

Comparing Utilization of Life-Sustaining Treatments with Patient and Public Preferences

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OBJECTIVE: The movement for advance planning of end-of-life care was motivated in part by the assumption that medical intervention for terminally ill patients varies from what these patients would prefer. We examined the validity of this assumption by comparing actual life-sustaining treatment practices for patients in critical illness scenarios and surveyed patients' advance care preferences.

MEASUREMENTS AND MAIN RESULTS: We selected at random and reviewed 7,400 inpatient medical records from a single urban teaching hospital during the period just prior to the Patient Self-Determination Act. Records of 198 patients with conditions that matched advance directive scenarios were examined, and practices to withhold or withdraw seven life-sustaining treatments were documented. Practices were compared with surveyed preferences of 102 members of the general public and 495 outpatients who were followed by the same physicians as the 198 patients. Concordance of practices and preferences for the 19 surveyed outpatients who eventually fell into one of the scenarios was also evaluated. One hundred sixty-seven inpatient cases met review criteria for the scenario *coma with a small chance of recovery*. Hospital patients received medical interventions that were not consistently greater or less than the preferences of the surveyed outpatients or members of the general public. Resuscitation, the most frequently withheld treatment (94% of cases), was withheld more often than surveyed preferences to decline it (56% of outpatients, $p < .001$). Four treatments—mechanical breathing, artificial nutrition, major surgery, and hemodialysis—were utilized comparably to surveyed outpatients' preferences (range $p = .704-.055$). Antibiotics and artificial hydration were withheld (9% and 6%, respectively) less often than surveyed outpatient's prior preferences to decline them (48% and 52%, respectively, $p < .001$ for each). Conversely, treatments given to the 19 surveyed patients who subsequently developed one of the illness scenarios were often incongruent with the patients' prior preferences. Again, in some cases more interventions were provided (26 of 63 declined treatments were given), and in some cases less (10 of 21 desired treatments were withheld).

CONCLUSIONS: This study does not support the assumption that, collectively, patients' advance care preferences are less interventionist than actual practices for patients in corresponding scenarios. Nevertheless, these results do support the assumption that life-sustaining treatment decisions do not conform well to individual patients' specific preferences. Progress in end-of-life care should focus on shared decision making at the patient-proxy-physician level rather than on overall life-sustaining treatments utilization.

KEY WORDS: advance directives; life support care; critical care; patient participation; treatment refusal.

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Life-sustaining treatment decisions made for unconscious patients in the absence of advance directives are often assumed, first, to be discordant with individuals' prior preferences,¹ and second, to result in more treatments at the end of life than patients would have wanted.²⁻⁵ Actual data on life-sustaining treatment practices have not been available to challenge or support either of these assumptions.

Surrogate decisions about eventual end-of-life care often differ from patients' own stated preferences,^{6,7} which is indirect evidence that the first assumption is valid. A more definitive assessment could be obtained by directly measuring the concordance between actual treatment practices and individuals' own advance preferences for care. The few studies in which patients' preferences and their eventual treatments were examined prospectively came to differing conclusions.^{8,9} One reported about overtreatment, but not about undertreatment.⁹ No study has prospectively followed a full range of life-sustaining treatment preferences and eventual treatments.

It could also be informative to compare preferences with practices over a range of life-sustaining treatments to estimate the effect that advance directives might have on resource utilization. Treatment preferences of surveyed populations, physicians, nurses, patients and their families and proxies, medical students, and the general public are available.^{6,7,10-18} Although data exist on life-sustaining treatments for certain diagnoses and among deceased patients, these are less suited for investigating utilization in common advance directive scenarios. The present study compares preferences selected in a general advance directive survey and actual treatment practices for patients with conditions described in the advance directive scenarios.

We documented the life-sustaining treatment practices at an urban teaching hospital where outpatients and members of the general public in the vicinity had been surveyed with an advance directive.¹³ For each of seven life-sustaining treatments, we asked whether it was provided more than, less than, or the same as surveyed pref-

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ferences for that treatment in advance directive scenarios. The period of study was just prior to the Patient Self-Determination Act, when care was virtually uninfluenced by advance directives.¹⁸

We also followed the surveyed patients prospectively to compare their advance care preferences with the actual treatments they received when in one of the scenarios. The overall aim was to find evidence supporting or refuting the stated common assumptions about advance care planning.

