

Patient, Physician, and Family Member Understanding of Living Wills

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This study examines understanding of living wills by patients, family members, and physicians. Questionnaires were used to examine whether each cohort understood patients' living wills regarding endotracheal intubation and cardiopulmonary resuscitation (CPR). Of 4,800 patients admitted during the study period, 206 reported having living wills, all of which precluded intubation and CPR for "terminal conditions." Of 140 admitted to the general hospital wards, 17 (12%) wanted their living wills to preclude intubation/mechanical ventilation and 12 (8.6%) did not want resuscitation under any circumstances. Seven of 120 (6%) physicians and 4 of 108 family members would not intubate or perform CPR even if there was a chance of recovery. Of 88 patients with complete data (including physicians and family members), 29 (33%) wanted their living wills to block intubation/mechanical ventilation only if they were deemed terminal and 46 (52%) wanted the living will to block intubation even if there was a 10% chance of recovery. Thirteen (15%) wanted to block intubation even if the chance of recovery was ≥ 50 . Results were similar for wishes regarding CPR. These data suggest substantial differences of patient, physician, and family member understanding of living wills. Living wills did not reflect fully patients' expectations of receiving (or not receiving) life-sustaining modalities.

Keywords: living will; advance directive; end-of-life; critical care; death

Living wills are written documents used by patients to convey wishes for medical care should they become acutely ill and unable to communicate with caregivers. Since 1990, the Federal Patient Self-Determination Act has required that patients admitted to hospital be asked whether they have a living will, and if not, whether they want information to help them make one. Not infrequently, patients experience impaired competence or inability to communicate during critical illness. Physicians must determine, with the help of surrogates (usually family members), medical treatments that the patient would want. Living wills are invoked to infer the wishes of patients for life-sustaining therapies under specified circumstances. However, intensivists who often oversee the care of such patients have had no prior relationship with them, and therefore are not often privy to the formulation of living wills. Intensivists must thus depend on family members and patients' primary care physicians to aid in making end-of-life decisions and actuation of living wills.

The wording of most living wills, particularly the clause "if my condition is deemed terminal or if it is determined that I will be permanently unconscious, I be allowed to die and not kept alive through life support systems" (1), may lead to signifi-

cant ambiguity for patients, doctors, and families (2). Previous studies have demonstrated that physicians often do not appropriately institute and apply living wills (3).

No published study has assessed whether patients, family members, and physicians understand patients' living wills and if the living wills, as currently written, truly reflect patients' end-of-life wishes. In this study, we hypothesize that ambiguity in the language of living wills could lead frequently to misunderstanding. We examine this hypothesis by interviewing patients who have living wills, and their physicians and family members to examine their understanding of the living wills with respect to the use of cardiopulmonary resuscitation (CPR) and endotracheal intubation/mechanical ventilation.

METHODS

The study was undertaken in a 325-bed community teaching hospital. The hospital serves an inner-city population of about 300,000 and its suburbs. Our hospital's Investigational Review Board approved this study. The admitting clerk asked all adult patients who were admitted to the hospital whether they had, and if not, whether they wished to obtain, information about advance directives. All patients admitted between July and October 2001, who indicated they had living wills, were eligible for the study. For the purposes of this study, we define living will as a particular type of advance directive that includes, at a minimum, a statement regarding conditions in which a patient would not want endotracheal intubation/mechanical ventilation or cardiopulmonary resuscitation (CPR). Patients were not interviewed for this study if they had mental status changes preventing them from answering simple questions regarding their living wills and/or if they refused to participate.

Oral questionnaires were administered to each patient, the primary care physician, and a family member, who the patient considered "closest" and able to answer questions regarding the living will. Three investigators conducted all interviews using uniform questionnaires; samples are included in the APPENDIX and complete copies in the online data supplement. Patients recovering from critical illness who had living wills were interviewed on or after their third day after discharge from the intensive care unit (ICU). Validation questions were also administered to patients to determine whether they understood the questions in the primary patient questionnaire.

