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*Issue #12* *March 2003*

# Advance Care Planning: Preferences for Care at the End of Life

## Introduction

### Patient preferences are often not known

Predicting what treatments patients will want at the end of life is complicated by the patient's age, the nature of the illness, the ability of medicine to sustain life, and the emotions families endure when their loved ones are sick and possibly dying. When seriously ill patients are nearing the end of life, they and their families sometimes find it difficult to decide on whether to continue medical treatment and, if so, how much treatment is wanted and for how long. In these instances, patients rely on their physicians or other trusted health professionals for guidance.

In the best of circumstances, the patient, the family, and the physician have held discussions about treatment options, including the length and invasiveness of treatment, chance of success, overall prognosis, and the patient's quality of life during and after the treatment. Ideally, these discussions would continue as the patient's condition changed. Frequently, however, such discussions are not held. If the patient becomes incapacitated due to illness, the patient's family and physician must make decisions based on what they think the patient would want.

### Research can help guide decisionmaking

This report is intended to show how physicians and other health care professionals can help their patients with advance care planning and assess patient preferences for care at the end of life. Section 1 discusses research findings from studies funded by the Agency for Healthcare Research and Quality (AHRQ), as well as those from other research. For readers who want more detailed information, Section 2 contains charts and tables showing the quantitative results of the studies supported by AHRQ. While no one can predict exactly what patients will want or need when they are sick or dying, this research can help providers offer end-of-life care based on preferences (both real and hypothetical) held by the majority of patients under similar circumstances.[1]

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**Suggested Citation: Kass-Bartelmes BL, Hughes R, Rutherford MK. Advance care planning: preferences for care at the end of life. Rockville (MD): Agency for Healthcare Research and Quality; 2003. Research in Action Issue #12. AHRQ Pub No. 03-0018.**

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**Terms patients should understand**

***Advance directives*** **are also known as living wills. These are formal legal documents specifically authorized by State laws that allow patients to continue their personal autonomy and that provide instructions for care in case they become incapacitated and cannot make decisions. An advance directive may also be a durable power of attorney.**

**A *durable power of attorney* is also known as a health care proxy. This document allows the patient to designate a surrogate, a person who will make treatment decisions for the patient if the patient becomes too incapacitated to make such decisions**

## Section 1. Discussion of research findings

AHRQ research indicates that most patients have not participated in advance care planning, yet many are willing to discuss end-of-life care. One way to determine patients' preferences for end-of-life care is to discuss hypothetical situations and find out their opinions on certain treatment patterns. These opinions can help clarify and predict the preferences they would be likely to have it if they should become incapacitated and unable to make their own decisions.

### Patients need more effective advance care planning

Studies funded by AHRQ indicate that many patients have not participated in effective advance care planning. The Patient Self-Determination Act guarantees patients the right to accept or refuse treatment and to complete advance medical directives.[2-12] However, despite patients' rights to determine their future care, AHRQ research reveals that:

- Less than 50 percent of the severely or terminally ill patients studied had an advance directive in their medical record.[5,6,8,13]
- Only 12 percent of patients with an advance directive had received input from their physician in its development.[6]
- Between 65 and 76 percent of physicians whose patients had an advance directive were not aware that it existed.[6,13]
- Having an advance directive did not increase documentation in the medical chart regarding patient preferences.[6,11]
- Advance directives helped make end-of-life decisions in less than half of the cases where a directive existed.[6]
- Advance directives usually were not applicable until the patient became incapacitated[14] and "absolutely, hopelessly ill."[2]
- Providers and patient surrogates had difficulty knowing when to stop treatment and often waited until the patient had crossed a threshold over to actively dying before the advance directive was invoked.[2]
- Language in advance directives was usually too nonspecific and general to provide clear instruction.[5]
- Surrogates named in the advance directive often were not present to make decisions or were too emotionally overwrought to offer guidance.[2]
- Physicians were only about 65 percent accurate in predicting patient preferences and tended to make errors of undertreatment, even after reviewing the patient's advance directive.[15]
- Surrogates who were family members tended to make prediction errors of overtreatment, even if they had reviewed or discussed the advance directive with the patient or assisted in its development.[16,17]

AHRQ research shows that care at the end of life sometimes appears to be inconsistent with the patients' preferences to forgo life-sustaining treatment and patients may receive care they do not want.[5] For example, one study found that patient preferences to decline cardiopulmonary resuscitation (CPR) were not translated into do-not-resuscitate (DNR) orders.[5,6,11] DNR orders are requests from the patient or the patient's surrogate to the physician that certain forms of treatment or diagnostic testing not be performed.[18] CPR is a procedure frequently addressed in DNR orders. Another study found that patients received life-sustaining treatment at the same rate regardless of their desire to limit treatment.[18]

### Patients with chronic illness need advance planning

Because physicians are in the best position to know when to bring up the subject of end-of-life care, they are the ones who need to initiate and guide advance care planning discussions.[19] Such discussions are usually reserved for

people who are terminally ill or whose death is imminent, yet research indicates that people suffering from chronic illness also need advance care planning.

The majority of people who die in the United States (80 to 85 percent) are Medicare beneficiaries age 65 and over, and most die from chronic conditions such as heart disease, cerebrovascular disease, chronic obstructive pulmonary disease (COPD), diabetes, Alzheimer's disease, and renal failure.[20] Only about 22 percent of deaths in people age 65 and over are from cancer.[20]

People with terminal cancer generally follow an expected course, or "trajectory," of dying.[21,22] Many maintain their activities of daily living until about 2 months prior to death, after which most functional disability occurs.[21] In contrast, people with chronic diseases such as heart disease or COPD go through periods of slowly declining health marked by sudden severe episodes of illness requiring hospitalization, from which the patient recovers.[21,22] This pattern may repeat itself over and over, with the patient's overall health steadily declining, until the patient dies.[21,22] For these individuals there is considerable uncertainty about when death is likely to occur. Patients who suffer from chronic conditions such as stroke, dementia, or the frailty of old age go through a third trajectory of dying, marked by a steady decline in mental and physical ability that finally results in death.[21] Patients are not often told that their chronic disease is terminal, and estimating a time of death for people suffering from chronic conditions is much more difficult than it is for those dying of cancer.[22]

When patients are hospitalized for health crises resulting from their chronic incurable disease, medical treatment cannot cure the underlying illness, but it is still effective in resolving the immediate emergency and thus possibly extending the patient's life.[2] At any one of these crises the patient may be close to death,[21] yet there often is no clearly recognizable threshold between being very ill and actually dying.[2] Patients may become too incapacitated to speak for themselves,[23-26] and decisions about which treatments to provide or withhold are usually made jointly between the patient's physician and family or surrogate.[27]

## Patients value advance care planning discussions

According to patients who are dying and their families who survive them, lack of communication with physicians and other health care providers causes confusion about medical treatments, conditions and prognoses, and the choices that patients and their families need to make.[2,22,24,28-31] One AHRQ study indicated that about one-third of patients would discuss advance care planning if the physician brought up the subject and about one-fourth of patients had been under the impression that advance care planning was only for people who were very ill or very old.[32] Only 5 percent of patients stated that they found discussions about advance care planning too difficult.[32]