METHODS

Data Collection

We collected data on life-sustaining treatments provided between February 1987 and June 1989, corresponding to the time period of two advance directive surveys.¹³ One survey had been administered to a convenience sample of outpatients drawn from the waiting rooms of all the physicians in practice at an urban teaching hospital's ambulatory care unit and AIDS clinic. There were five interviewers: a physician, a nurse, and three research assistants trained in the interview process. Only patients with a major psychiatric diagnosis or a language barrier were excluded. A separate telephone survey had been administered by a survey research facility to members of the general public drawn at random from the hospital's vicinity.

Subjects were read the texts of four illness scenarios and 11 treatment options for each scenario, with repeated readings if requested. Outpatients' and the public's treatment options were identical except that artificial hydration was not offered as an option in the public's survey. The scenarios are referred to as *coma with a small chance of recovery*, *dementia*, *dementia with a terminal illness*, and *persistent vegetative state*. The first reads: "If, in the opinion of my physician and two consultants, I am in a coma, with a small and uncertain chance of regaining higher mental functions, and a greater chance of recovering with some residual damage, and a much greater chance of not recovering at all, then my wishes, if medically reasonable, for this and any additional illness would be:" The text of each scenario is available.¹⁹ Respondents were asked which they would want from the list of possible medical interventions and for each treatment in each of the scenarios they were asked to choose from the following: "I want"; "I want treatment tried. If no clear improvement, stop"; "I am undecided"; or "I do not want."

With Human Studies Review Board approval, we reviewed randomly selected charts of patients who had been admitted to the hospital in the designated time period by the same private physicians whose ambulatory patients were surveyed. We used specific criteria, developed by four physicians, for identifying scenarios and recognizing whether treatments were given (see Appendix A). They consisted of signs, symptoms, and test results normally recorded in medical charts, and they included alterna-

tives where applicable. We classified each of the treatments as having been *given*, *withheld* (medically indicated and not received), *withdrawn* (medically indicated and received, but later withdrawn and patient allowed to die), or *not medically indicated*.

Each chart was reviewed according to the criteria to determine if the patient's condition corresponded to one of the four scenarios. We screened 7,400 charts, and 198 cases were identified. We also reviewed the charts of all 495 patients who had been surveyed. For each case, we recorded patient's age, gender, attending physician, primary diagnosis, any corresponding advance directive scenario, and use of any of seven life-sustaining treatments (cardiopulmonary resuscitation, mechanical ventilation, artificial hydration, artificial nutrition, major surgery, hemodialysis, and antibiotics) while in the scenario. Socio-demographic data of inpatients and outpatients (age, gender, marital status, place of residence, and health insurance) were obtained from the hospital administrative record.

Three trained reviewers applied the criteria to 50 randomly selected charts to assess interrater reliability for identifying cases and to 49 randomly selected charts to assess interrater reliability for determining treatment utilization.

Data Analyses

Analyses focused on the scenario *coma with a small chance of recovery* because it accounted for 84% of the cases identified. Contingency table analyses and Pearson's χ^2 statistic were used for discrete comparisons among surveyed preferences, utilization rates, and sociodemographic features. The Bonferroni adjustment was made for multiple comparisons.²⁰ Logistic regression was used to determine whether utilization differed overall from surveyed preferences, accounting for age, gender, specific treatment type, and scenario.

Separate logistic regression models compared practices with surveyed preferences of either outpatients or the general public. The treatment decision made, either surveyed preference or actual practice, was the dependent variable in each of the models. This variable was defined in two alternative ways. One modeled actual *withholding* of treatment and preferences to decline the treatment, and the other modeled the broader category of *limiting* (withholding or withdrawing) the treatment and preferences to either decline or accept a limited trial of the treatment. We assumed that requests for treatment trials are analogous to providing and later withdrawing treatments, and that actions guided by "uncertain" treatment preferences would usually lead initially to a treatment trial. The main independent variable tested in the regressions was whether the observation was a surveyed preference or a documented treatment practice.