Demographic data including age, sex, race, level of education, comorbidities, and APACHE (acute physiology and chronic health evaluation) II scores on admission were also recorded/computed. Levels of agreement were assessed using stratified analyses. Comparisons between groups, defined on the basis of specific responses, were performed using ANOVA for continuous outcome variables, Chi-squares for differences between outcome proportions or categorical variables, and nonparametric methods (Kruskal-Wallis and Mann-Whitney U-test) for differences between medians. Analyses were facilitated by the use of EpiInfo 2000 (Centers for Disease Control and Prevention, Atlanta, GA) (4) and STATISTICA software packages (Statsoft Inc., Tulsa, OK). *p* Values < 0.05 signified statistical significance.

RESULTS

During the study period, 4,800 patients were admitted to the hospital. Figures 1A and 1B show the racial mix of all admitted patients and the 206 (4.3%) who were identified as having living wills. White patients were 23.2 times as likely to have living wills as admitted

(Received in original form June 3, 2002; accepted in final form September 10, 2002)

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This article has an online data supplement, which is accessible from this issue's table of contents online at www.atsjournals.org

Am J Respir Crit Care Med Vol 166, pp 1430-1435, 2002

Originally Published in Press as DOI: 10.1164/rccm.200206-503OC on September 11, 2002
Internet address: www.atsjournals.org

