MEASURING PUBLIC SENSIBILITIES IN END-OF-LIFE MEDICAL DECISION MAKING: A FACTORIAL VIGNETTE SURVEY

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In recent years the celebrated cases of Karen Quinlan, Nancy Cruzan, Baby K, and others have drawn media and public attention to the question of the appropriateness of medical treatment in catastrophic illness and at the end of life. At the same time, the rapid rise in health care costs, which have grown considerably faster than the overall rate of inflation, has made policy makers, the public, and the medical community ever more concerned about cost containment. Although the notion has been debunked that withholding "futile" care can save massive amounts of money (Emanuel and Emanuel, 1994; Teno, Murphy, Lynn, et al., 1994), concern has grown for both patient autonomy and health care expenditures at the end of life (Angell, 1994).

People bring a variety of values to the table in making policy decisions involving life and death. A recent nationwide survey of adult Americans illustrates the paradoxes inherent in this matter (Harvard, 1994). When asked whether "health plans should pay for any treatments which will save lives, even if it costs a million dollars to save one life," 62% said they agreed. Yet two-thirds (68%) agreed that "there are so many new, expensive treatments, surgical procedures, transplants and medical devices that it is impossible for health plans to pay for them all."

The responses to these questions point out a simultaneous concern for patient care and for cost. Both of these values must be respected in creating an acceptable policy on end-of-life decision-making. We do not believe that value-oriented questions such as these can shed much light on this inherent trade-off. We assume that the way in which the general public prefers to see these issues resolved is complex and difficult for the average citizen to articulate. We therefore argue for the merits of a survey design in which respondents' revelations about how they evaluate *particular cases* may be used to *infer* the value structure behind their preferences. Such a procedure is not entirely new, but we feel it has not been used systematically enough in health care policy research.

In this report we describe the results of a survey that employs multivariate vignettes to engage the potentially detailed decision rules used by real people in actual decision situations. We detail a randomized factorial method for construction of vignettes. We then show how responses to these vignettes reveal the content of rules used for specific judgments about medical decisions at the end of life.

METHODS

Sample.

We employed a representative random-digit telephone sample of households in Virginia. We further randomized respondents within households by asking to interview the adult with the next birthday, calling back if that person was not immediately available. We excluded from the study any household where any member was employed in the health care sector, including providers, administrators and insurers (5.1% of households contacted). Since the questionnaire instrument contained questions calling for recommendations about medical decisions in terminal cases, we also excluded on compassionate grounds any respondent who reported either that their current health was "poor" or who had participated within the past year in an end-of-life decision for a loved one (3.7% of households contacted). Including both completed interviews and excluded respondents, the study received the cooperation of 40.3% of all households contacted. The resulting sample contained 503 complete interviews. Overall, the sample slightly under-represents males and African-Americans in the general population in Virginia, and weights are used in most analyses to adjust for this rather typical sampling outcome.

Questionnaire.

The survey instrument was administered by telephone using computer-assisted telephone interviewing (CATI) technology. The mean interview time was approximately 18 minutes. The questionnaire had several major sections: a contact protocol including screening questions; overall perception of health care system and related health care items; eleven hypothetical vignettes describing critically ill patients with varying medical and social characteristics, and request-

ing a judgment about the continuation or termination of care; ratings of the personal importance of five quality of life criteria; ratings of the general fairness of five publicly debated health care financing and cost control proposals; six questions on religious affiliation and belief; and demographic and social position items.

Vignette design.

In order to explore the general public's attitudes and sensibilities about appropriate treatment decisions in end-of-life cases, we used a series of multivariate vignettes in the questionnaire. This technique attempts to overcome two limitations of traditional vignette research used to study ethics and justice: limited domain when all respondents receive the same vignettes, and maturation over a fixed question sequence. We instead composed abstract vignettes assembled by randomly combining six variables which specified distinct scenarios, and administered a small subset of those possible to each respondent in random order. This technique allows us to assess, by aggregating the ratings of many respondents, whether and how each dimension contributes to a judgment by the average respondent, or a subset of similar respondents. By randomly constructing vignettes with only minor restraints for plausibility, we also improve the power of the analysis relative to the natural distribution of medical and social attributes in end-of-life and futility cases in reality. This randomized multivariate technique has been used successfully in a variety of studies of social judgments (Rossi and Nock, 1982).

The vignette section followed some simple "warm-up" questions, and asked respondents to make recommendations in hypothetical cases, using "whatever rules for making up your mind that you think are fair and responsible." Here is a sample vignette:

> A 45-year-old mother or father has been run down by a drunk driver and requires artificial life support to survive, costing about $200,000 per year. She will probably live another 2-5 years that way, but will be totally paralyzed. The patient is not competent to decide about treatment, and the family is divided about going ahead. Private insurance will pay most of the cost.

