The Terrible Choice: Re-Evaluating Hospice Eligibility Criteria for Cancer

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ABSTRACT

Purpose

To be eligible for the Medicare Hospice Benefit, cancer patients with a life expectancy of 6 months or less must give up curative treatment. Our goal was to determine whether willingness to make this choice identifies patients with greater need for hospice services.

Patients and Methods

Three hundred patients with cancer and 171 family members were recruited from six oncology practices. Respondents completed conjoint interviews in which their perceived need for five hospice services was calculated from the choices they made among combinations of services. Patients' preferences for treatment were measured, and patients were followed for 6 months or until death.

Results

Thirty-eight patients (13%) said they would not want cancer treatment even if it offered an almost 100% chance of 6-month survival. These patients, who would have been eligible for hospice, did not have greater perceived need for hospice services compared with other patients ($n = 262$; mean, 1.75 v 1.98; Wilcoxon rank sum test, $P = .46$), nor did their family members (mean, 1.95 v 2.04; Wilcoxon rank sum test, $P = .80$). Instead, independent predictors of patients' perceived need for hospice services included African American ethnicity, less social support, worse functional status, and a greater burden of psychological symptoms. For families, predictors included caregiver burden, worse self-reported health, working outside the home, and caring for a patient with worse functional status.

Conclusion

The requirement that patients forgo life-sustaining treatment does not identify patients with greater perceived need for hospice services. Other characteristics offer a better way to identify the patients who are most likely to benefit from hospice.

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INTRODUCTION

The Medicare Hospice Benefit was enacted in 1982 as a way to provide patients in the last 6 months of life with valuable services, including a visiting nurse, a chaplain, a home health aide, and respite care. However, the Medicare Hospice Benefit requires that patients accept "the palliative rather than curative nature of hospice care."¹ This eligibility criterion was meant to ensure that the costs of hospice care would be offset by reduced expenditures for aggressive treatment, making hospice care cost-neutral.²

Other Medicare benefits are not constrained by analogous restrictions. Even though Medicare eligibility is based on age, Medicare pays for services based on medical necessity.³ Therefore, many have argued that Medicare forces patients to make a terrible choice between treatment and hospice

services,⁴⁻⁶ which constitutes a significant barrier to hospice use.⁷⁻¹⁰

This might not actually constitute a terrible choice if it identifies patients with need for hospice services. That is, if patients who are willing to forgo curative treatment have greater need, this criterion is a way of determining medical necessity, albeit indirectly. However, it is not known whether these patients, or their families, have greater perceived need for hospice services.

If the terrible choice associated with hospice does not identify patients and families with the greatest perceived need for hospice services, then hospice arguably fails a crucial test of fairness in the care it provides for these vulnerable patients. If this is the case, alternative eligibility criteria should be considered. Therefore, the goals of this study were to determine whether the requirement that patients

give up life-sustaining treatment identifies those patients and families with the greatest perceived need for hospice services, and if not, whether more clinically useful eligibility criteria could be developed.

PATIENTS AND METHODS

Setting and Sample

We conducted this study in patients with cancer, which is the most common diagnosis in admission to hospice.¹¹ Patients and accompanying family members were recruited from six oncology practices in the University of Pennsylvania Comprehensive Cancer Center Network (Philadelphia, PA). Efforts were made to approach all patients with a scheduled visit if they had evidence of active disease, if they were receiving chemotherapy or radiation therapy, and if their oncologist believed they would have a life expectancy of 6 months or less if they were to discontinue cancer-focused life-sustaining treatment (eg, chemotherapy). This prognostic estimate, conditional on refusal of treatment, mirrors Medicare's requirement that physicians certify a prognosis of 6 months or less if patients' disease were to run its usual course (ie, without treatment).¹ This study was approved by the institutional review boards of participating sites.

