 2000110]
22. Sulmasy DP, Geller G, Faden R, Levine DM. The quality of mercy. Caring for patients with “do not resuscitate” orders. JAMA. 1992;267:682-6. [PMID: 1731135]
23. The care of dying patients: a position statement from the American Geriatrics Society. AGS Ethics Committee. J Am Geriatr Soc. 1995;43:577-8. [PMID: 7537290]
24. President’s Commission for the Study of Ethical Problems in Medicine and Biomedical Research: Deciding to Forgo Life-Sustaining Treatment. Washington, DC: U.S. Government Printing Office; 1983.
25. American College of Physicians Ethics Manual. Third edition. Ann Intern Med. 1992;117:947-60. [PMID: 1443957]
26. Swartz RD, Perry E. Advance directives are associated with “good deaths” in chronic dialysis patients. J Am Soc Nephrol. 1993;3:1623-30. [PMID: 8507819]
27. Mower WR, Baraff LJ. Advance directives. Effect of type of directive on physicians’ therapeutic decisions. Arch Intern Med. 1993;153:375-81. [PMID: 8427540]
28. Hammes BJ, Rooney BL. Death and end-of-life planning in one midwestern community. Arch Intern Med. 1998;158:383-90. [PMID: 9487236]
29. Schneideman IJ, Kronick R, Kaplan RM, Anderson JP, Langer RD. Effects of offering advance directives on medical treatments and costs. Ann Intern Med. 1992;117:599-606. [PMID: 1524334]
30. Virmani J, Schneideman IJ, Kaplan RM. Relationship of advance directives to physician-patient communication. Arch Intern Med. 1994;154:909-13. [PMID: 8154954]
31. Goodman MD, Tarnoff M, Slotman GJ. Effect of advance directives on the management of elderly critically ill patients. Crit Care Med. 1998;26:701-4. [PMID: 9595607]
32. Luchins DJ, Hanrahan P. What is appropriate health care for end-stage dementia? J Am Geriatr Soc. 1993;41:25-30. [PMID: 7678104]
33. Pearlman RA, Cain KC, Patrick DL, Appelbaum-Maizel M, Starks HE, Jecker NS, et al. Insights pertaining to patient assessments of states worse than...
34. Hofmann JC, Wenger NS, Davis RB, Teno J, Connors AF Jr, Desbiens N, et al. Patient preferences for communication with physicians about end-of-life decisions. SUPPORT Investigators. Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment. Ann Intern Med. 1997;127:1-12. [PMID: 9214246]

35. Blackhall LJ, Cobb J, Moskowitz MA. [PMID: 9214246].

36. Faber-Langendoen K, Lanken PN. Do surrogates understand older patients’ preferences for future health states? [Abstract] J Am Geriatr Soc. 1994;42:SA67.

37. Faber-Langendoen K, Lanken PN. Dying patients in the intensive care unit: forgoing treatment, maintaining care. ACP-ASIM End-of-Life Care Consensus Panel. Ann Intern Med. 2000;133:886-93. [PMID: 11103859]

38. Hofmann JC, Wenger NS, Davis RB, Teno J, Connors AF Jr, Desbiens N, et al. The stability of DNR orders on hospital readmission. The SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. J Clin Ethics. 1996;7:48-54. [PMID: 8790698]

39. Uhlmann RF, Pearlman RA, Cain KC. Understanding of elderly patients’ resuscitation preferences by physicians and nurses. West J Med. 1989;150:705-7. [PMID: 2750162]

40. Seckler AB, Meier DE, Mulvihill M, Paris BE. Substituted judgment: how accurate are proxy predictions? Ann Intern Med. 1991;115:92-8. [PMID: 2058868]

41. Gerety MB, Chioldo LK, Kanten DN, Tuley MR, Cornell JE. Medical treatment preferences of nursing home residents: relationship to function and concordance with surrogate decision-makers. J Am Geriatr Soc. 1993;41:953-60. [PMID: 8204138]

42. Gregory JJ, Dunn D. Implementation of the Patient Self-Determination Act in a community hospital. N J Med. 1995;92:438-42. [PMID: 7659304]