Each vignette is followed by a simple rating question: "Would you say, in this case, considering the best interests of the patient and family, that treatment should be given?" Possible responses are yes (provide treatment), no (withhold treatment), and undecided.

The six specific dimensions that define vignette scenarios were formulated and validated by using a more traditional vignette approach in two focus groups. Table 1 describes the levels used for each dimension. Two dimensions determined our description of the basic medical scenario: the age of the hypothetical patient, and whether the patient had contributed to his or her own condition by drinking, smoking or drug use. To offset a possibly low level of medical knowledge on the part of respondents, a specific but simple medical condition was assigned contingent on these two attributes: congenital heart defect, auto accident, brain, lung, or colon cancer, pneumonia. Treatment was specified as some plausible combination of major surgery, intensive care and chemotherapy. The gender of the patient was left unspecified. Treatment cost was held constant at $200,000 (per year if life support was involved).

Two variable attributes specified the medical prognosis after the proposed treatment: expected duration of life, and quality of life expected for that duration of life after treatment (severe limitation or relatively full function for both physical and mental function separately). Exact phrasing varied slightly to fit common usage and expectations. For example, where 18- or 45-year-old adults were described as "paralyzed" the elderly were described as "bed-ridden." Disabilities for infants were expressed as developmental. For simplicity, coma was used in place of more technical terms such as "persistent vegetative state." Two additional, non-medical contingencies were also allowed to vary. One specified the source of payment for treatment. The second specified whether the hypothetical patient was competent to choose, or if not, whether an advance directive was in force.

Respondents were asked to evaluate eleven vignettes each. The first was treated as practice by interviewers and ignored in the analysis. After reading the vignette, the interviewer asked the respondent for a rating, and probed noncommittal responses by asking whether respondent "leaned" one way or the other. Respondents were allowed to state they were undecided, unable to evaluate the specific vignette, or unwilling to continue the series. In the analyses that follow, we examined the binary outcome of whether the respondent specifically recommended that treatment be employed or withheld. Responses indicating inability or unwillingness to rate a vignette one way or the other were excluded entirely from analysis. Our 503 respondents made usable ratings in a total of 4839 vignettes. We found no evidence of respondent fatigue over the series of eleven vignettes.

RESULTS

Complete randomization of vignette contents simplifies analysis in two ways. First, even excluding

Table 1: Vignette Attributes.
PATIENT AGE
1   infant
2   18-year-old
3   45-year-old "family head"
4   70-year-old
CONTRIBUTION TO MEDICAL
CONDITION
1   none
2   substance abuse
LENGTH OF LIFE
1   less than a week,
2   3-6 months,
3   2-5 years,
4   live indefinitely,
QUALITY OF LIFE
1   extreme mental and physical disability
2   physical disability
3   mental diability
4   physically and mentally functional
INSURANCE
1   Private insurance will pay most of the cost of treatment.
2   The family will have to pay most of the cost of treatment from its own resources.
3   Treatment will be partly paid for by the hospital itself as charity and partly by Medicaid.
    FOR ELDERS, ALSO:
4   Medicare will pay most of the cost of treatment.
PATIENT CHOICE
1   (nothing stated)
2   The patient is not competent to decide about treatment, and the family is divided about going ahead.
3   The patient had prepared written instructions saying they would like to die in a situation like this, but the family is divided about treatment.

nonsensical vignette combinations, individual characteristics covary little if at all. Second, randomly assigned vignette characteristics cannot covary with respondent characteristics. As a result, multivariate analytic methods add very little to the interpretation of the effects of vignette characteristics on ratings (although we did use them for assessments of statistical significance). We therefore present most results on vignette ratings as simple percentage comparisons. Some interaction effects among vignette variables and between vignette and respondent variables did exist, as reported below.

Overall, respondents recommended termination of treatment in 81% of vignettes involving advance directives, which were always described as indicating that the hypothetical patient "would want to die in a situation like this." Other vignettes not involving advance directives received recommendations to terminate care 45% of the time. Because the effects of most other variables were contingent on the presence or absence of advance directives, we analyze vignettes with and without advance directives separately (3781 and 1058 usable ratings across all respondents, respectively).

Analysis by vignette characteristics.

Table 2 presents the percentage of vignettes where termination was recommended for each combination of expected duration and quality of life. The left panel describes vignettes without advance directives. These were most likely to receive a recommendation of termination, 77% of the time, when the prognosis after treatment was less than one week of additional life, spent in a coma. At the other extreme, only 6% of vignettes received this rating when full physical and mental function were expected, and length of life would be indefinite -- in other words, a full recovery. Between these two extremes, respondents favored termination of care much more often for all "coma" scenarios, for paralyzed patients expected to live less than a week, and for patients expected to have sever mental disability and lifespan of 3-6 months. Willingness to terminate decreased when mental disability was not predicted, or as expected lifespan increased. Finally, respondents did not seem to discriminate much between lifespans of 2-5 years and of unlimited duration.