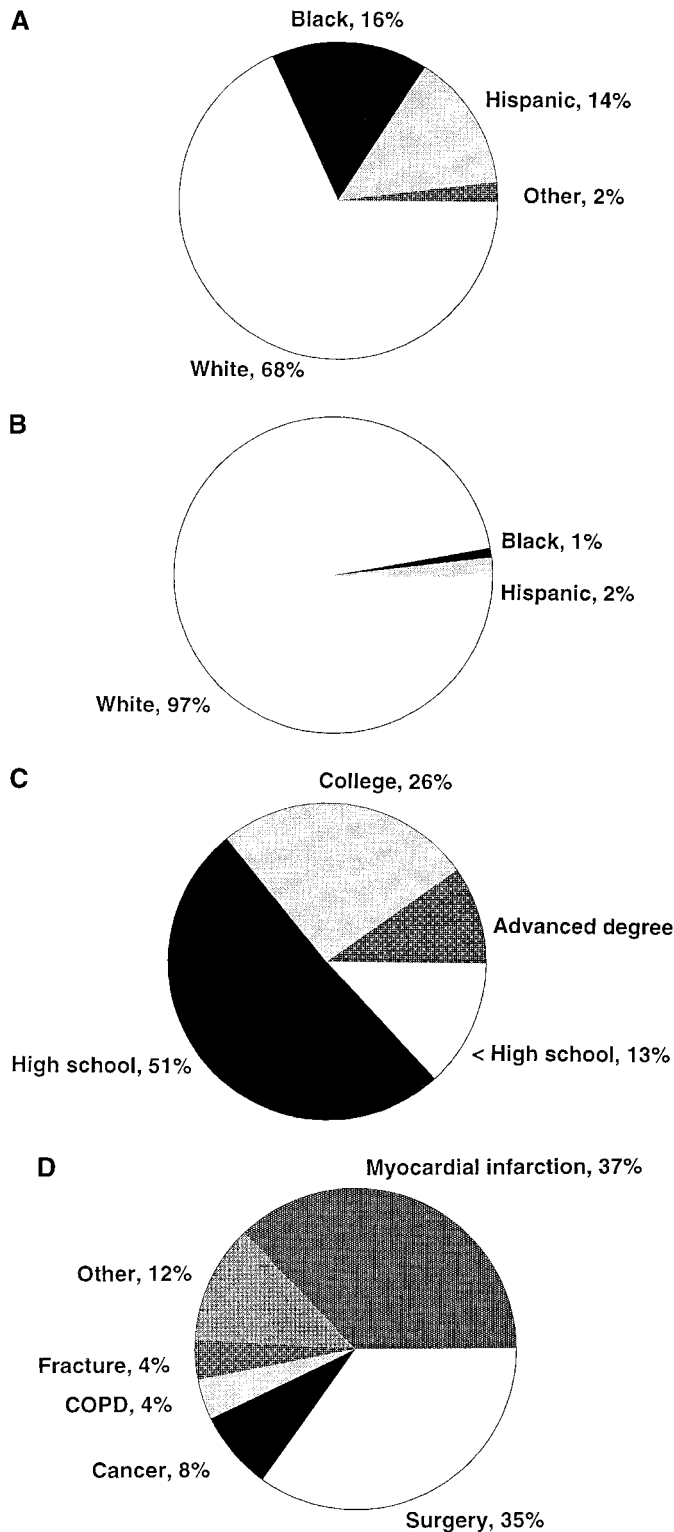


Figure 1. Demographics of patients admitted with and without living wills during the study period. *A* shows the racial profile of all patients admitted to hospital during the study. *B* shows the racial profile of patients with living wills. *C* shows the highest level of education. *D* shows the reasons for admission of those with living wills.

Black patients (relative risk [RR] = 23.2; 95% confidence interval [CI] = 5.8–93.0) and 10.5 times as likely as Hispanic patients (RR = 10.5; 95% CI = 3.9–28.2).

Fifty-five of the 206 patients with living wills were excluded

from the study. Twenty-five patients had been discharged before they could be interviewed, 15 had gross mental status changes, 10 refused participation, 3 were admitted twice (first answers counted), and 2 died while in the ICU. One hundred fifty-one patients (70 men and 81 women, ranging in age from 25–91 years; mean = 71 years, SE = 1.0 years), 70 physicians (caring for 120 of the patients), and 108 family members participated in the study. Highest levels of education and reasons for admission are shown in Figures 1C and 1D, respectively. APACHE II scores of patients ranged from 0 to 33 with a mean of 7.5 and median of 6.

All living wills of the cohort were examined by study personnel. All included language that was identical or similar to the Connecticut Attorney General's Office sample, i.e., "if my condition is deemed terminal or if it is determined that I will be permanently unconscious, I be allowed to die and not kept alive through life support systems" (1). All patients had specifically checked or stipulated that they did not want CPR or intubation in these situations. Eleven living wills also stipulated surrogate decision-makers, and none precluded other therapies beyond CPR and intubation.

Did You Want Your Living Will to Block Intubation or CPR?

Eleven patients were initially admitted to the ICU and received endotracheal intubation and/or CPR during admission. All were interviewed at least 3 days after discharge from the ICU when they were able to communicate clearly. All 11 had not wanted their living wills to block CPR or mechanical ventilation for nonterminal illnesses.

The remaining 140 patients were able to communicate, and none were intubated or received CPR during admission. Answers to the primary and validation questions were 100% consistent. Seventeen of 140 (12.1%) patients wanted their living wills to preclude intubation/mechanical ventilation under any circumstances, even if there was a possibility of recovery. Similarly, 12 of 140 (8.6%) patients did not want CPR under any circumstances (9 of whom also did not want intubation). People who did not want to be intubated were older than those who would consent to be intubated under certain circumstances (77 versus 70 years, $p = 0.02$). Similarly, those who did not want CPR under any circumstance were older (79 versus 69 years, $p = 0.01$). There were no significant differences in APACHE II scores, levels of education, or comorbidities (including presence of metastatic cancer) in those who wished no intubation or CPR under any circumstances (versus those who preferred it). Seven of 140 wanted CPR, even if there was no chance of recovery, but did not want mechanical ventilation unless there was a chance of survival.

Of 120 responses obtained from 70 physicians who had been in practice for a mean of 19 (range = 1–48) years, 7 said they would not intubate or perform CPR on their patients with living wills under any circumstances. Three of these patients wanted intubation and CPR if there was a chance of recovery. One patient was deemed terminal by her physician, who executed the living will with a formal "do not intubate/no CPR" order. This was the only patient who had a formal "do not resuscitate" order written in her chart. Physicians who would neither intubate nor perform CPR, even if there was a chance of recovery, were in practice for similar lengths compared with those who would.

There were two physicians who would have administered a trial of intubation and/or CPR even if they thought that the patient had no chance of recovery. These patients and their families stated that they would want intubation and CPR only for a reversible condition.