AHRQ-funded studies have shown that discussing advance care planning and directives with their doctor increased patient satisfaction among patients age 65 years and over.[33,34] Patients who talked with their families or physicians about their preferences for end-of-life care had less fear and anxiety, felt they had more ability to influence and direct their medical care, believed that their physicians had a better understanding of their wishes, and indicated a greater understanding and comfort level than they had before the discussion.[16,33] Compared to surrogates of patients who did not have an advance directive, surrogates of patients with an advance directive who had discussed its content with the patient reported greater understanding, better confidence in their ability to predict the patient's preferences, and a stronger belief in the importance of having an advance directive.[16]

Finally, patients who had advance planning discussions with their physicians continued to discuss and talk about these concerns with their families.[33] Such discussions enabled patients and families to reconcile their differences about end-of-life care and could help the family and physician come to agreement if they should need to make decisions for the patient.[15,33]

## Opportunities exist for advance planning discussions

AHRQ studies indicate that physicians can conduct advance care planning discussions with some patients during routine outpatient office visits.[32] Hospitalization for a serious and progressive illness offers another opportunity.[35] The Patient Self-Determination Act requires facilities such as hospitals that accept Medicare and Medicaid money to provide written information to all patients concerning their rights under State law to refuse or accept treatment and to complete advance directives.[2,3,5-12] Patients often send cues to their physicians that they are ready to discuss end-of-life care by talking about wanting to die or asking about hospice.[35] Certain situations, such as approaching death or discussions about prognoses or treatment options that have poor outcomes, also lend themselves to advance care planning discussions.[35] Predicting when patients are near

death is difficult, but providers can ask themselves the question: are the patients "sick enough today that it would not be surprising to find that they had died within the next year (or few months, or 6 months)"?[22]

## A structured process for discussions is helpful

Researchers sponsored by AHRQ have suggested a five-part process that physicians can use to structure discussions on end-of-life care:

***1. Initiate a guided discussion.*** During this discussion, the physicians should share their medical knowledge of hypothetical scenarios and treatments that are applicable to a patient's particular situation and find out the patient's preferences for providing or withholding treatments under certain situations. The hypothetical scenarios should cover a range of possible prognoses and any disability that could result from treatment. By presenting various hypothetical scenarios and probable treatments and noting when the patient's preferences change from "treat" to "do not treat," the physician can begin to identify the patient's personal preferences and values.[19]

The physician can also determine if the patient has an adequate understanding of the scenario, the treatment, and possible outcomes.[19] One AHRQ-funded study indicated that elderly patients have enough knowledge about advance directives, CPR, and artificial nutrition/hydration on which to base decisions for treatment at the end of life, but they do not always understand their realistic chances for a positive outcome.[36] Other research indicates that patients significantly overestimate their probability of survival after receiving CPR and have little or no understanding of mechanical ventilation.[37] In one study, after patients were told their probability of survival, over half changed their treatment preference from wanting CPR to refusing CPR.[38] Patients also may not know of the risks associated with the use of mechanical ventilation that a physician is aware of, such as neurological impairment or cardiac arrest.[23]

***2. Introduce the subject of advance care planning and offer information.*** Patients should be encouraged to complete both an advance directive and durable power of attorney.[19] The patient should understand that when no advance directive or durable power of attorney exists, patients essentially leave treatment decisions to their physicians and family members.[13] Physicians can provide this information themselves; refer the patient to other educational sources, including brochures or videos; and recommend that the patient talk with clergy or a social worker to answer questions or address concerns.[19]

***3. Prepare and complete advance care planning documents.*** Advance care planning documents should contain specific instructions. AHRQ studies indicate that the standard language contained in advance directives often is not specific enough to be effective in directing care.[5] Many times, instructions do not state the cutoff point of the patient's illness that should be used to discontinue treatment and allow the person to die.[5,16] Terms such as "no advanced life support" are too vague to offer guidance on specific treatments.[5] If a patient does not want to be on a ventilator, the physician should ask the patient if this is true under all circumstances or only specific circumstances.[19] One AHRQ-funded study found that because patient preferences were not clear in advance directives, life-sustaining treatment was discontinued only when it was clearly medically futile.[2]

***4. Review the patient's preferences on a regular basis and update documentation.*** Patients should be reminded that advance directives can be revised at any time.[19] Although AHRQ studies show that patients' preferences were stable over time when considering hypothetical situations,[39,40] other research indicates that patients often changed their minds when confronted with the actual situation or as their health status changed.[1] Some patients who stated that they would rather die than endure a certain condition did not choose death once that condition occurred.[1]

Other research shows that patients who had an advance directive maintained stable treatment preferences 86 percent of the time over a 2-year period, while patients who did not have an advance directive changed their preferences 59 percent of the time.[41] Both patients with and patients without a living will were more likely to change their preferences and desire increased treatment once they became hospitalized, suffered an accident, became depressed, or lost functional ability or social activity.[41] Another study linked changes in depression to changes in preferences for CPR.[42] Increased depression was associated with patients' changing their initial preference for CPR to refusal of CPR, while less depression was associated with patients' changing their preference from refusal of CPR to acceptance of CPR.[42] It is difficult for people to fully

imagine what a prospective health state might be like. Once they experience that health state, they may find it more or less tolerable than they imagined.

During reviews of advance directives, physicians should note which preferences stay the same and which change. Preferences that change indicate that the physician needs to investigate the basis for the change.[19]

***5. Apply the patient's desires to actual circumstances.*** Conflicts sometimes arise during discussions about end-of-life decisionmaking. AHRQ-sponsored research indicates that if patients desired nonbeneficial treatments or refused beneficial treatments, most physicians stated that they would negotiate with them, trying to educate and convince them to either forgo a nonbeneficial treatment or to accept a beneficial treatment. If the treatment was not harmful, expensive, or complicated, about one-third of physicians would allow the patient to receive a nonbeneficial treatment. Physicians stated that they would also enlist the family's help or seek a second opinion from another physician.[43]

Many patients do not lose their decisionmaking capacity at the end of life. Physicians and family members can continue discussing treatment preferences with these patients as their condition changes.[14] However, physicians and families may encounter the difficulty of knowing when an advance directive should become applicable for patients who are extremely sick and have lost their decisionmaking capacity but are not necessarily dying.[2] There is no easy answer to this dilemma. One AHRQ study found that advance directives were invoked only once patients had crossed a threshold to being "absolutely, hopelessly ill."[2] The patients' physicians and surrogates determined that boundary on an individual basis.[2] AHRQ studies have shown that patients' treatment was generally consistent with their preferences if those preferences were clearly stated in an advance directive and the physician was aware that they had an advance directive.[2,14]

Even if patients require a decision for a situation that was not anticipated and addressed in their advance directive, physicians and surrogates still can make an educated determination based on the knowledge they have about the patients' values, goals, and thresholds for treatment.[19] AHRQ research indicates that patients choose treatment based on the quality of the prospective health state, the invasiveness and length of treatment, and possible outcomes.

## Patients have preference patterns for hypothetical situations

AHRQ-funded studies indicate that patients are more likely to accept treatment for conditions they consider better than death and to refuse treatment for conditions they consider worse than death.[39] Results from the study conducted on health states considered worse than death are shown in Figures 1 and 2 of Section 2 in this report. Patients also were more likely to accept treatments that were less invasive such as CPR than invasive treatments such as mechanical ventilation (Figure 3).[17,39,44] Patients were more likely to accept short-term or simple treatments such as antibiotics than long-term invasive treatments such as permanent tube feeding (Figures 4-6 and Table 1).