The right panel of Table 2 demonstrates the powerful effect of advance directives on our respondents' ratings. The percentage of recommendations to terminate care was substantially higher in every combination of length and quality of life, ranging from 94% for patients expected to live less than one week in a coma, to 62% for essentially full recoveries. Thus, the overall level of termination ratings is higher for advance directives, and furthermore, respondents are somewhat less discriminating about issues of prognosis when presented with the advance directive. Nonetheless, many respondents are unwilling to terminate cases that will be mentally functional and are not imminently terminal is quite important. In the case where death is not imminent, the applicability of the advance directive itself is challenged, both legally and, in the minds of some respondents, morally.

Differences were much smaller for other kinds of vignette attributes. In vignettes that did not specify an advance directive, the percentage of termination ratings varied by the hypothetical patient's age from 43% for young adults to 49% for elders. Respondents were about 3% more likely to recommend termination of care (47% versus 44%) for patients who had directly contributed to their own illness (or an infant's) by drug abuse, drunk driving or smoking. The chances of a termination rating increased from 43% to 48% when a vignette described a patient as incompetent to decide about treatment and the family as divided. All these differences are small, though statistically significant. In vignettes that did specify an advance directive, no non-prognosis vignette characteristic had a significant effect on the recommendation to terminate.

Among vignettes without advance directives, a recommendation to terminate was given only in 42% of all cases where the vignette stated that private insurance would cover most of the cost of treatment. The percentage was 44% when the cost is described as being paid by "Medicaid and the hospital, as charity." The percentage to terminate goes up to 50% if the vignette states that "the family will have to pay a great deal out of their own resources" and to 52% when the cost is to be wholly financed through Medicare (elderly patients only).

Effects of respondent characteristics.

The effects of several respondent characteristics were significant, although smaller in magnitude than those of the major vignette variables. We limit discussion to only a few of these effects in this report. White respondents recommended termination in 34% more vignettes without advance directives, and 62% more with such directives. Men and women did not differ significantly in their ratings of either type of vignette. Progressively older respondents have higher odds of recommending termination for any vignette without an advance directive: the odds were 57% higher than average for respondents aged 65 and over, but 36% lower than average for those aged 18 to 34.

We asked respondents to rate five items as to how crucial they were in assessing their own quality of life: strenuous exercise and work, mental acuity, visiting in person or by phone with family and friends, personal toileting, and pain. We computed an average rating for these items, called "quality of life sensitivity," ranging from one to four, with a high score meaning each is very important to quality of life. For each full point of this scale, a respondent was 23% more likely to give a terminate rating to any vignette without an advance directive. Finally, respondents who have executed or plan to execute a "living will" are also more likely than others to recommend termination across vignettes without advance directives. Neither quality of life sensitivity nor the preparation of a living will significantly influenced the ratings of vignettes that specified advance directives.

Interactions between vignettes and respondents.

Our final analysis addressed the issue of whether differing types of respondents gave equal weight to one or more vignette attributes in formulating their recommendations. For example, we might expect respondents with differing religious affiliation to give differential weight to the patient's expected quality of life or the existence of an advance directive. In testing a wide

Table 2: Percentage of vignettes recommending "terminate" care, by expected length of life and quality of life.

Expected length of life:	Vignettes without advance directive. disability:				Vignettes with advance directive. disability:			
	coma	physical	mental	none	coma	physical	mental	none
< week	77%	66	--	--	94	93	--	--
3-6 months	72	39	69	31	88	74	89	83
2-5 years	68	21	49	8	85	73	89	63
indefinite	68	17	47	6	92	75	86	62

variety of such hypotheses, we found only one instance of such differences that could not be attributed to chance sampling error.

Religion definitely plays a role in conditioning the ratings of vignettes. Table 3 shows how our five major religious groups differed in their consideration of advance directives in rating each vignette. Among those whose religious affiliation was known, respondents recommended termination of care in 43% of vignettes that specified nothing about incompetency or family conflicts, and in 82% of vignettes that specified an advance directive. For some specific religious groups both these percentages are lower (e.g., Evangelical Christians), and for others both are higher (e.g., respondents with no religious affiliation). The gap, however, tends to stay consistent, from about 27% to 41% (differences in the gap fail tests of statistical significance). So all religious groups give substantial priority to the existence of an advance directive. A similar result holds when respondents are broken down by their position on abortion, asked in the form "considering current laws, do you think abortions should be easier to get than they are now, harder to get, or should the laws stay the same?"