Five of 108 family members understood the living will to preclude intubation under any circumstances, even if there were a possibility of recovery. In two of these cases, the patients indicated they wanted intubation for reversible conditions. Four family members would not want CPR for the patient based on their understand-

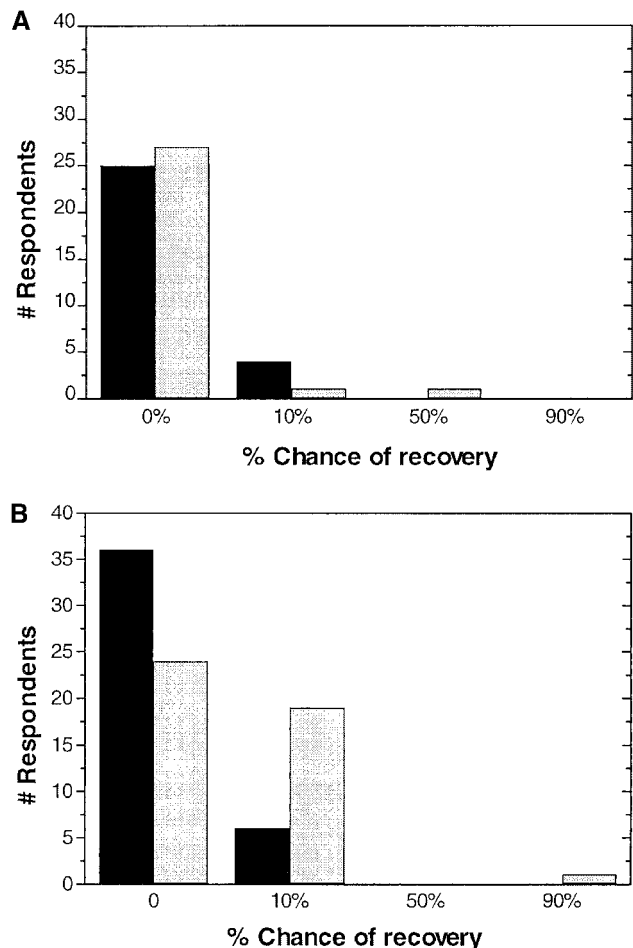


Figure 2. Responses of physicians and family members of patients who "wanted the living will to block use of a breathing machine at no chance (A) and a 10% chance (B) of recovery. The dark bars represent physician responses and the light bars family responses. A demonstrates responses of physicians and family members of patients who wanted their living will to block intubation only if they had no chance of recovery. The bars represent the number of physicians and family members of these patients who would intubate at varying thresholds of prognosis. For example, four physicians and one family member would not intubate at a 10% chance of recovery in these patients who only wanted the living will to block intubation if there was no chance of recovery. B demonstrates these responses for patients who wanted their living will to block intubation at a 10% chance of recovery.

ing of the living will. In one of these cases, the patient wanted CPR to be performed if there was a chance of recovery.

Are There Any Circumstances in Which You Would Want Your Living Will to Block Intubation or CPR?

There were 88 patients for whom there was complete information from patients, physicians, and family members regarding intubation at varying levels of possibility of survival. Twenty-nine (33%) of these patients indicated that they intended the living will to block intubation only if they were deemed terminal, and 46 patients wanted the living will to block intubation at a 10% chance of recovery. Figure 2 demonstrates responses of physicians and family members for these patients. Thirteen patients wanted to block intubation even if the chance of recovery was $\geq 50\%$; two of their physicians and five family members agreed.

There were 89 patients for whom there was complete informa-

tion from patients, physicians, and family members regarding CPR at varying levels of possibility of survival. Four patients wanted CPR even if there was no chance of recovery. Thirty-one (35%) patients indicated that they intended the living will to block CPR only if they were deemed terminal, and 43 patients wanted the living will to block CPR at a 10% chance of recovery. Levels of physician and family agreement were very similar to those shown for intubation. Eleven patients wanted to block CPR even if the chance of recovery was $\geq 50\%$; two of their physicians and three family members agreed.