Overview of Methods Used to Assess Perceived Need for Services

The perceived need of patients and families for hospice services was assessed using techniques of conjoint analysis, which refers to the process through which participants consider several attributes (services) jointly.¹² One advantage of this approach is that patients determine the value of each service while considering other services, making choices more natural. In addition, participants must choose the services that are most important to them, so the ceiling effects of direct ratings are avoided. This study used a hybrid form of conjoint analysis,¹³ which incorporated both direct ratings and choices between services in an interactive, self-administered computer program (Adaptive Conjoint Analysis [ACA] package for Windows, version 4.0; Sawtooth Software, Sequim, WA). Although they were developed for use in marketing,¹² conjoint techniques have been used increasingly to study health-related choices about treatment options and services.¹⁴⁻²⁰

Data Collection

After providing informed consent, patients and family members completed separate interviews using Tablet PCs. First, they provided basic demographic data: self-described ethnicity, age, marital status, and household finances (eg, money available at the end of the month).²¹ Next, they reviewed a brochure describing five of the hospice services required by Medicare: a visiting nurse, a chaplain, a home health aide, a counselor, and respite care¹ (Table 1). These services were selected based on previous studies in which they were found to be among the most valuable to patients and families.²²⁻²⁴ We asked patients and families to assume that these services would be provided in the home, because we reasoned that they would thus be able to best assess their current needs. Other core hospice services for which preferences were not assessed in this study include the provision of medications related to the hospice diagnosis, durable medical equipment, and the services of a social worker and bereavement counselor.

We used two sets of questions to measure perceived need for services. (Fig 1) First, patients and families used the laptop touch screen to rate the importance to them of each service on a scale from one (not important) to seven (extremely important). Second, they were asked to choose between pairs of programs presented side by side, each containing two services (eg, a nurse and chaplain v a home health aide and respite care).

Next, patients were asked whether they would want to continue receiving their current cancer treatment to achieve various probabilities of survival for 6 months (almost 100%, 90% to 99%, 50% to 89%, 10% to 49%, 1% to 9%, and almost 0%). This question was adapted from previous work in seriously ill populations.^{25,26} These probabilities were varied in the same way for all patients (from lowest to highest and then back to the second-lowest probability) to balance order effects. The lowest probability of 6-month survival for which

Table 1. Hospice Services

Service	Description
Nurse	A nurse monitors and explains the patient's condition, and can help reduce symptoms the patient may be having, such as pain or nausea. A nurse helps manage patient medications, and can answer questions from patients and families.
Chaplain	A chaplain provides spiritual and emotional support, and can discuss concerns about the future.
Home health aide	A home health aide provides help with personal needs, such as bathing and dressing, housework, cleaning, and laundry.
Counselor	A counselor is available to discuss concerns about the patient's illness, and can identify depression, anxiety, or other conditions about which the physician should know.
Respite care	Respite care offers a place where a patient can stay for a few days to give family members or other caregivers a rest.

a patient would be willing to continue receiving treatment was recorded, creating a seven-level ordinal variable (one level for each of the six responses above, and one for those patients who would not want to continue treatment even for an almost 100% chance of surviving for 6 months). This last category was used to identify those patients who would have been eligible for hospice.

We used this conservative definition of hospice eligibility to be certain that these patients had preferences appropriate for hospice. These patients were willing to give up all chemotherapy and radiation therapy, even if such treatment offered a 100% chance of 6-month survival. We reasoned that these patients would be most likely to have greater perceived need for hospice services.

To identify alternative eligibility criteria that might offer better predictors of perceived need, patients also completed assessments using the Global Distress Index (GDI) of the Memorial Symptom Assessment Scale,²⁷ the Functional Assessment of Cancer Therapy-General (FACT-G),²⁸ the tangible subscale of the Medical Outcomes Survey Social Support Scale,²⁹ a single-item global rating of health,³⁰ and the patient-reported Eastern Cooperative Oncology Group performance status scale (ECOG-PS),³¹ and completed an assessment of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living.^{32,33} Families completed the same single-item global rating of their own health, and rated their caregiver burden using the Zarit scale.³⁴ To determine patients' survival, patients were observed for up to 6 months through regular updates from their oncologist and/or the oncologist's staff.

Data Analysis

ACA software uses least squares regression to calculate a β coefficient for each individual's preferences about each service, on the basis of the ratings of each service's importance and choices among combinations of services presented together, as described in data collection. ACA software calculates an initial β coefficient on the basis of the first direct-rating question, and then updates the model on the basis of the results of each subsequent choice between groups of services. This hybrid approach, which incorporates both direct ratings and choices, produces five β coefficients for each respondent (one for each service), corresponding to the perceived need for that service (the service's utility).³⁵ These utilities are analogous to better-known health utilities that describe the value of a health state to an individual.