43. Morrison RS, Olson E, Mezz T, Meier DE. The inaccessibility of advance directives on transfer from ambulatory to acute care settings. JAMA. 1995;274:478-82. [PMID: 7629957]

44. Wenger NS, Oye RK, Desbiens NA, Phillips RS, Teno JM, Connors AF Jr, et al. The stability of DNR orders on hospital readmission. The SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. J Clin Ethics. 1996;7:48-54. [PMID: 8790698]

45. Faber-Langendoen K. The clinical management of dying patients receiving mechanical ventilation. A survey of physician practice. Chest. 1994;106:880-8. [PMID: 8082372]

46. Wenger NS, Bellamy PE, Phillips RS, Liu HH, Connors AF, Dawson NV, et al. Variation in withdrawing the ventilator from dying patients. J Gen Intern Med. 1997;12(Suppl 1):105.

47. Sulmasy DP, Dwyer M, Marx E. Do the ward notes reflect the quality of end-of-life care? J Med Ethics. 1996;22:344-8. [PMID: 8961119]

48. Drane JF. Competency to give an informed consent. A model for making clinical assessments. JAMA. 1984;252:925-7. [PMID: 6748193]

49. Appelbaum PS, Grisso T. Assessing patients’ capacities to consent to treatment. N Engl J Med. 1988;319:1635-8. [PMID: 3200278]

50. Lo B, McLeod GA, Saika G. Patient attitudes to discussing life-sustaining treatment. Arch Intern Med. 1986;146:1613-5. [PMID: 3729645]

51. Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and decision-making preferences of hospitalized adult cancer patients. Soc Sci Med. 1988;27:1139-45. [PMID: 3206248]

52. Levin JR, Wenger NS, Ouslander JG, Zellman G, Schnelle JF, Buchanan JL, et al. Life-sustaining treatment decisions for nursing home residents: who discusses, who decides and what is decided? J Am Geriatr Soc. 1999;47:82-7. [PMID: 9920234]

53. Schneidman LJ, Jecker NS. Wrong Medicine. Baltimore: Johns Hopkins Univ Pr; 1995.

54. Withholding and withdrawing life-sustaining therapy. This Official Statement of the American Thoracic Society was adopted by the ATS Board of Directors, March 1991. Am Rev Respir Dis. 1991;144:726-31. [PMID: 1892317]

55. Brody H, Campbell ML, Faber-Langendoen K, Ogle KS. Withdrawing intensive life-sustaining treatment—recommendations for compassionate clinical management. N Engl J Med. 1997;336:652-7. [PMID: 9032053]

56. Campbell ML. Forgoing Life-Sustaining Therapy. Aliso Viejo, CA: AACN Critical Care Publication; 1998:61-90.

57. Terminal Weaning of Mechanical Ventilator Support. UCLA Hospital Policy 0027.2. Los Angeles, CA: Univ of California; 1998.

58. Palliative care in neurology. The American Academy of Neurology Ethics and Humanities Subcommittee. Neurology. 1996;46:870-2. [PMID: 8618714]

59. American Pain Society Task Force on Pain, Symptoms and End of Life Care. Treatment of pain at the end of life: a position statement from the American Pain Society. APS Bulletin. 1997;7:1-3.

60. Palliative care: towards a consensus in standardized principles of practices. Ottawa, Ontario: Canadian Palliative Care Assoc; 1995.

61. Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, et al. Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preference for Outcomes and Risks of Treatments. Ann Intern Med. 1997;126:97-106. [PMID: 9005760]

62. Tolle SW, Tilden VP, Hickman SE, Rosenfeld AG. Family reports of pain in dying hospitalized patients: a structured telephone survey. West J Med. 2000;172:374-7. [PMID: 10854381]

63. Desbiens NA, Wu AW, Yasui Y, Lynn J, Alzola C, Wenger NS, et al. Patient empowerment and feedback did not decrease pain in seriously ill hospitalized adults. Pain. 1998;75:237-46. [PMID: 9583759]

64. Ehman JW, Ott BB, Short TH, Ciampa RC, Hansen-Flaschen J. Patient satisfaction with the pain management of seriously ill hospitalized patients. Pain. 1998;75:237-46. [PMID: 9583759]