Family members of patients who were admitted to the ICUs were more than two times as likely (RR = 2.4; 95% CI = 1.5–3.9) to withhold intubation at a $\leq 10\%$ chance of recovery compared with patients admitted to the hospital floors. Similarly, compared with the patients on the floors, these patients were more than two times as likely to be refused CPR by family members if the chance of recovery was $\leq 10\%$ (RR = 2.2; 95% CI = 1.2–4.4). There were no differences in physician responses based on whether the patient was admitted to the floors or the ICUs. Similarly, patient choices for intubation and CPR did not depend on the floor where they were treated.

DISCUSSION

Although other studies have examined the effects of advance directives on physician perceptions and patient care at the end-of-life (2, 3, 5–7), to our knowledge this is the first study to examine the understanding of patients, doctors and family members of patients' living wills. Our data demonstrate convincingly that there is a lack of clarity among patients, physicians and family members about what a living will mandates and under what circumstances it is appropriately executed. Although the three cohorts had a very high (> 87%) concordance of understanding regarding the "use of life support systems to keep (patient) alive," 71% of patients, 42% of family members, and 27% of physicians answered that the living will could be used to guide treatments in situations with a $\geq 10\%$ likelihood of survival.

There are several possible explanations for our results. First, living wills are drafted frequently by patients without the presence or input of a physician. Many of the concepts inherent in living wills, e.g., the meaning of "terminal" and the efficacy of "life-support" systems, may not be fully understood by patients and perhaps attorneys. The term "terminal" is not an absolute; studies have demonstrated convincingly a great deal of interphysician variability in designating "terminal condition" (8). Our study suggests that many patients may consider terminal to mean a very low but not zero chance of survival or they simply intend the living will to imply their wishes in such situations. Also, patient understanding of "life-support" may be poor. We suspect that few patients fully comprehend the concept of a "trial of intubation" to determine whether a condition is reversible or the many facets and risks associated with critical care. Some patients also do not understand CPR; 5% of patients wanted CPR but rejected intubation/mechanical ventilation under any circumstances. They may also fail to comprehend the likelihood of good survival after CPR (9–12). Murphy and coworkers reported that half of patients who initially said they wanted CPR changed their minds after they learned the true probability of survival (9). Accordingly, physicians must become participants in the process of end-of-life decision-making. If these discussions do not occur before the patient becomes moribund, there is often little hope of ascertaining patients' wishes, especially regarding subterminal conditions. Most living will constructs stipulate that the document is not enough; that to ensure a living will is honored, wishes should be discussed with physicians and family members. Yet physicians often do not know their patients have living wills (13).

Our study suggests that a minority of hospitalized patients and few non-white patients have living wills. A preliminary report suggests that living wills are not uniformly reported on hospital admission (14). Little is known about cross-cultural differences in attitudes regarding the acceptability of advance directives. In a study regarding end-of-life discussions and preferences among persons with HIV, race (black and Hispanic), and low education levels were associated with absence of advance directives (15). However, discussion of end-of-life decision-making was the single most powerful predictor of having a living will, and physicians were less likely to engage non-whites in end-of-life discussions. The reasons for these racial differences are not clear.

There are several limitations of this study. Every effort was made to study consecutively admitted patients, but some (52) patients could not be included. Selection bias is possible. Also, we cannot determine the degree to which answers of the various respondents reflected their understanding of the living wills versus their own personal, *current* beliefs. Patients' answers may have reflected changes of their wishes that had evolved from the time their living wills were drafted. Some physicians and patients may have had additional conversations; information that supplemented the living will in physicians' knowledge of patient preferences. Although the questionnaires were not validated *a priori*, redundant "validation" questions were answered concordantly in 100% of cases, suggesting, but not proving, that patients understood the questions well.