These five utilities were analyzed individually, and also added together to create a single variable representing the individual's total service utility, which reflected his or her perceived need for all five hospice services combined. Because these total service utility were not normally distributed, nonparametric tests were used. To identify independent predictors of patients' and families' perceived need (their total service utility), a multivariable linear regression model was used, with log transformation of the total service utility to account

Examples of questions used in conjoint interviews (direct ratings of importance and comparisons of pairs of services)**Direct ratings of importance**

If two home care service plans were acceptable to you in **all other ways**, how important would this difference be in your enrollment decision?

A nurse available to visit 5 times/week

vs

No nurse

1   2   3   4   5   6   7
Not   Somewhat   Very   Extremely
important   important   important   important

Choose the number that best describes your opinion

Pairs questions

If these two home care service plans were **exactly** the same in every other way, which would you prefer?

A nurse
available to visit 5 times/week

A home health aide
available to visit 5 times/week

OR

A chaplain available to
visit as needed

Respite care
as needed

1   2   3   4   5   6   7   8   9
Strongly   Indifferent   Strongly
prefer the   prefer the
program   program
on the left   on the right

Please choose the number that best describes how you feel.

Fig 1. Examples of questions used in conjoint interviews (direct ratings of importance and comparisons of pairs of services).

for non-normal distribution. Potential predictors were considered for inclusion in the model if they had a significance value $< .25$.³⁶ Potential predictors were added sequentially and retained if they were significant, or if their addition to the model resulted in a significant likelihood ratio test. β coefficients of the final model were exponentiated, allowing readers to interpret them as they would the coefficients of a nontransformed model.

We recruited 300 patients to determine whether patients who were willing to forgo treatment had greater perceived need for hospice services compared with patients who wanted to continue receiving treatment, assuming that at least 12% would be willing to give up treatment. This sample size provided adequate power ($1 - \beta = .80$) to detect 0.50 standardized difference, a moderate effect size,³⁷ assuming $n = 36$ and $n = 264$, and $\alpha = .05$, two-sided. Stata software (Stata 8.0; StataCorp LP, College Station, TX) was used for all analyses.

RESULTS

Patient and Family Characteristics

Patients who participated (300 [85%] of 352) were similar to those who refused with respect to age, ECOG-PS score, ethnicity,

household finances, and education. However, women were somewhat more likely than men to participate (152 [90%] of 169 v 148 [81%] of 183; Fisher's exact test, $P = .023$). Patient and family characteristics are described in Tables 2 and 3. None of these patients was receiving hospice or home care services at the time of the interview.

Perceived Need for Services and Willingness to Forgo Treatment

The perceived need for hospice services (total service utility) ranged from 0 to 6, with means of 1.95 for patients and 2.04 for families. Thirty-eight patients (13%) said they would not want further cancer treatment that offered an almost 100% chance of 6-month survival. Although these patients would have been eligible for hospice, they did not have greater perceived need for all five hospice services combined (total service utility) than other patients ($n = 262$; range of total service utility, 0 to 6; mean, 1.75 v 1.98; Wilcoxon rank sum test, $P = .40$), nor did their family members ($n = 24$ v $n = 147$; range of total service utility, 0 to 6; mean, 1.95 v 2.04; Wilcoxon rank sum test,

Table 2. Patient Characteristics (N = 300)

Characteristic	No.	%
Sex		
Male	148	49
Age, years		
Mean	58	
Range	20-89	
Ethnicity		
African American	81	27
White/non-Hispanic	202	67
Hispanic	4	1
Asian/Filipino	4	1
Pacific Islander	1	0
Other	8	3
Marital status		
Single	45	15
Married	174	58
Divorced/separated	45	15
Widowed	22	7
Living with partner	14	5
Household finances at end of month		
Money left over	142	47
Just enough to make ends meet	80	27
Not enough to make ends meet	52	17
Refused to answer	26	9
Highest level of education achieved		
Did not graduate from high school	24	8
High school	85	28
Some college or technical school	76	25
College	55	18
Graduate school	60	20
ECOG PS score		
0	90	30
1	32	11
2	124	41
3	46	15
4	8	3
Cancer type		
Breast	84	28
GI	53	18
Hematologic	37	12
Lung	36	12
Prostate	35	12
Oropharynx	29	10
Genitourinary	18	6
Sarcoma	5	2
Melanoma	2	1
Glioblastoma	1	0
GDI symptoms		
Lack of appetite	111	37
Lack of energy	204	68
Pain	164	55
Drowsiness	171	57
Constipation	94	31
Dry mouth	137	46
Sadness	116	39
Worrying	170	57
Irritability	121	40
Nervousness	116	39