## Patient preference patterns can predict other choices

Acceptance or refusal of invasive and noninvasive treatments under certain circumstances can predict what other choices the patient would make under the same or different circumstances. According to AHRQ research, patients' refusal of noninvasive treatments was predictive of their refusal of invasive treatments, and accepting invasive treatments predicted their acceptance of noninvasive treatments. Refusal of noninvasive treatments such as antibiotics strongly predicted that invasive treatments such as major surgery would also be refused. Decisions with the strongest predictive ability were refusing antibiotics or simple tests and accepting major surgery or dialysis (Table 2).[45]

AHRQ research also reveals that patients were more likely to refuse treatment under hypothetical conditions as their prognosis became worse.[7,32] For example, more adults would refuse both invasive and noninvasive treatments for a scenario of dementia with a terminal illness than for dementia only (Figure 7). Adults were also more likely to refuse treatment for a scenario of a persistent vegetative state than for a coma with a chance of recovery (Figure 8). More patients preferred treatment if there was even a slight chance for recovery from a coma or a stroke (Figure 9).[32] Fewer patients would want complicated and invasive treatments if they had a terminal illness (Figure 10). Finally, patients were more likely to want treatment if they would remain cognitively intact rather than impaired (Figure 11).

### AHRQ funds studies to improve end-of-life care

AHRQ continues to fund research to improve the quality of care at the end of life. Ongoing AHRQ research includes the following studies.

- **Impact of Ethics Consultation in the Intensive Care Unit**; University of California, San Diego, Grant No. R01 HS10251. This project examines the benefits of ethics consultations between families and hospital staff and whether such consultations reduce resource use.
- **Nursing Home Care at the End of Life: Cost and Quality**; Brown University, Grant No. R01 HS10549. This research project is testing preliminary findings indicating that hospice care in nursing homes positively influences pain management, acute hospitalization rates, and terminal care costs.
- **Improving Physician Skill at Providing End-of-Life Care**; University of Washington, Grant No. R01 HS11425. This study will identify specific strengths and weaknesses in the end-of-life care provided by physicians. Researchers will then develop educational and systemic interventions to improve the quality of end-of-life care.
- **Medical Care at End of Life: Rural vs. Urban Minnesota**; Duluth Clinic, Ltd., Grant No. R03 HS13022. This research project is investigating similarities and differences in end-of-life care among rural and urban nursing home residents with severe cognitive impairment.
- **Center for Patient Safety at the End of Life**; Rand Corporation, Grant No. P20 HS11558. The Center's focus is to improve the reliability of health care by effecting change and educating providers about safe and correct care of patients with chronic heart failure or chronic obstructive pulmonary disease.

### Advance planning helps physicians provide care that patients want

Most people will eventually die from chronic conditions. These patients require the same kind of advance care planning as those suffering from predictably terminal conditions such as cancer. Understanding preferences for medical treatment in patients suffering from chronic illness requires that physicians and other health care providers consider patients' concerns about the severity of prospective health states, length and invasiveness of treatments, and prognosis. While predicting what patients might want is difficult, AHRQ research offers some insights into treatment patterns and preferences under hypothetical situations that can give providers more insight into their patients' desires under similar circumstances. By discussing advance care planning during routine outpatient visits, during hospitalization for exacerbation of illness, or when the patient or physician believes death is near, physicians can improve patient satisfaction with care and provide care at the end of life that is in accordance with the patient's wishes.

## Section 2. Patient preferences for treatment

The results from AHRQ research presented in this section were collected from studies conducted with patients, many of whom were suffering from chronic disease, and physicians. Given hypothetical situations, patients described patterns of preferences for care based on health status, invasiveness and length of treatment, and prognosis.

### Patients view some health states as worse than death

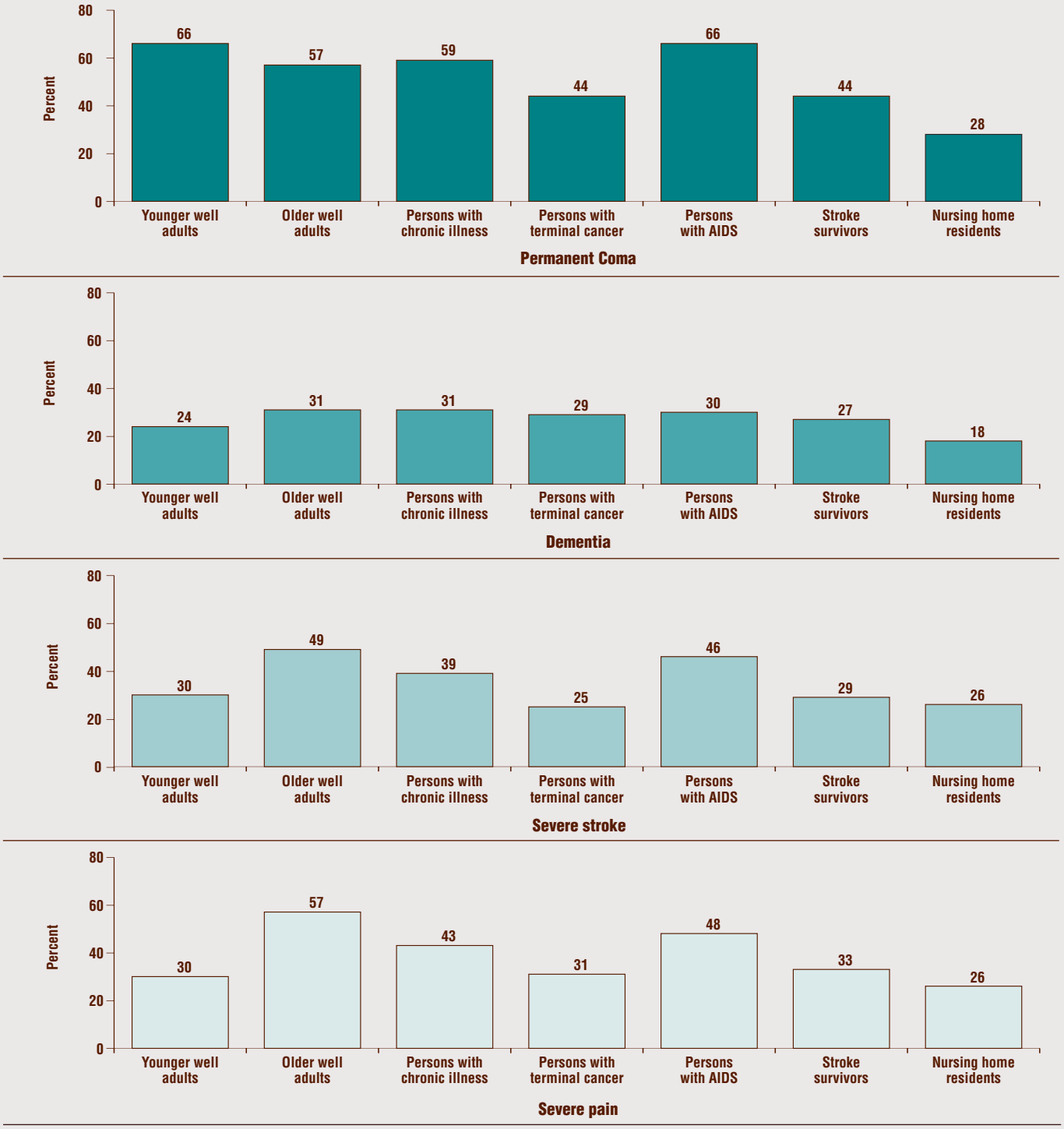
AHRQ research shows that adults of various ages whose current health states ranged from well to terminally ill differed in their perception of hypothetical health states as being worse than death (Figure 1). For example, 66 percent of younger well adults rated permanent coma as being worse than death, compared to only 28 percent of nursing home residents. However, the proportions of adults rating dementia as being worse than death were similar among all groups, ranging from 18 to 31 percent.[39]