Six dummy variables representing the seven treatments were introduced in the regressions so that comparisons between practices and preferences could be made

for each treatment. Each subject therefore generated six observations. Huber's formula for estimates of maximum likelihood standard errors was used to account for correlation between these multiple observations per subject.²¹

The κ statistic, a measure of agreement that adjusts for chance, was used to assess interrater reliability.²² (κ is given by $[p_o - p_e]/[1 - p_e]$, where p_o is the observed proportion of agreement, and p_e is the proportion of agreement expected by chance.) Statistical analyses were performed with STATA Statistical Software (Release 4.0. College Station, Tex: Stata Corp.; 1995).

RESULTS

Interrater Reliability

The κ interrater reliability statistics were .89 for identifying cases; .40 to .49 for classifying cases into scenarios and for determining utilization of mechanical breathing, artificial hydration, major surgery, hemodialysis, and antibiotics; .86 for determining utilization of cardiopulmonary resuscitation; and .30 for determining utilization of artificial nutrition. Values of at least .4 are often taken as reasonable agreement beyond the level of chance.

Study Sample

Of 7,400 randomly selected charts, 198 admissions (3%) matched one of the scenarios. Of these, 167 case subjects were in coma with a small chance of recovery, 17 had dementia, 10 had dementia with a terminal illness, and 4 were in a persistent vegetative state. Thirteen case subjects met criteria for more than one scenario and were classified according to the earliest cause of mental incompetence (5 in coma with a small chance of recovery and 8 in one of the remaining scenarios). Case subjects were treated by 109 attending physicians and had 36 primary diagnoses. Only one chart referred to an advance directive, and 68% had any preferences regarding care noted including those of patients or family or proxy. Of these, 123 (91%) were either treatment declines or requests for comfort measures only.

Of an initial pool of 829 outpatients, 495 (60%) responded to the surveys, and 102 (76%) of an initial pool of 135 members of the general public responded.¹³ Nineteen of the outpatients had subsequently been admitted to the hospital and were in a situation corresponding to one of the scenarios by February 1995, seven years later. Demographic features are displayed in Table 1. Race was not recorded consistently in charts and could not be included.

Demographic Factors

Outpatient and general public prior preferences were previously found not to be associated with health or demographic characteristics.¹³ Logistic regression analysis

Table 1. Demographic Features of Subjects

Demographics	Outpatients	General Public*	Chart Cases
Age (mean) years	65	43	56
Female gender, %	57	53	44
Marital status, %		NA	
Married	56		58
Single	24		17
Divorced, widowed, or separated	20		25
Health insurance, %		NA	
Private	69		32
Public	21		64
None	10		4
In-state residence, %	94	94	100

*NA indicates not available.

confirmed that there was no association between prior preferences (either to decline or to limit any of the treatments) and gender, marital status, health insurance, or place of residence in either group ($p > .15$ in each instance). Age alone was associated with outpatients' prior preferences to withhold or to limit treatments ($p \leq .012$) and to withhold hemodialysis among the general public ($p = .042$), although the effect was small. None of these demographic features was associated with actual practices of withholding or withdrawing treatment ($p > .10$). The one exception, an association between limiting hemodialysis and health insurance, was not significant after adjusting for multiple comparisons ($p = .14$).

Life-Sustaining Treatment Utilization and Preferences

Life-sustaining treatments were limited, with incidences ranging from 20% for artificial hydration to 94% for cardiopulmonary resuscitation (Table 2). Surveyed preferences have been reported.¹³ Preferences to have a trial of treatment or to decline treatments in coma with a small chance of recovery are shown in Tables 3 and 4 with the frequencies they were found to be actually withheld. Preferences to have a trial only of treatments ranges from 48% to 69% among outpatients and from 41% to 79% among the public.