Abbreviations: ECOG PS, Eastern Cooperative Oncology Group performance status; GDI, Global Distress Index.

Table 3. Family Member Characteristics (N = 171)

Characteristic	No.	%
Sex		
Male	74	43
Age, years		
Mean	56	
Range	17-83	
Ethnicity		
African American	26	15
White	137	80
Other	8	5
Marital status		
Single	20	12
Married	129	75
Divorced/separated	5	3
Widowed	9	5
Living with partner	8	5
Residence		
Living with patient	127	74
Household finances at end of month		
Money left over	111	65
Just enough to make ends meet	30	18
Not enough to make ends meet	13	8
Refused to answer	17	10
Highest level of education achieved		
Did not graduate from high school	7	4
High school	43	25
Some college or technical school	44	26
College	36	21
Graduate school	41	24

$P = .71$). Neither these patients nor their families had greater perceived need for any of the five hospice services, examined individually. Finally, neither these patients nor their families exhibited greater objective evidence of illness severity (eg, ECOG-PS score, patient or family global ratings of health, and GDI score), functional status (ADLs and Instrumental ADLs), quality of life (FACT-G score), or caregiver burden (Zarit burden score).

Alternative Hospice Eligibility Criteria

During the 6-month follow-up period, 44 patients (15%) died, and five (2%) were lost to follow-up. Patients who died within 6 months had greater perceived need for all hospice services combined, compared with patients who were still alive (mean of total service utility, 2.80 ± 1.80 ; Wilcoxon rank sum test, $P < .001$). These patients had greater perceived need for a counselor (range, 0 to 3.03; mean, 0.58 ± 0.41 ; $P < .001$), a nurse (range, 0 to 2.12; mean, 0.79 ± 0.37 ; $P < .001$), a home health aide (range, 0 to 1.84; mean, 0.41 ± 0.30 ; $P < .001$), a chaplain (range, 0 to 2.10; mean, 0.41 ± 0.30 ; $P = .021$), and respite care (range, 0 to 2.12; mean, 0.49 ± 0.32 ; $P < .001$). Family members ($n = 28$) of patients who died did not have greater perceived need compared with other family members ($n = 140$; mean of total service utility, 2.53 ± 1.93 ; Wilcoxon rank sum test, $P = .15$). Only perceived need for a home health aide was higher for families of patients who died within 6 months (range, 0 to 1.72; mean, 0.56 ± 0.39 ; Wilcoxon rank sum test, $P = .021$).

We also examined other characteristics that might predict perceived need for hospice services. (Table 4) In a multivariable model of patients' perceived need (range of total service utility, 0 to 6), African

Table 4. Predictors of Patients' and Families' Perceived Need for All Hospice Services

Predictors of Perceived Need	Range	β Coefficient*	95% CI	P
Patient				
Number of ADL impairments	0-5	.46	.11 to .80	.012
Ethnicity, non-white		.43	.04 to .83	.031
Social support, Medical Outcomes Survey tangible support subscale score	1-5	-.04	-.09 to .00	.049
Psychological symptom burden, GDI psychological subscale	0-4	.19	.06 to .32	< .001
Family member				
Patient's ADL score	0-5	.40	.02 to .77	.042
Zarit caregiver burden score	0-20	.04	.02 to .06	< .001
Working outside the home		.59	.17 to 1.01	.012
Self-rating of own health	1-5	-.21	-.41 to -.01	.043

Abbreviations: ADL, Activity of Daily Living; GDI, Global Distress Index.

*A log transformation was applied to patients' and families' perceived need (the sum of each individual's utility rating for all five hospice services). β coefficients and CIs have been exponentiated (back-transformed).