Our patient cohort consisted of patients who were not seriously ill; only 10 of the 151 patients had APACHE II greater than 15. When severe illness or death were more imminent, our patients and families answered questions about living wills differently than did stable, hospitalized patients. This may limit generalizability of the findings to patients with similar degrees of illness. Finally, our hospital has no standardized educational programs to enhance patient participation in writing living wills, nor educating physicians about their proper use. Although most physicians were the patients' primary caregivers, some physicians may not have discussed these issues with their patients. Accordingly, our results may not be generalizable to institutions where such programs or practices are more common. Nonetheless, the SUPPORT study demonstrated that most advance directives are completed without physician input and physicians are often unaware that patients have a living will (7). Thus, our local practice is likely similar to those found in the large cross-sectional reference sample. Also, our study demonstrates a lack of concordance in understanding living wills but does not examine the impact on patient care outcomes.

Some studies have examined similar, but not identical, questions. Virmani and coworkers demonstrated that 27 of 38 physicians did not know that their seriously ill cancer patients had written advance directives (13). When over 5,000 patients admitted to hospital with serious illness were interviewed for the SUPPORT study, 36% preferred to forgo CPR on that hospitalization. Their physicians thought more than half (54%) wanted CPR. Misunderstanding was associated with a lower frequency of and later "do not resuscitate" orders recorded in patients' charts (7). This study did not indicate whether advance directives impacted these observations. Knowledge of an advance directive does not necessarily translate to its use, especially if the directive is nonspecific. For example, physicians were much more likely to withhold CPR if directives were treatment-specific as opposed to general (3). Coppola and colleagues reported that scenario- and outcome-based advance directives did not improve hypothetical substituted judgment of patients' primary physicians or their family members (6). Danis and colleagues showed that among 126 patients in a skilled nursing facility, care (in the nursing home and during hospitalizations) was consistent with the wishes stated in their advance directives in only 75% of cases. But presence of the advance directive

in the hospital chart was associated with a trend toward care that was discordant with the directives (16), suggesting that care consistent with patients' wishes was provided despite, not because of, the directives. Our findings are unique in that they demonstrate misunderstanding of the applicable situations and protections provided by living wills. These findings are consistent with the above-cited literature on other forms of advance directives in that they demonstrate serious shortcomings of these systems put in place by state and federal governments to enhance autonomy at the end of life.

In conclusion, patients, families, and primary physicians frequently have differing understandings of living wills. Living wills reflect incompletely patients' wishes regarding life-sustaining therapies and may provide a false sense of security to patients that their intentions will be actualized. Better understanding of these issues, by all parties involved, is required to ensure that care provided to patients is consistent with their wishes, as expressed in their living wills and through enhanced physician-patient-family dialogue.

References

1. Manthous CA, Tobin M. A primer on critical care for patients and their families. Available at: <http://www.thoracic.org/assemblies/cc/cc.html/primer:8/27/02>.
2. Silveira MJ, DiPiero A, Gerrity MS, Feudtner C. Patients knowledge of options at the end of life: ignorance in the face of death. *JAMA* 2000;284:2483-2488.
3. Mower WR, Baraff LJ. Advance directives: effect of type of directive on physicians' therapeutic decisions. *Arch Intern Med* 1993;153:375-381.
4. Dean AG, Arner TG, Sangam S, Sunki GG, Friedman R, Lantinga M, Zubieta JC, Sullivan KM, Smith DC. Epi Info 2000, a database and statistics program for public health professionals for use on Windows 95, 98, NT and 2000 computers. Centers for Disease Control and Prevention, Atlanta, GA, 2000.
5. Goodman MD, Tarnoff M, Slotman GJ. Effect of advance directives on the management of elderly critically ill patients. *Crit Care Med* 1998;26:701-704.
6. Coppola KM, Ditto PH, Danks JH, Smucker WD. Accuracy of primary care and hospital-based physicians predictions of elderly outpatients' treatment preferences with and without advance directives. *Arch Intern Med* 2001;161:431-440.
7. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA* 1995;274:1591-1598.
8. Helft PR, Siegler M, Lantos J. The rise and fall of the futility movement. *N Engl J Med* 2000 343:293-296.
9. Murphy DJ, Burrows D, Santilli S, Kemp AW, Tenner S, Kreling B, Teno J. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. *N Engl J Med* 1994;330:545-549.
10. Miller DL, Jahnigen DW, Gorbien MJ, Simbartl L. Cardiopulmonary resuscitation: how useful? Attitudes and knowledge of an elderly population. *Arch Intern Med* 1992;152:578-582.
11. Schonwetter RS, Walker RM, Kramer DR, Robinson BE. Resuscitation decision making in the elderly: the value of outcome data. *J Gen Intern Med* 1993;8:295-300.
12. Bedell SE, Delbanco TL, Cook F, Epstein FH. Survival after cardiopulmonary resuscitation in the hospital. *N Engl J Med* 1983;309:569-576.
13. Virmani M, Schneiderman LJ, Kaplan RM. Relationship of advance directives to physician-patient communication. *Arch Intern Med* 1994;154:909-913.
14. Kavic S, Atweh N, Possenti P, Manthous CA, Ivy M. Living will use by terminal critically ill patients. *Am J Respir Crit Care Med* 2002;165:A21.
15. Wenger NS, Kanouse DE, Collins RL, Liu H, Schuster MA, Gifford AL, Bozzette SA, Shapiro MF. End-of-life discussions and preferences among persons with HIV. *JAMA* 2001;285:2880-2887.
16. Danis M, Southerland LI, Garrett JM, Smith JL, Hielema F, Pickard CG, Egner DM, Patrick DL. A prospective study of advance directives for life-sustaining care. *N Engl J Med* 1991;324:882-888.