Treatments Received by Outpatients Who Entered a Described Scenario

Nineteen (4%) of the outpatients surveyed were eventually hospitalized at the study site and faced with one of the four scenarios. Fifteen cases subjects were classified as in coma with a small chance of recovery, three as having dementia with a terminal illness, and one was in a persistent vegetative state. Treatments given or limited are shown in Table 5 together with the patients' prior sur-

Table 2. Frequencies of Withholding or Withdrawing Life-Sustaining Treatments*

Treatment	Coma (n = 167)	DTI (n = 10)	DEM (n = 17)	PVS (n = 4)	Total (n = 198)
Cardiopulmonary resuscitation					
Withheld or withdrawn, %					93.6
Withheld, n	145	8	5	2	160
Withdrawn, n	—	—	—	—	—
Medically indicated, n	155	9	5	2	171
Mechanical breathing					
Withheld or withdrawn, %					66.9
Withheld, n	82	8	5	0	95
Withdrawn, n	16	0	0	2	18
Medically indicated, n	153	9	5	2	169
Artificial hydration					
Withheld or withdrawn, %					20.0
Withheld, n	8	0	0	0	8
Withdrawn, n	25	1	3	1	30
Medically indicated, n	162	10	14	4	190
Artificial nutrition					
Withheld or withdrawn, %					62.1
Withheld, n	37	2	2	0	41
Withdrawn, n	40	2	2	2	46
Medically indicated, n	122	6	8	4	140
Major surgery					
Withheld or withdrawn, %					57.4
Withheld, n	37	1	1	0	39
Withdrawn, n	—	—	—	—	—
Medically indicated, n	55	2	7	4	68
Hemodialysis					
Withheld or withdrawn, %					85.5
Withheld, n	45	4	2	1	52
Withdrawn, n	12	0	1	0	13
Medically indicated, n	67	5	3	1	76
Antibiotics					
Withheld or withdraw, %					31.8
Withheld, n	12	3	1	1	17
Withdrawn, n	29	0	2	0	31
Medically indicated, n	128	7	13	3	151

*Coma indicates coma with a small chance of recovery; DTI, dementia with a terminal illness; DEM, dementia; PVS, persistent vegetative state.

veyed preferences. There were few indications for major surgery and hemodialysis in these patients.

DISCUSSION

This study documents utilization patterns of a wide range of life-sustaining treatments and compares these practices with surveyed preferences for advance directive scenarios.

Patterns of withholding or limiting life-sustaining treatments exhibited wide variation. This wide variation contrasted with the relative homogeneity in patients' surveyed preferences and may reflect less discrimination between treatments among patients and members of the general public than among physicians.²³⁻²⁵ Cardiopulmonary resuscitation was usually withheld from patients, and arti-

cial hydration was usually provided. Hemodialysis and mechanical breathing were withheld frequently, but withdrawn infrequently. These observations are consistent with those from other studies that indicate that withholding resuscitation is generally the first step in decisions to limit aggressive treatment, whereas intravenous fluids are forgone relatively rarely.^{26,27}

Although the observation that cardiopulmonary resuscitation was withheld more often than surveyed preferences would have dictated is consistent with other data, this finding may obscure the likelihood that many patients wanting no resuscitation receive it and many patients wanting resuscitation do not receive it.^{8,28}

Artificial hydration and antibiotics were given to patients more often than prior preferences would have directed. These findings are consistent with the view that

Table 3. Treatments Withheld in Coma Compared with Preferences to Decline*

Treatment	Chart Cases WH, % (n)	Outpatient Declines, % (n = 495)	p Value	Adjusted Odds Ratio (95% CI)	Public Declines, % (n = 102)	p Value	Adjusted Odds Ratio (95% CI)
Cardiopulmonary resuscitation	94 (155)	56	<.001	10.5 (5.38, 20.6)	52	<.001	9.28 (4.20, 20.5)
Mechanical breathing	54 (153)	53	.704	0.84 (0.57, 1.22)	49	.575	0.78 (0.43, 1.43)
Artificial hydration	6 (162)	52	<.001	0.05 (0.02, 0.10)	—	—	—
Artificial nutrition	44 (122)	55	.055	0.58 (0.36, 0.94)	46	.782	0.64 (0.33, 1.24)
Major surgery	67 (55)	61	.350	1.21 (0.65, 2.24)	70	.763	0.61 (0.28, 1.36)
Hemodialysis	68 (67)	57	.088	1.45 (0.84, 2.52)	45	.004	1.78 (0.88, 3.59)
Antibiotics	9 (128)	48	<.001	0.09 (0.05, 0.17)	41	<.001	0.09 (0.04, 0.21)

*Odds ratio are from logistic regression models using Huber estimates of variance and adjusting for age and gender. WH indicates treatments withheld; p value is for contingency table χ^2 statistic; CI, confidence interval; likelihood ratio tests of interaction terms (treatment type by practice vs preference) of models using outpatients' preferences (and 6 df) and public's preferences (with 5 df) p values were < .001.

physicians may find their administration routine and less subject to withdrawal or withholding.