Patients were more likely to accept life-sustaining treatment for states they considered better than death than for states they considered worse than death. For example, of all the hypothetical health states posed, patients were least likely to indicate that they would want CPR if they were in a permanent coma (Figure 2).[39]

### Invasiveness and length of treatment affect preferences

Patients were likely to accept or refuse treatment based on how invasive they perceive that treatment to be and how long the treatment is expected to last.[17,39,44,46] Presented with hypothetical scenarios, patients from three AHRQ studies were more likely to want CPR than long-term mechanical ventilation if they were in their current state of health (Figure 3). When given a hypothetical scenario of a stroke, fewer patients would opt for either CPR or mechanical ventilation.[17,39,44]

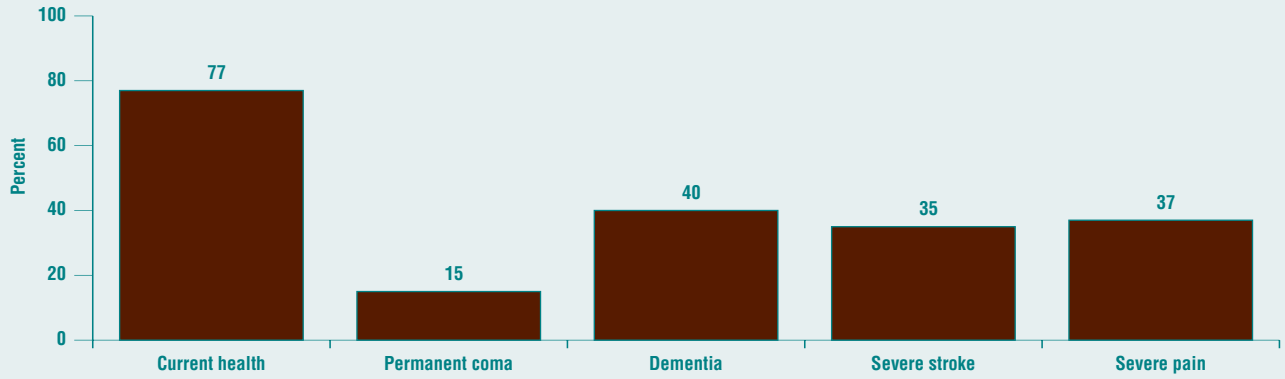
## Figure 1. Percent of sampled adults[a] who rate four hypothetical states as worse than death




[a]Sample included 50 well adults ages 21-65 years, 49 well adults older than 65, 49 older adults with chronic illness, 48 adults with terminal cancer, 50 adults with AIDS, 45 stroke survivors, and 50 nursing home residents.

**Source:** Patrick DL, Pearlman RA, Starks HE, et al. Validation of preferences for life-sustaining treatment: implications for advance care planning. Ann Intern Med 1997;127(7):509-17.

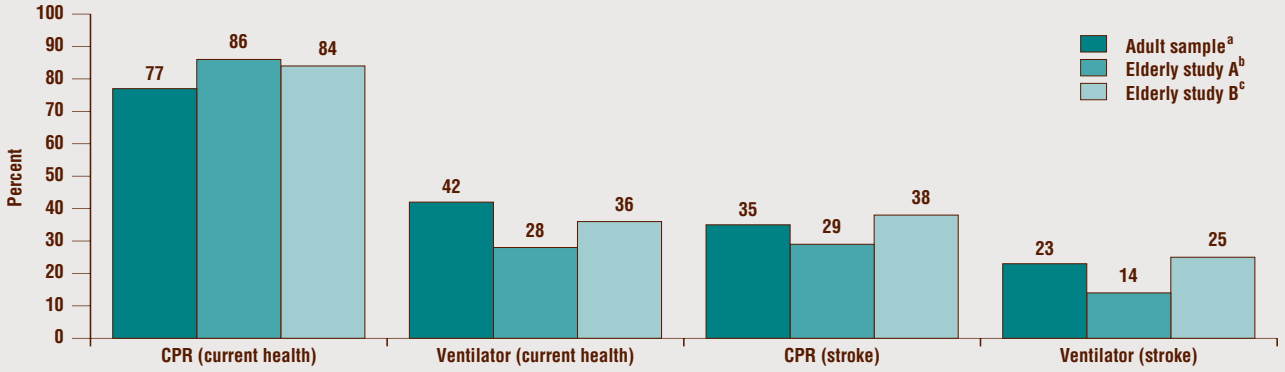
## Figure 2. Percent of sampled adults[a] who would want cardiopulmonary resuscitation if in hypothetical health states




[a]Sample included 50 well adults ages 21-65 years, 49 well adults older than 65, 49 older adults with chronic illness, 48 adults with terminal cancer, 50 adults with AIDS, 45 stroke survivors, and 50 nursing home residents.

**Source:** Patrick DL, Pearlman RA, Starks HE, et al. Validation of preferences for life-sustaining treatment: implications for advance care planning. Ann Intern Med 1997;127(7):509-17.

## Figure 3. Percent of adults who would want cardiopulmonary resuscitation (CPR) or long-term mechanical ventilation if in current health or after hypothetical stroke




[a]Sample included 50 well adults ages 21-65 years, 49 well adults older than 65, 49 older adults with chronic illness, 48 adults with terminal cancer, 50 adults with AIDS, 45 stroke survivors, and 50 nursing home residents. **Source:** Patrick DL, Pearlman RA, Starks HE, et al. Validation of preferences for life-sustaining treatment: implications for advance care planning. Ann Intern Med 1997;127(7):509-17.

[b]Patients were 65 years or over with at least 1 chronic disease, at least 1 visit to the physician in the past 6 months and 2 visits in the past year, no dementia, and not terminally ill. **Source:** Uhlmann RF, Pearlman RA, Cain KC. Understanding of elderly patients' resuscitation preferences by physicians and nurses. West J Med 1989;150(6):705-7.

[c]Patients were 65 years or over with at least 1 chronic disease, at least 2 visits to the physician in the last 12 months, no dementia, and not terminally ill. **Source:** Uhlmann RF, Pearlman RA, Cain KC. Physicians' and spouses' predictions of elderly patients' resuscitation preferences. J Gerontol 1988;43(5):M115-21.