APPENDIX

Living Will Questionnaires

Full questionnaires are listed in the online data supplement. The first question of each section is intended to determine subjects' understanding

of the living will (as regards intubation, in question #1, or CPR, in question #2). Each question is followed by a choice of two answers and a follow-up question to assure (by reiteration) that subjects understood their answer. For those who answered that they intended their living will only to preclude life-sustaining therapies in the case of terminal situations, a final question was asked to determine whether they had thresholds of prognosis for withholding therapies (no chance, 10% chance, 50% chance, 90% chance of recovery).

Patient Questions

Question 1. If you were to get very sick and could not tell the doctors what to do, did you want your living will to block use of life support systems, like a breathing machine, if it was needed to keep you alive?

- A. One purpose of the living will was to prevent me from going on a breathing machine for any reason. I would want to be kept comfortable and allowed to pass away without pain or suffering.
- B. I would want to go on the breathing machine and get treatments in the hope of getting better.

If A:

If there was some possibility that you could get better from the sickness, would you still want your living will to block the use of a breathing machine?

I don't want a breathing machine under any circumstances, even if it means I will pass away.

If my doctors felt there was any hope, I would want to go on the breathing machine.

If B:

Are there any circumstances in which you would want your living will to block the use of a breathing machine?

- a. If I had no chance of getting better as judged by my doctor.
- b. If I had a 10% chance of getting better as judged by my doctor.
- c. If I had a 50% chance of getting better as judged by my doctor.
- d. If I had a 90% chance of getting better as judged by my doctor.

Question 2. If your heart was to stop and electrical shocks or "CPR" were needed to restart your heart, did you intend that your living will block this?

- A. One purpose of the living will was to prevent me from getting CPR for any reason.
- B. I would want to get CPR in the hope of getting better.

If A:

If there was some possibility that you could get better from the sickness, would you still want your living will to block the use of CPR?

I don't want CPR under any circumstances; if my heart stops leave me be.

If my doctors felt there was any hope, I would want CPR.

If B:

Are there any circumstances in which you would want your living will to block the use of CPR?

- a. If I had no chance of getting better as judged by my doctor.
- b. If I had a 10% chance of getting better as judged by my doctor.
- c. If I had a 50% chance of getting better as judged by my doctor.
- d. If I had a 90% chance of getting better as judged by my doctor.

Physician Questions

Question 1. Your patient _____ has a living will. If he/she were to become acutely ill, requiring intubation and mechanical ventilation in order to continue supportive treatments and he/she was unable to communicate his/her wishes and you could contact no family members, would you intubate and mechanically ventilate if it was otherwise indicated?

- A. I would make the patient comfortable and allow him/her to pass away with no suffering.
- B. I would intubate, mechanically ventilate and proceed with treatments.