We found no other significant differences in our respondents' weighting of advance directives, expected length and quality of life, patient's contribution to illness, or insurance status. In addition to religion and abortion position, this finding also includes comparisons by race, education, age, smoking status, and receipt of health benefits from public aid. Smokers did not differentially evaluate the role of smoking, alcohol or drugs in formulating appropriate decisions, nor did public aid recipients see insurance status differently from the privately insured. Respondents did not treat patients of their own age group any differently from those in other age groups.

DISCUSSION

Our respondents' recommendations about end-of-life treatment decisions are most strongly connected to two norms: patient quality of life and patient choice. We feel, however, that the overall pattern of vignette recommendations may not reflect a very realistic picture of what advance directives can and cannot do, and treat them as an easy "technical fix" to these interacting issues. Other research on physician behavior reinforces the conclusion that advance directives have little impact on clinical decision making (Davidson, et al., 1989). Compared to issues of prognosis and advance directives, our respondents seemed to give little weight to non-medical criteria presented in vignettes, for example "lifestyle" issues such as smoking.

In vignettes without advance directives, respondents recommended termination of care more frequently when they: were white, mainstream Protestant or non-religious, and older; gave higher priority to level of function in assessing their quality of life; and had prepared or planned to prepare a living will. On the

Table 3: Effect of advance directive on vignette ratings, by religion and abortion position.

Respondent characteristic	Category	Percentage of vignettes given "terminate" rating		
		vignettes without advance directive	vignettes with advance directive	difference in percentage
Religion	Protestant (not evangelical)	47	86	39
	Catholic	41	77	36
	Evangelical Christian	37	78	41
	Non-Christian	40	73	33
	No Religious Preference	59	86	27
Abortion Position	Should be easier to get	51	88	37
	Should stay the same	45	81	36
	Should be harder to get	35	77	42
	Should be outlawed entirely	31	83	52

whole, however, respondent characteristics did not have great predictive power within vignettes without advance directives. Measured in terms of ability to predict ratings, simply predicting that no respondent would recommend termination in any vignette that did not specify an advance directive by the patient would be accurate about 55% of the time. Adding vignette attributes in a logistic regression increases the percentage correctly predicted to about 74%. Adding respondent characteristics to such a model raises the percentage correctly predicted only to 75%. We take this to indicate that most respondents are unwilling to project much of their personal perspective onto the choices of others.

One of the assumptions (in this case, testable) initially motivating research with multivariate vignette techniques was that all respondents share a common "referential structure" with which they compare empirical cases for the purpose of justice evaluations. Our finding of a general lack of interaction between respondents' social characteristics and their weighting of vignette attributes strongly suggests that the rules that people use to formulate decisions about appropriate care in end-of-life situations are universalistic ones that vary only marginally by social differences. The social differences that are quite divisive in other health care matters, such as abortion and euthanasia, have not so far been activated in any debate about end-of-life issues.

Finally, it is interesting to note a number of parallels between the vignette ratings and related health outcomes and attitudes, For example, we noted that race, age, religion, and the personal execution of a "living will" affected the propensity to recommend termination in vignettes without advance directives. There are parallel variations in the likelihood of various groups in the statewide population having a living will. One-third (32%) of Virginians age 65 and over have a living will, while only 11% of 18-to-34 year-olds have one. Nearly one in four whites (23%) have living wills, compared to 9% of African Americans. While 27% of non-religious Virginians have living wills, only 15% of Evangelicals do.

CONCLUSION -- PUBLIC OPINION AND ETHICS

In conclusion it is worth reflecting on the role of public opinion in relation to the ethical dimension of public policy concerning limitation of treatment. Is public opinion relevant to ethics? The mainstream traditions in moral philosophy and religious ethics would answer "No" to this question. Although few experts in these areas today would embrace the notion of elite monopoly over moral knowledge, most would

continue to reject the notion that ethics ought to be influenced by public opinion.

But public policy in a democracy is doomed to failure if it cannot win the support of the public. The classic example here is the effort to ban the sale and consumption of alcoholic beverages. The temperance movement was convinced of the moral evil of alcohol, but the effort to translate this into public policy failed miserably. In a pluralistic society, moral issues may be deeply contested. For example, reasonable and conscientious persons differ on the ethics of abortion, euthanasia, and rationing health care. The formation of public policy in the face of such disagreements demands the search for a satisfactory resolution. When there is no clear constitutional provision in favor of or against a proposed public policy, then assessment of public opinion is relevant and appropriate to policy formation.

We believe that our survey addresses several prominent ethical and moral questions directly, and provides ethicists, public policy makers, and leaders in health care with insights into public opinion that are: 1) testable in a national context; and 2) relevant to the ethical dimension of any national or state policy of health care reform. Our findings show a strong consensus in social, legal and medical opinion for continuing use of benefit/burden assessments in catastrophic and end-of-life situations, and for the sharing of decisions between physicians, patients, and authorized surrogates.

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