In the AHRQ study examining health states worse than death, patients were more likely to accept short-term mechanical ventilation than long-term mechanical ventilation for all health states (Figure 4).[39]

When asked to consider a hypothetical scenario of chronic lung disease, the majority of elderly patients wanted resuscitation but not the use of a long-term ventilator.[44] These results are comparable to the preferences of patients actually suffering from lung cancer or COPD, who were also less likely to want the use of a ventilator than to want resuscitation only (Figure 5).[47]

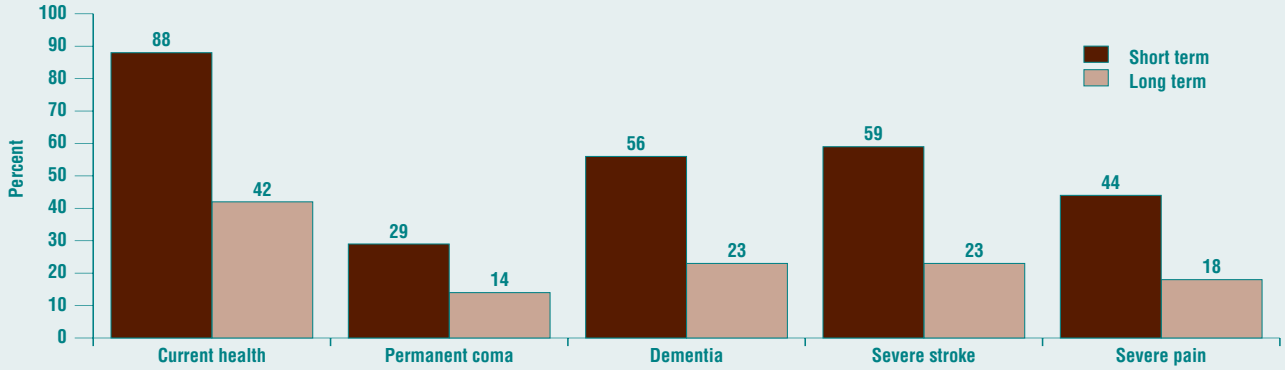
For all health states, patients were more likely to accept treatment on a trial basis if the treatments were simple, such as receiving antibiotics (Figure 6).[39] In another AHRQ-funded study, patients age 64 and over were more inclined to choose simple treatments such as antibiotics and blood transfusion for their current state of health as well as future hypothetical states of being mentally confused or unconscious (Table 1).[46] Patients also preferred temporary respiration and tube feeding to permanent respiration and tube feeding.[46]

## Patterns regarding invasiveness can predict patient preferences

AHRQ studies show that declining antibiotics, noninvasive diagnostics, and intravenous fluids strongly predicted that more invasive treatments such as major surgery would also be refused (Table 2). Conversely, accepting more invasive treatments such as a major operation or dialysis was the strongest predictor that the patient would accept less invasive treatments, although it was not as strongly predictive as refusing a noninvasive treatment. Although refusing CPR or mechanical ventilation has some ability to predict a patient's refusal or acceptance of other treatments, a patient's refusal of resuscitation does not necessarily predict that the patient would decline other less invasive treatments.[45]

Treatments that the patient considered comparable were predictive of each other. For example, refusing resuscitation was predictive of refusing major surgery, and refusing mechanical ventilation was predictive of refusing dialysis. Accepting a procedure such as endoscopy was predictive of accepting minor surgery, and accepting intravenous hydration or artificial nutrition were predictive of each other.[45]

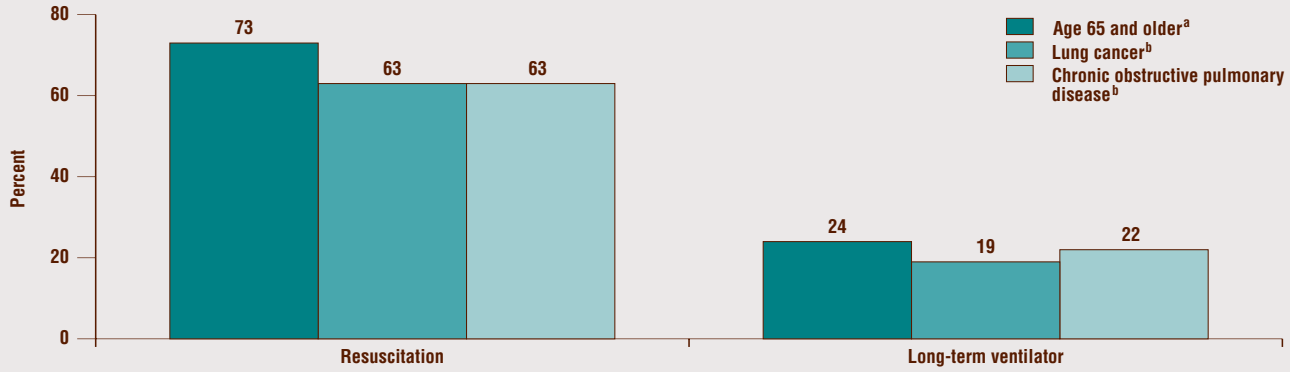
**Figure 4. Percent of sampled adults who would want short-term or long-term mechanical ventilation if in hypothetical health states[a]**




[a]Sample included 50 well adults ages 21-65 years, 49 well adults older than 65, 49 older adults with chronic illness, 48 adults with terminal cancer, 50 adults with AIDS, 45 stroke survivors, and 50 nursing home residents.

**Source:** Patrick DL, Pearlman RA, Starks HE, et al. Validation of preferences for life-sustaining treatment: implications for advance care planning. Ann Intern Med 1997;127(7):509-17.

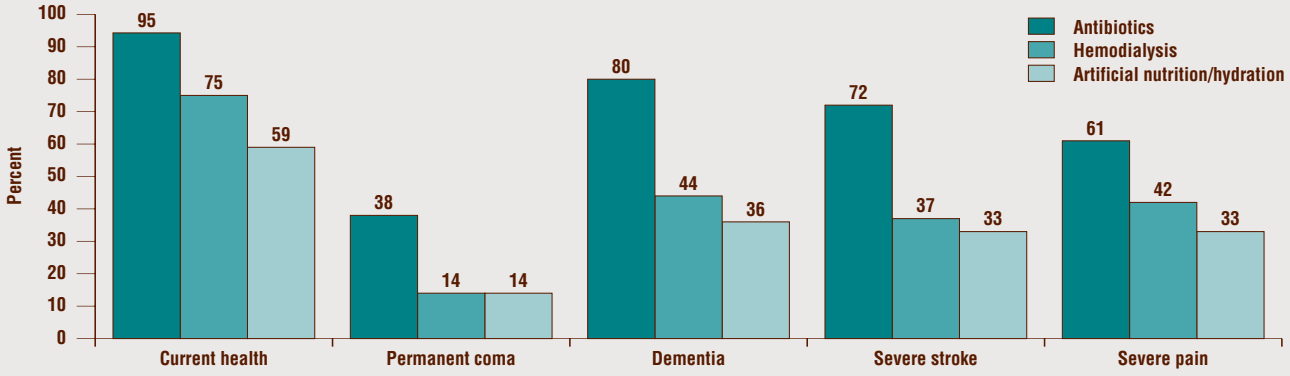
## Figure 5. Percent of adults who would want resuscitation or use of a ventilator for a hypothetical scenario of chronic lung disease




[a]Patients were 65 years or over with at least 1 chronic disease, at least 1 visit to the physician in the past 6 months and 2 visits in the past year, no dementia, and not terminally ill. **Source:** Uhlmann RF, Pearlman RA, Cain KC. Understanding of elderly patients' resuscitation preferences by physicians and nurses. West J Med 1989;150(6):705-7.

[b]Patients were 18 and over and had acute exacerbation of chronic obstructive pulmonary disease and non-small-cell lung cancer, Stage III or IV. **Source:** Claessens MT, Lynn J, Zhong Z, et al. Dying with lung cancer or chronic obstructive pulmonary disease: insights from SUPPORT. J Am Geriatr Soc 2000;48(5):S146-S153.

## Figure 6. Percent of sampled adults who would want selected treatments if in hypothetical health states[a]




[a]Sample included 50 well adults ages 21-65 years, 49 well adults older than 65, 49 older adults with chronic illness, 48 adults with terminal cancer, 50 adults with AIDS, 45 stroke survivors, and 50 nursing home residents.