These data are limited in that the surveyed patients are not the same as the observed inpatients. Nevertheless, given these limitations, these data do not support the common view that patients receive more intervention than they would wish. Three of the seven treatments investigated were withheld or limited at rates comparable to outpatients' and the public's surveyed preferences. The four for which practices and preferences differed were not consistent in the direction of either overtreatment or undertreatment.

Among the 19 subjects who later found themselves in surveyed scenarios, prior preferences and later treatments were often incongruent. Overtreatment and undertreatment patterns were approximately similar to the collective level, but correspondence of practices with individuals' wishes was poor for all treatments.

It is not yet clear what is required to attain congruence between individuals' prior preferences and practices. One possibility is that surveyed preferences may not be stable. However, a follow-up study of the same cohort of outpatients demonstrated reasonable stability.²⁹ Another

possibility is that family members or the physician may have been unaware of, or overrode the patient's preferences.^{7,14,15} Some patients may wish to allow their physicians latitude when acting on their preferences, as other commentators have suggested.³⁰ These possibilities are best studied prospectively, as evidence of conflicting judgment is not often found in the medical record.

An important limitation of this study is the comparability of the chart-reviewed and surveyed patients, although the groups came from the same region and did not differ in sociodemographic characteristics. Another limitation is the use of scenarios, which may not capture all elements of patients' preferences.

This study challenges the common assumption that collectively treatments are not withheld or limited as much as patients would prefer. It does support the notion that, at least in the absence of advance directives, specific treatment practices deviate from individuals' prior preferences. An important implication of these findings is that if advance directives are regularly completed and followed, utilization of some treatments might increase, and others might decrease or remain the same. To improve congruence between preferences and practice, research and pro-

Table 4. Treatments Limited (Withheld or Withdrawn) in Coma Compared with Preferences to Decline or for a Limited Trial*

Treatment	Chart Cases WH or WD, % (n)	Outpatient Declines or Trials, % (n = 495)	p Value	Adjusted Odds Ratio (95% CI)	Public Declines or Trials, % (n = 102)	p Value	Adjusted Odds Ratio (95% CI)
Cardiopulmonary resuscitation	94 (155)	56	<.001	10.8 (5.51, 21.1)	52	<.001	9.51 (4.32, 20.9)
Mechanical breathing	63 (153)	69	.172	0.71 (0.48, 3.00)	79	.005	0.30 (0.16, 0.59)
Artificial hydration	20 (162)	65	<.001	0.13 (0.08, 0.20)	—	—	—
Artificial nutrition	62 (122)	67	.250	0.72 (0.46, 1.11)	73	.088	0.42 (0.22, 0.79)
Major surgery	67 (55)	61	.350	1.28 (0.69, 2.36)	70	.763	0.63 (0.29, 1.39)
Hemodialysis	85 (67)	67	.002	2.70 (1.34, 5.42)	73	.051	1.56 (0.68, 3.59)
Antibiotics	32 (128)	48	.001	0.45 (0.29, 0.69)	41	.109	0.44 (0.23, 0.84)

*Odds ratios are from logistic regression models using Huber estimates of variance and adjusting for age and gender. WH or WD indicates treatments limited; p values for contingency table χ^2 statistic; CI, confidence interval; likelihood ratio tests of interaction terms (treatment type by practice vs preference) of models using outpatients' preferences (and 6 df) and public's preferences (with 5 df) p values were < .001.