If A:

If you thought there was some possibility that the patient might recover, would you still withhold intubation and mechanical ventilation?

I would withhold intubation irrespective of the patient's prognosis.

If I felt there was any hope of recovery, I would intubate and mechanically ventilate.

If B:

Are there any circumstances in which you would NOT intubate and mechanically ventilate?

- a. If I felt the patient had no chance of recovery.
- b. If I felt the patient had a 10% chance of recovery.
- c. If I felt the patient had a 50% chance of recovery.
- d. If I felt the patient had a 90% chance of recovery.

Question 2. In this same patient, would you withhold CPR if it was required?

- A. I would withhold CPR.
- B. I would provide CPR.

If A:

If you thought there was some possibility that the patient might recover, would you still withhold CPR?

I would withhold CPR irrespective of the patient's prognosis.

If I thought there was any hope of recovery, I would perform CPR if it were needed.

If B:

Are there any circumstances in which you would NOT perform CPR?

- a. If I felt the patient had no chance of recovery.
- b. If I felt the patient had a 10% chance of recovery.
- c. If I felt the patient had a 50% chance of recovery.
- d. If I felt the patient had a 90% chance of recovery.

Family Member Questions

Do you know whether your loved one has a living will saying what medical treatments they want if they get very sick and can't tell their doctor?

If Yes, then proceed.

If No, STOP (to maintain confidentiality of the patient; they may have not told others for a reason).

Question 1. If he/she was to get very sick and could not tell the doctors what to do, and he/she needed to go on a breathing machine and the doctor asked you what to do, would you ask that he/she be put on the breathing machine?

- A. I would ask that he/she be put on the breathing machine and continue treatments.
- B. I would ask that he/she NOT be put on the breathing machine and be given medicines allowing him/her to pass away without suffering.

Is that your wish or is that how you interpret the living will?

If A:

If the doctor said there was some possibility that he/she might get better, would you still ask that he/she not be put on the breathing machine?

I would not be in favor of putting him/her on a breathing machine under any circumstances.

If the doctors thought there was some hope, I would allow him/her to be put on the breathing machine.

Is that your wish or is that how you interpret the living will?

If B:

Are there any circumstances in which you would NOT ask that he/she be put on the breathing machine?

- a. If the doctor said there was no chance of recovery.
- b. If the doctor said there was a 10% chance of recovery.
- c. If the doctor said there was a 50% chance of recovery.
- d. If the doctor said there was a 90% chance of recovery.

Question 2. If your loved one's heart stopped and electrical shocks or "CPR" were needed to restart it, would you ask that CPR not be done?

- A. I would ask that CPR not be done.
- B. I would ask that CPR be done in the hope of him/her getting better.

Is that your wish or is that how you interpret the living will?

If A:

If there was some possibility that he/she might get better from the sickness, would you still ask that CPR not be done?

I would not want CPR for him/her under any circumstances.

If doctors thought there was some chance of recovery, I would ask that CPR be done.

If B:

Are there any circumstances in which you would ask that CPR NOT be done?

- a. If he/she had no chance of getting better as judged by the doctor.
- b. If he/she had a 10% chance of getting better as judged by the doctor.
- c. If he/she had a 50% chance of getting better as judged by the doctor.
- d. If he/she had a 90% chance of getting better as judged by the doctor.

If any respondent asks whether there is a reversible process that has led

to the acute illness, we respond that “the reason may be reversible, but we can never tell 100% for sure.”

Validation Questions (for patients)

Question 1. Did you make the living will to block you from going on a breathing machine for any reason?

- A. I made the living will to block me from being put on a breathing machine, even if I had a sickness that might get better.
- B. My living will was not made to block me from being put on a breathing machine. It was intended to take me off a breathing machine if I got very sick and doctors felt I had little or no chance of getting better.

Question 2. Did you make the living will to block you from getting electrical shocks or “CPR” if your heart stopped?

- A. I made the living will to block me from getting CPR no matter what.
- B. My living will was made to block CPR only if my doctor thought I had no chance of getting better.