**Source:** Patrick DL, Pearlman RA, Starks HE, et al. Validation of preferences for life-sustaining treatment: implications for advance care planning. Ann Intern Med 1997;127(7):509-17.

**Table 1. Rank order of treatment preferences among patients age 64 and over,[a] from most to least preferred**

| |
|---|
| Antibiotics |
| Blood transfusion |
| Temporary tube feeding |
| Temporary respirator |
| Radiation |
| Amputation |
| Dialysis |
| Chemotherapy |
| Resuscitation |
| Permanent respirator |
| Permanent tube feeding |

[a]Patients admitted to a unit within the hospital's internal medicine department who were not acutely ill.

**Source:** Cohen-Mansfield J, Droge JA, Billig N. Factors influencing hospital patients' preferences in the utilization of life-sustaining treatments. Gerontologist 1992;32(1):89-95.

**Table 2. Rank order of treatment preferences as predictors of preferences for other treatments from strongest to weakest predictive ability among adult hospital outpatients**

| Decline predictors | Acceptance predictors |
|---|---|
| Antibiotics | Major operations |
| Noninvasive diagnostics | Dialysis |
| Intravenous fluids | Mechanical ventilation |
| Minor operations | Tube feeding |
| Tube feeding | Blood transfusions |
| Dialysis | Cardiopulmonary resuscitation |
| Invasive diagnostics | Intravenous fluids |
| Blood transfusions | Minor operations |
| Mechanical ventilation | Invasive diagnostics |
| Cardiopulmonary resuscitation | Antibiotics |
| Major operations | Noninvasive diagnostics |

**Source:** Emanuel LL, Barry MJ, Emanuel EJ, et al. Advance directives: can patients' stated treatment choices be used to infer unstated choices? Med Care 1994;32(2):95-105.

### Treatment preference patterns are based on prognoses

According to AHRQ research, patients were consistently more likely to refuse treatment for a scenario with a worse prognosis. For example, more adult patients would refuse treatment if they had dementia with a terminal illness than if they only had dementia (Figure 7).[32] Similarly, more patients would refuse treatment for a persistent vegetative state than they would if they were in a coma with a chance of recovery (Figure 8).[32] Prognosis was a significant factor for patients age 65 and over in determining whether or not to accept life-sustaining treatment. Patients were more likely to choose antibiotics, cardiopulmonary resuscitation, surgery, and artificial nutrition/hydration when there was even a slight chance of recovery from a stroke or a coma than when there was no hope of recovery (Figure 9). Patients also were more likely to want treatment if terminal cancer had no associated pain than if pain medication was required constantly.[7]

An AHRQ-funded study of patients age 75 and over and patients with chronic disease indicates that as treatments become more complicated and invasive, fewer patients would want them if they had a terminal illness (Figure 10).[48] The results of other research on preferences for care in the case of terminal illness conducted among the elderly, the majority of whom had chronic illnesses, are also shown in Figure 10.[49]

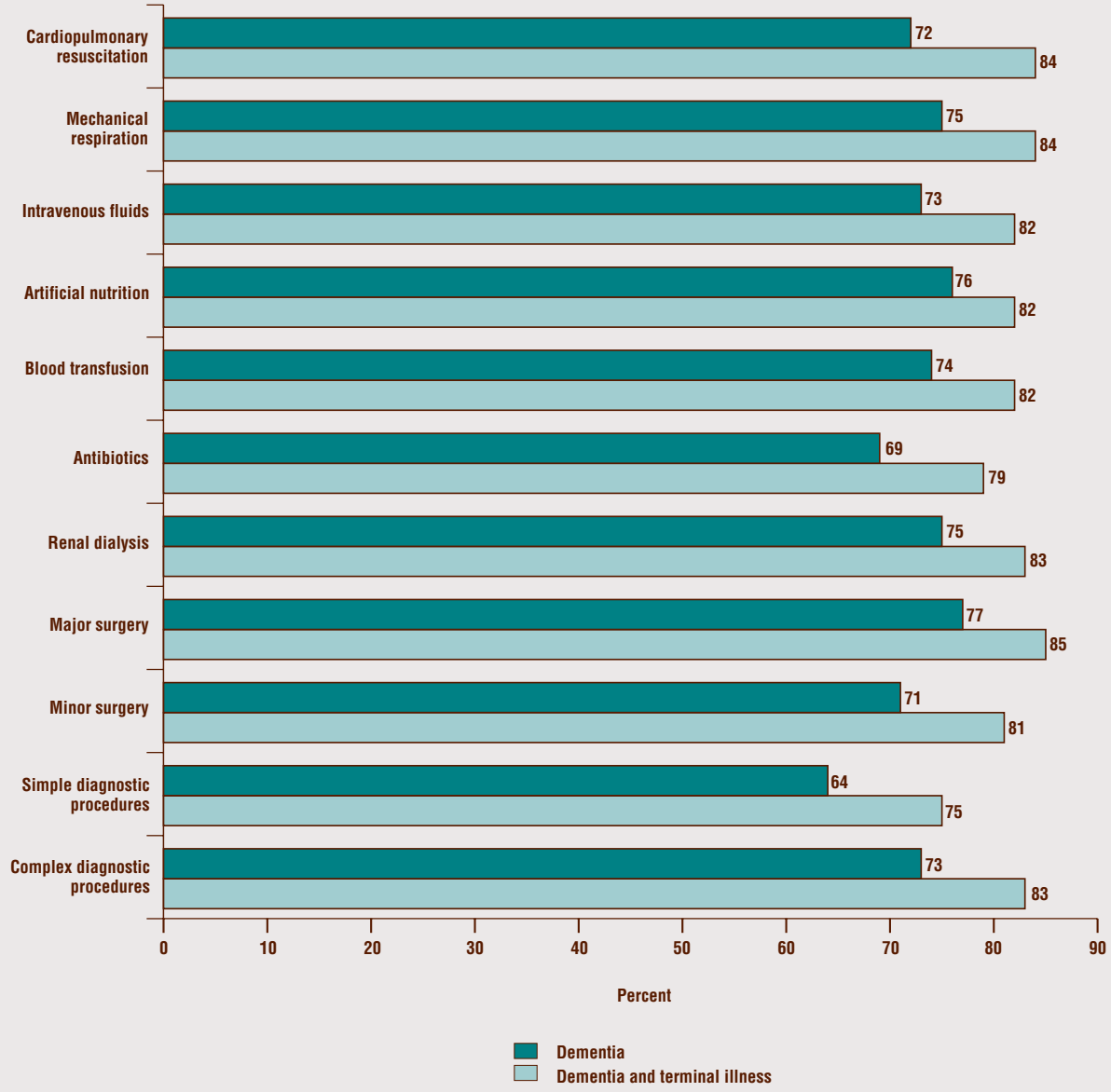
### Patients prefer treatment if they will retain cognitive awareness

AHRQ-funded research showed that about two-thirds (66 percent) of patients age 64 and over who were admitted to a hospital's internal medicine department but were not acutely ill had a cognitive-dependent treatment pattern: they desired less treatment if they were to become more cognitively impaired.[46] Another AHRQ-funded study showed that elderly patients are far less likely to accept treatment if presented a hypothetical scenario for a cognitive impairment such as Alzheimer's disease than for a physical impairment such as emphysema (Figure 11).[7]

## For more information

For further information on care at the end of life, please contact Ronda Hughes, Ph.D., at rhughes@ahrq.gov or by telephone at 301-594-0198.