Table 5. Individuals' Preferences and Actual Treatment Utilization*

Treatment and Actual Utilization	Prior Preferences		Percentage Agreement
	Number Accepts	Number Declines	
Cardiopulmonary resuscitation			
Given	0	1	
Withheld or withdrawn	4	13	72
Mechanical breathing			
Given	1	3	
Withheld or withdrawn	2	9	67
Artificial hydration			
Given	2	10	
Withheld or withdrawn	0	6	44
Artificial nutrition			
Given	0	4	
Withheld or withdrawn	1	9	64
Antibiotics			
Given	3	2	
Withheld or withdrawn	4	3	50
Total			
Given	6	20	
Withheld or withdrawn	11	40	60

*Treatment-limiting preferences and actual practices corresponding to 19 case subjects who were in one of the four scenarios (15 coma, 3 dementia with a terminal illness, and 1 persistent vegetative state).

grams should target communication at the patient-proxy-physician level.

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APPENDIX A

*Criteria for Identification of Cases and Treatment Utilization***Identification of Cases***Coma with a small chance of recovery*

Glasgow Coma Scale score ≤ 3 (less than 3 if eye opening, motor, or verbal responses unmeasurable; and metabolic or traumatic etiology versus drug-induced).

Dementia

Needs complete assistance with eating and toileting; can no longer recognize doctor or loved ones; cannot do any of the things that used to make one happy; cannot talk anymore; and suffering from medical complication of dementia (e.g., falls, urinary incontinence, or pneumonia).

Dementia with terminal illness

Dementia with malignancy or multiple chronic organ failure.

Persistent vegetative state

Absence of evidence of awareness of self or surroundings; meaningful or consistent communication; comprehensible speech or mouthing of words; emotional response to verbal input; consistent relationship of smiling, frowning, or crying to any apparent stimulus; any voluntary movement or behavior; motor behavior suggesting learned behavior or mimicry; bladder or bowel continence; visual following of target stimuli. Presence of sleep-wake cycles, blood pressure and cardiorespiratory function.

Treatment Utilization*Cardiopulmonary resuscitation*

Withdrawn: cardiac/respiratory arrest; resuscitation commenced, duration <5 minutes; patient died.

Withheld: no resuscitation; patient died.

Mechanical breathing

Withdrawn: respiratory failure, ventilator started and stopped, death in <24 hours.

Withheld: respiratory failure indicated by arterial blood gas $P_{O_2} < 50$ on $FiO_2 > .5$ or $PCO_2 > 50$ and $Ph < 7.25$; respiratory rate > 32 or < 8 on 2 occasions > 30 minutes apart; patient noted to be in respiratory failure; ventilator not started; death in <24 hours.

Artificial nutrition

Withdrawn: tube feeding or TPN started and stopped; patient continues to consume inadequate calories; death in <14 days (no fluids) or <30 days (with fluids).

Withheld: inadequate calorie intake > 5 days; tube feeding/TPN not started; death in <14 days (no fluids) or <30 days (with fluids).

Artificial hydration

Withdrawn: TPN or IV fluids started and stopped; inadequate fluid intake; death in <14 days.

Withheld: inadequate fluid intake; TPN or IV fluids not started; death in <14 days.

Hemodialysis

Withdrawn: hemodialysis started and stopped; renal failure continues; no renal transplant given; death in <21 days.

Withheld: renal failure: more than one of: uremia, refractory hyperkalemia, acidemia, creatinine $> 1,000$ mmol/L, pulmonary edema, oliguria < 400 mL/d > 3 days; no renal transplant given; death in <14 days.

Major surgery

Withdrawn: not applicable.

Withheld: surgical consultation for procedure or record of any of the following: acute abdomen, gangrenous leg, ruptured aneurysm, trauma intracranial bleed; surgery not performed; death in <72 hours.

Antibiotics

Withdrawn: antibiotics started and stopped despite more than one of: fever $> 101^\circ F$ $> 2x/day$ > 2 days, WBC > 10 and not leukemic, blood or tissue culture, chest x-ray c/w pneumonia, death <10 days.

Withheld: more than one of: fever $> 101^\circ F$ > 2 x day > 2 days, WBC > 10 and not leukemic, blood or tissue culture, chest x-ray c/w pneumonia; antibiotics not given; death <10 days.