Americans had greater perceived need than other patients (mean of adjusted total service utility, 2.42 ν 1.66), and patients with at least four ADL dependencies had greater perceived need compared with those who were independent in all ADLs (mean, 4.83 ν 1.66). Patients with the worst tangible social support score of 1 had greater perceived need compared with patients with the best score of 5 (mean, 2.90 ν 1.66), and those with a maximum psychological symptom burden score of 4 had greater perceived need compared with those without any psychological symptoms (mean, 2.45 ν 1.55).

In a multivariable model of families' perceived need (Table 4), families with Zarit burden scores of 40 had greater perceived need compared with those with a burden score of 0 (mean of adjusted total service utility, 3.55 ν 1.05). Compared with family members with the best self-reported health rating, those with the worst rating also had greater perceived need (mean, 2.33 ν 1.70). Families who worked outside the home had greater perceived need (mean, 3.12 ν 1.50), as did families who cared for patients with four or fewer ADL impairments, compared with those who cared for patients with no ADL dependencies (mean, 3.61 ν 1.62).

Because ADL scores were associated with both patients' and families' perceived need for hospice services, we looked for a threshold value that could be clinically useful. Forty patients reported a need for assistance in at least one ADL. These patients had significantly greater need for hospice services (mean of total service utility, 2.55 ν 1.86; rank sum test, $P = .001$), as did their family members (mean of total service utility, 2.62 ν 1.92; $P = .041$).

In a multivariable model, adjusting for other independent predictors of patients' perceived need listed in Table 4, the presence of one ADL dependency remained significantly associated with perceived need (β coefficient, 0.66; 95% CI, 0.14 to 1.18; $P = .011$). This reflected a 42% relative increase, and a 13% absolute increase, in perceived need for services (mean, 2.58 ν 1.82; range, 0 to 6). In a multivariable model that adjusted for other independent predictors of families' perceived need listed in Table 4, the presence of at least one ADL dependency was also associated with families' perceived need for services (β coefficient, .42; 95% CI, .04 to .79; $P = .03$). This was a 40% relative increase, and an 11% absolute increase, in perceived need for services (mean, 2.66 ν 1.90; range, 0 to 6).

Patients with at least one ADL dependency also had greater illness severity by other measures. For instance, they reported a worse quality

of life (FACT-G score, 44 ν 50; Wilcoxon rank sum test, $P = .001$) and greater symptom burden (GDI score, 5.6 ν 4.5; Wilcoxon rank sum test, $P = .003$). They also had higher (worse) ECOG-PS scores (mean, 2.4 ν 1.4; Wilcoxon rank sum test, $P < .001$), and their families had higher Zarit caregiver burden scores (mean, 23 ν 18; rank sum test, $P = .028$). Finally, patients with at least one ADL impairment also had a higher mortality rate (log-rank test, $P < .001$), and a significantly higher 6-month mortality (16 [41%] of 39 ν 28 [11%] of 256; χ^2 , $P < .001$), compared with patients who were independent in all ADLs. In contrast, patients who were willing to give up treatment did not have a higher mortality rate (log-rank test, $P = .78$) or a higher 6-month mortality (five [13%] of 38 ν 39 [15%] of 262; χ^2 , $P = .80$).

DISCUSSION

The Hospice Medicare Benefit provides services to patients in the last 6 months of life only if they are willing to give up life-sustaining treatment, and Medicaid and many private insurers have employed this criterion as well. Although this criterion might be justifiable if it were to help identify those patients and families with greater perceived need for hospice services, the results of this study suggest that this is not the case. Furthermore, patients who were willing to give up treatment did not have greater perceived need by other measures (eg, quality of life, functional impairment, and symptom burden), nor did their family members report having a greater caregiver burden. Therefore, this eligibility criterion should be reconsidered, and might be replaced by criteria derived from perceived need and functional status.

This change would be an important step in making hospice eligibility criteria similar to the eligibility criteria of other Medicare benefits. For instance, to receive skilled home nursing, which is the most comparable Medicare benefit, patients must be homebound, and must have a skilled care need.³ Therefore, hospice eligibility criteria based on need and functional status would help to ensure consistent eligibility policies for all Medicare beneficiaries.