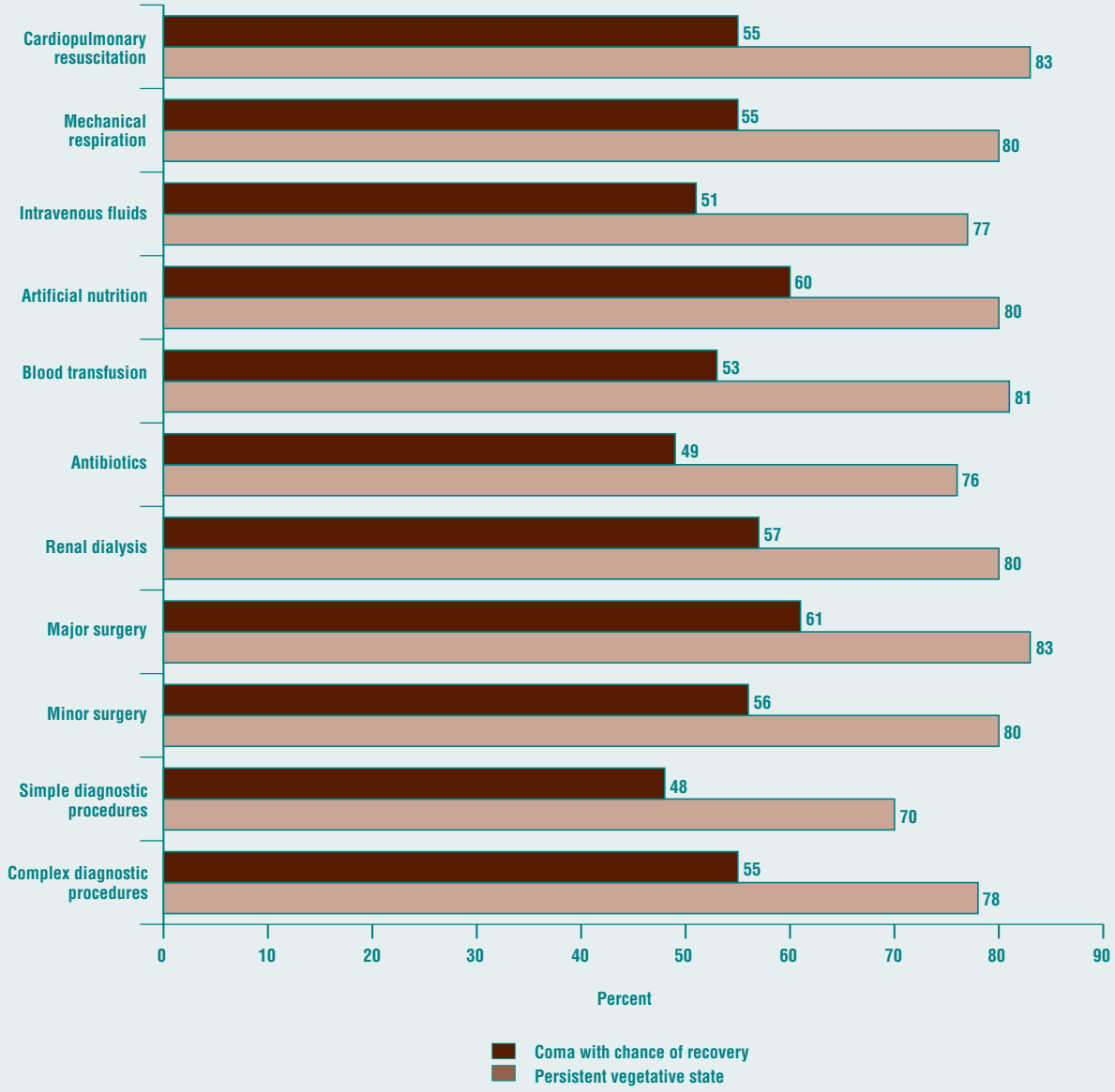
## Figure 7. Percent of adults refusing selected treatments for hypothetical health scenarios of dementia or dementia with a terminal illness[a]




[a]Sample included adult outpatients of primary care physicians and members of the general public.

**Source:** Emanuel LL, Barry MJ, Stoeckle JD, et al. Advance directives for medical care–a case for greater use. N Engl J Med 1991;324(13):889-95.

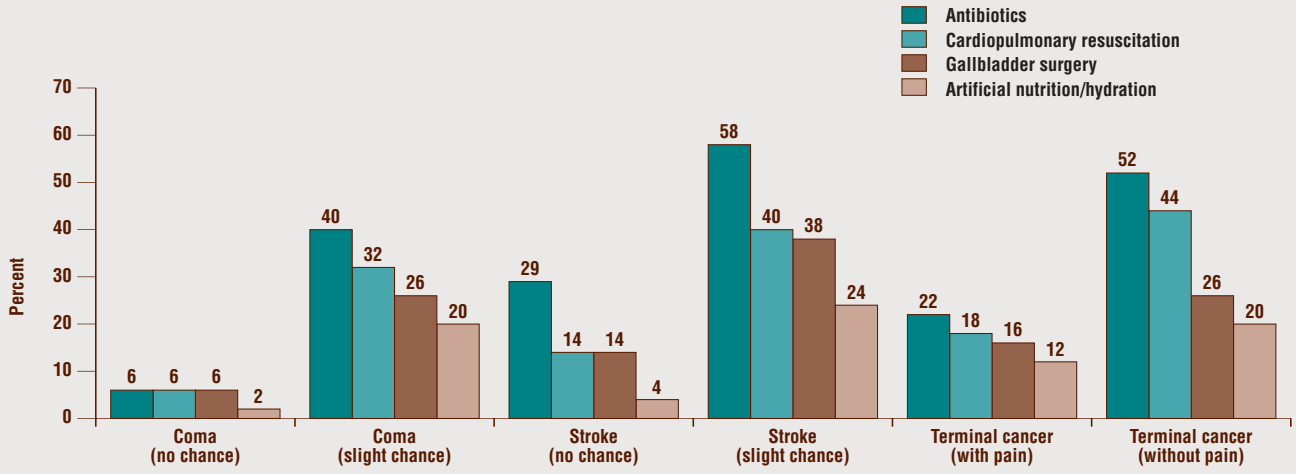
**Figure 8. Percent of adults refusing selected treatments in hypothetical health scenarios of coma with a chance of recovery or a persistent vegetative state[a]**




[a]Sample included adult outpatients of primary care physicians and members of the general public.

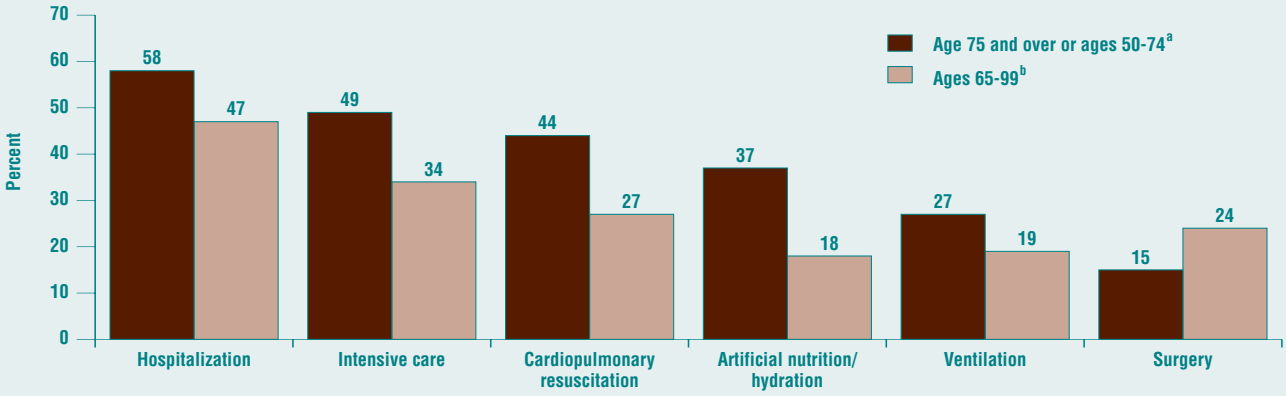
**Source:** Emanuel LL, Barry MJ, Stoeckle JD, et al. Advance directives for medical care–a case for greater use. N Engl J Med 1991;324(13):889-95.