Of course, the requirement that patients give up access to treatment is not the only barrier to hospice enrollment for patients with cancer. For instance, expensive palliative medication (eg, octreotide) or radiation therapy exceeding Medicare's per diem payment may exclude patients from enrolling. But this is a financial barrier that can

be overcome by larger hospices through economies of scale, and by smaller hospices through philanthropic support. In contrast, the barrier created by Medicare's requirement that patients forgo treatment cannot be addressed without costly parallel open-access programs, or a fundamental change to Medicare eligibility criteria.³⁸ In considering such changes, it will be useful to look to other payers and health care systems for guidance, such as the Veterans Health Administration, which does not require patients who enroll in hospice programs to forgo treatment.

This study has two limitations that should be noted. First, it is possible that these patients and families could not adequately appreciate how the services described here could benefit them. However, patients and families arguably are the best judges of their own needs, even if those assessments are imperfect. Moreover, this study also found that patients' and families' perceived need for services was strongly associated with measures such as ADLs, social support, quality of life, and caregiver burden.

Second, many eligibility criteria were evaluated in this study, and some of the observed associations between patient and/or family characteristics and perceived need for hospice services may be the spurious products of multiple comparisons. However, all of these characteristics were selected based on a priori plausibility, which increases the validity of the results reported here. Nevertheless, future research should examine these and other potential predictors of need for hospice services.

Every year, more than 1,000,000 patients receive hospice care, and growing data indicate that hospice can deliver high-quality care,

with high levels of satisfaction.³⁹⁻⁴¹ In short, hospice appears to be an important Medicare benefit that is widely valued by patients and families. Therefore, it is essential that access to this benefit be guided by eligibility criteria that are fair and consistent.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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REFERENCES