## Figure 9. Percent of elderly adults choosing selected treatments in hypothetical scenarios based on chance of recovery or presence of pain




**Source:** Coppola KM, Bookwala J, Ditto PH, et al. Elderly adults' preferences for life-sustaining treatments: the role of impairment, prognosis, and pain. Death Studies 1999;23:617-34.

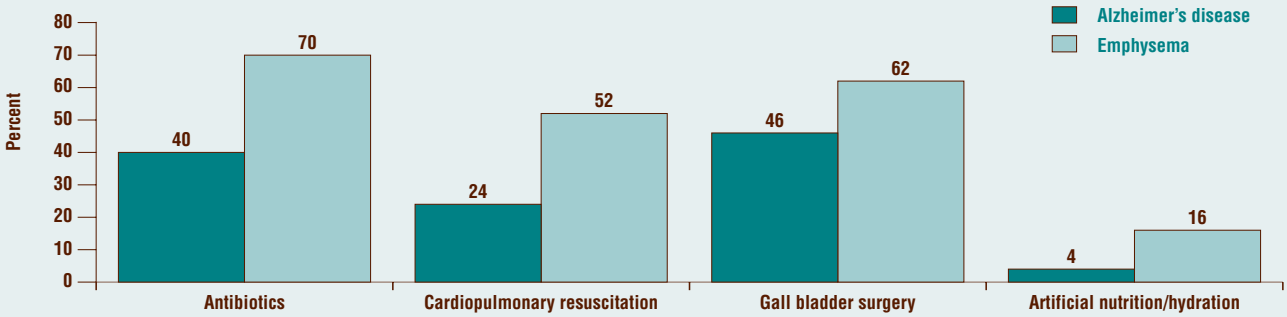
## Figure 10. Percent of patients choosing selected treatments in hypothetical scenarios of terminal illness




[a]Patients were age 75 and over or ages 50-74 with congestive heart failure, ischemic heart disease, cancer, chronic lung disease, stroke or transient ischemic attacks, chronic renal insufficiency or chronic liver disease. **Source:** Gramelspacher GP, Zhou X, Hanna MP, et al. Preferences of physicians and their patients for end-of-life care. J Gen Intern Med 1997;12:346-51.

[b]Patients were ages 65-99: 14 percent with no major illness, 19 percent with minor chronic illness, 50 percent with major chronic illness, and 15 percent with severe chronic illness or advanced cancer. **Source:** Garrett JM, Harris RP, Norburn JK, et al. Life-sustaining treatments during terminal illness. Who wants what? J Gen Intern Med 1993;8(7):361-68.

**Figure 11. Percent of elderly adults choosing selected treatments in hypothetical scenarios of Alzheimer's disease or emphysema**




**Source:** Coppola KM, Bookwala J, Ditto PH, et al. Elderly adults' preferences for life-sustaining treatments: the role of impairment, prognosis, and pain. Death Studies 1999;23:617-34.

## AHRQ-Sponsored/Funded Research Projects on End-of-Life Care

*Quality-of-Life Factors in Geriatric Medicine Decisions,* 1984-86, Grant No. HS05303, University of Washington: Compared similarities and differences among elderly patients, spouses, and physicians regarding their quality-of-life values.

*Effects of Advance Directives on Medical Care*, 1987-91, Grant No. HS05617, University of California, San Diego: Examined the effect of advance directives on the costs of health care, satisfaction with health care, and well-being among patients with life-threatening illnesses.

*Living Wills: For Primary Care, AIDS, and Cancer Patients*, 1989-91, Grant No. HS06120, Massachusetts General Hospital: Studied use of living wills, stability of preferences, and discussions between physicians and ambulatory patients.

*Long-Term Stability of Treatment Preferences*, 1989-95, Grant No. HS06343, University of Washington: Determined the long-term stability and predictive validity of preferences for life-sustaining treatment and health states that patients consider worse than death.

*Making Choices and Allocating Resources Near Life's End,* 1990-95, Grant No. HS06655, University of North Carolina: Explored treatment preferences and congruency among elderly patients with severe heart disease, lung disease, and cancer.

*Advance Directives—Effectiveness of Mandatory Notice*, 1991-94, Grant No. HS07075, Dartmouth College: Investigated the impact of the Patient Self-Determination Act, use of advance directives, and treatment preferences of severely ill patients.

*Advance Directives and Communication in Medical Care*, 1991-96, Grant No. HS06912, University of California, San Diego: Studied the effects of advance directives on personal autonomy, cost of health care, well-being, and patient-physician communication among patients with life-threatening illness.

*Nursing Home Residents' Treatment Preferences,* 1992-95, Grant No. HS06815, University of Pennsylvania: Examined the use of advance directives in nursing homes to ascertain whether there were institutional and/or individual factors associated with treatment preferences.

*Advance Directive Discussions With Elderly Outpatients*, 1993-95, Grant No. HS07660, Kent State University: Analyzed the impact of physician-initiated discussions regarding advance directives and physicians' ability to predict treatment preferences of their elderly outpatients.

*Ethnicity and Attitudes Toward Advance Care Directives*, 1993-96, Grant No. HS07001, University of Southern California: Explored attitudes toward medical technology, withholding and withdrawing treatment, and advance care documents among different ethnic groups.

*Advance Directives, Proxies, and Electronic Medical Records*, 1993-97, Grant No. HS07632, Indiana University: Studied the ability to encourage discussions about advance directives and documentation of patient treatment preferences through a computer system.

*Systematic Application of a Health Care Directive*, 1994-98, Grant No. HS07878, McMaster University: Examined the effects of the systematic application of the Let Me Decide directive on patient and family satisfaction with health care, health care use, and health care costs among nursing home residents.

*Resource Use in Seriously Ill Medicare Patients*, 1995-98, Grant Nos. HS08158/HS09129, Dartmouth College: Investigated Medicare beneficiaries' utilization of services, the Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment (SUPPORT) intervention to improve decisionmaking, and implementation of the Patient Self-Determination Act.

*Testing the Effectiveness of Advance Medical Directives*, 1995-2001, Grant No. HS08180, Kent State University: Compared different methods of collecting advance directive information to improve surrogates' ability to predict patient preferences for life-sustaining treatment and measured stability of patient treatment preferences over time.

*Medical Decisions and Advance Care Planning in the Nursing Home,* 1998-2000, Grant. No. HS09833, Hebrew Home of Greater Washington: Studied factors influencing end-of-life medical decisions and use of advance directives among nursing home residents.

*A Detailed Profile of End-of-Life Care in Medicare*, 1999-2001, Grant No. HS10561, RAND Corporation: Investigated health care use among Medicare beneficiaries at the end of life.

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AHRQ Pub. No. 03-0018
March 2003