- Medicare hospice regulations. 42 CFR § 418.22 (1996)
- Hearing before the Subcommittee on Health of the US House of Representatives Committee on Ways and Means: Coverage of hospice care under the Medicare program, 97th Cong, 2nd Sess, March 25, 1982
- Centers for Medicare and Medicaid Services: Your Medicare benefits. <http://www.medicare.gov/Publications/Pubs/pdf/10116.pdf>
- Gibson R: Palliative care for the poor and disenfranchised: A view from the Robert Wood Johnson Foundation. *J R Soc Med* 94:486-489, 2001
- Byock I: Testimony before the US House of Representatives Committee on Government Reform: Improving care at the end of life with complementary medicine, 106th Cong, 1st Sess, October 19, 1999
- Gelband H, Foley K: Improving Palliative Care for Cancer: Summary and Recommendations. Washington, DC, National Academies Press, 2001
- Byock IR, Forman VWB, Appleton M: Academy of hospice physicians' position statement on access to hospice and palliative care. *J Pain Symptom Manage* 11:69-70, 1996
- McGorty EK, Bornstein BH: Barriers to physicians' decisions to discuss hospice: Insights gained from the United States hospice model. *J Eval Clin Pract* 9:363-372, 2003
- Daugherty CK, Steensma DP: Overcoming obstacles to hospice care: An ethical examination of inertia and inaction. *J Clin Oncol* 20:2752-2755, 2002
- Miller SC, Weitzen S, Kinzbrunner B: Factors associated with the high prevalence of short hospice stays. *J Palliat Med* 6:725-736, 2003
- National Hospice and Palliative Care Organization: National Trend Summary 2006. Washington, DC, National Hospice and Palliative Care Organization, 1996
- Green P, Rao V: Conjoint measurement for quantifying judgmental data. *J Market Res* 8:355-363, 1971
- Green P: Hybrid models for conjoint analysis: An expository review. *J Market Res* 21:155-159, 1984
- Markham F, Diamond J, Hermansen C: The use of conjoint analysis to study patient satisfaction. *Eval Health Prof* 22:371-378, 1999
- Ryan M: A role for conjoint analysis in technology assessment in health care? *Int J Technol Assess Health Care* 15:443-457, 1999
- Ryan M, Farrar S: Using conjoint analysis to elicit preferences for health care. *BMJ* 320:1530-1533, 2000
- Shackley P, Slack R, Michaels J: Vascular patients' preferences for local treatment: An application of conjoint analysis. *J Health Serv Res Policy* 6:151-157, 2001
- Jan S, Mooney G, Ryan M, et al: The use of conjoint analysis to elicit community preferences in public health research: A case study of hospital services in South Australia. *Aust N Z J Public Health* 24:64-70, 2000
- Shea JA, Asch DA, Johnson RF, et al: What predicts gastroenterologists' and surgeons' diagnosis and management of common bile duct stones? *Gastrointest Endosc* 46:40-47, 1997
- Fraenkel L, Bogardus S, Wittink DR: Understanding patient preferences for the treatment of lupus nephritis with adaptive conjoint analysis. *Med Care* 39:1203-1216, 2001
- Cornoni-Huntley J, Ostfeld A, Taylor J, et al: Establishing populations for epidemiologic studies of the elderly: Study design and methodology. *Aging* 5:27-37, 1993
- Casarett D, Crowley R, Hirschman K: How should clinicians describe hospice to patients and their families? *J Am Geriatr Soc* 52:1923-1928, 2004
- Casarett D, Crowley R, Stevenson C, et al: Making difficult decisions about hospice enrollment: What do patients and families want to know? *J Am Geriatr Soc* 53:249-254, 2005
- Rickerson E, Harrold J, Carroll J, et al: Timing of hospice referral and families' perceptions of services: Are earlier hospice referrals better? *J Am Geriatr Soc* 53:819-823, 2005
- Fried TR, Bradley EH, Towle VR, et al: Understanding the treatment preferences of seriously ill patients. *N Engl J Med* 346:1061-1066, 2002
- Casarett D, Van Ness P, O'Leary J, et al: Are patient preferences for life-sustaining treatment really a barrier to hospice enrollment for older adults with serious illness? *J Am Geriatr Soc* 54:472-478, 2006
- Portenoy RK, Thaler HT, Kornblith AB, et al: The Memorial Symptom Assessment Scale: An instrument for the evaluation of symptom prevalence, characteristics and distress. *Eur J Cancer* 30A:1326-1336, 1994
- Cella DF, Tulskey DS, Gray G: The functional assessment of cancer therapy scale: Development and validation of the general measure. *J Clin Oncol* 11:570-579, 1993
- Sherbourne CD, Stewart AL: The MOS Social Support Survey. *Soc Sci Med* 32:705-714, 1991
- Jenkinson C, Wright L, Coulter A: Criterion validity and reliability of the SF-36 in a population sample. *Qual Life Res* 3:7-12, 1994
- Conill C, Verger E, Salameiro M: Performance status assessment in cancer patients. *Cancer* 65:1864-1866, 1990

32. Katz S, Akpom CA: Index of ADL. *Med Care* 14:116-118, 1976
33. Mahoney FI, Barthel DW: Functional evaluation: The Barthel Index. *MD State Med J* 14:62-65, 1965
34. Gaugler JE, Edwards AB, Femia EE, et al: Predictors of institutionalization of cognitively impaired elders: Family help and the timing of placement. *J Gerontol B Psychol Sci Soc Sci* 55:P247-255, 2000
35. ACA/Hierarchical Bayes Technical Paper: Sawtooth Software Technical Paper Series. Sequim, WA, Sawtooth Software Inc, 2001
36. Mickey J, Greenland S: A study of the impact of confounder-selection criteria on effect estimation. *Am J Epidemiol* 129:125-137, 1989
37. Cohen J. *Statistical Power Analysis for the Behavioural Sciences: The Effect Size*. Hillsdale, NJ, Lawrence Erlbaum Associates, 1988
38. Wright AA, Katz IT: Letting go of the rope: Aggressive treatment, hospice care, and open access. *N Engl J Med* 357:324-327, 2007
39. Teno J, Clarridge B, Casey V, et al: Family perspectives on end-of-life care at the last place of care. *JAMA* 291:88-93, 2004
40. Casarett D, Karlawish J, Crowley R, et al: Improving use of hospice care in the nursing home: A randomized controlled trial. *JAMA* 294:211-217, 2005
41. Miller S, Mor V, Wu N, et al: Does receipt of hospice care in nursing homes improve the management of pain at the end of life? *J Am Geriatr Soc* 50:507-515, 2002

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