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Ethics Consultants' Recommendations for Life-Prolonging Treatment of Patients in Persistent Vegetative State: A Follow-Up Study

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In 2003, we conducted a survey to learn how ethics consultants would respond to a set of hypothetical clinical cases involving a patient in a persistent vegetative state (PVS), as a follow-up study to a similar survey that was conducted in 1991.¹ The earlier study concluded that "a widespread ethical consensus has emerged only for the easiest cases."² It also concluded that the finding of wide variability in ethics consultants' recommendations "suggests a need to clarify standards for ethics consultation."³

In the years that separate the two studies, guidelines regarding the appropriate treatment of patients in PVS have been issued by several professional groups, including a Multi-Society Task Force⁴ and the American Academy of Neurology⁵ in the U.S., and the British Medical Association⁶ and the Royal College of Physicians in the U.K.⁷ Meanwhile, efforts to clarify ethics consultation standards have included a national consensus conference in the U.S. that resulted in consensus statements on the goals⁸ and desired outcomes⁹ of ethics consultation, a report on ethics consultation by the Council on Ethical and Judicial Affairs of the American Medical Association,¹⁰ a monograph by the American Society for Bioethics and Humanities (ASBH) entitled *Core Competencies for Health Care Ethics Consultation*,¹¹ and national guidance on ethics consultation published by the Veterans Health Administration.¹²

In light of these ongoing efforts, we wanted to assess if and how the findings of a 2003 study would differ from those of the 1991 study. Specifically, we addressed: What would ethics consultants recommend in response to PVS cases? To what degree is there consensus? What factors influence recommendations? Do recommendations conform to established guidelines? We especially wanted to see whether our findings would suggest increased agreement about the appropriate treatment of PVS patients and/or appropriate ethics consultation practices.

METHODS

SUBJECTS

The sample for the 1991 study consisted of attendees of the annual meeting of the Society for Bioethics Consultation, held in Toronto, Ontario, Canada, in that year. The Society for Bioethics Consultation no longer exists as a separate body, but has been folded into the larger ASBH. For the 2003 study, we surveyed every fourth registrant of the joint meeting of the ASBH and the Canadian Bioethics Society held in Montreal, Quebec, Canada. Whereas in the earlier study questionnaires were handed out at the meeting, in the current study, subjects were sent questionnaires by mail. In both studies, those who did not initially respond were sent two follow-up mailings.

QUESTIONNAIRE

The 2003 questionnaire was very similar to the 1991 questionnaire; relevant differences will be pointed out in the results section below. As in the 1991 study, the questionnaire presented several variations on the case presented in table 1. Seven variations differed only as to the patient's previously expressed wishes and/or the current wishes of the patient's family; an eighth variation asked, "If you were the patient described above, which of the following do you think the ethics consultant should recommend?"

For each variation, respondents were given five options and asked to choose the option that best described what they would recommend on ethical grounds (see table 1). The questionnaire also sought demographic data, including age, sex, religion, education, and professional background. Subjects were asked about their experiences as ethics consultant and ethics committee member and about whether they had completed an advance directive for themselves.

DATA ANALYSIS

Categorical variables were compared using the *chi*-square test of association. As in the earlier study, the degree to which the respondents agreed on a response to each case scenario was expressed as the proportion of agreeing pairs. The degree of agreement on responses across the first seven scenarios was expressed as an overall *kappa*. In addition to coding the questionnaire responses, we constructed a combined variable to distinguish respondents who indicated that, in their role either as a consultant or as a committee member, they had ever made specific recommendations about limiting a treatment for a particular patient.¹³ We duplicated Fox's "intensity of LPT" variable by assigning a numeric value of 1 through 4 to the ordinal responses A through D, and then summing the responses across the seven vignettes. Higher scores represented more choices to continue life-prolonging treatments. Associations with the intensity of LPT score were tested using Spearman's rank correlation coefficients. Written comments and responses to open-ended questions were transcribed and later grouped into categories.

RESULTS

CHARACTERISTICS OF RESPONDENTS

Of the 183 questionnaires that were mailed, 117 questionnaires were returned for a response rate of 64 percent. Table 2 is a comparison of the demographic characteristics of respondents from the 1991 and 2003 studies.

A majority of the respondents who answered the eighth variation question, (109 of 117) reported that they had completed some sort of written advance directive; of the respondents, 45 percent (49/109) had an advance directive that specified their preferences about life-sustaining treatment (a treatment directive); 52 percent had an advance directive that designated a proxy decision maker (a proxy directive); 42 percent had both; and 45 percent had neither.

With respect to experience as ethics consultants or ethics committee members, 69 percent (75/109) of the respondents had ever been members of ethics committees (former study — fs: 81 percent in the past three

years), while 35 percent had ever acted as an independent ethics consultant (fs: 62 percent in the past three years). Of the respondents who were consultants and/or committee members, approximately 61 percent served at university hospitals, 26 percent at private hospitals, and 13 percent at public hospitals. Of those respondents, 52 percent indicated that they had experience making recommendations about treatment limitations in their role as an ethics consultant or committee member (fs: 46 percent as an ethics consultant in the last three years). Among those who had served as an independent consultant, 16 percent had never made a recommendation to limit treatment; of those who had served on an ethics committee, 27 percent had not done so.

TABLE 1 The Case, Variations, and Recommendations Used in the Surveys

The case

Imagine that, as an ethics consultant, you are asked about limiting treatment for a theoretical unconscious patient who, you are certain, has no possible chance of ever regaining consciousness and absolutely no awareness of the outside world. Currently, the patient is receiving fluid and nutrition through artificial means as well as routine nursing care, but does not require any other life-prolonging treatments.

The variations

1. The patient left an advance directive which clearly and convincingly states that the patient **did not want** to be kept alive in the event of a permanently unconscious and unaware state. The family **agrees** with discontinuing all life-prolonging treatments.
2. The patient left an advance directive which clearly and convincingly states that the patient **did not want** to be kept alive in the event of a permanently unconscious and unaware state. The family **disagrees** with discontinuing all life-prolonging treatments.
3. The patient left an advance directive which clearly and convincingly states that the patient **wanted** to be kept alive in the event of a permanently unconscious and unaware state. The family **agrees** with continuing all life-prolonging treatments.
4. The patient left an advance directive which clearly and convincingly states that the patient **wanted** to be kept alive in the event of a permanently unconscious and unaware state. The family **disagrees** with continuing all life-prolonging treatments.
5. The patient left no oral or written advance directive of any kind. The family wants all life-prolonging treatments **discontinued**.
6. The patient left no oral or written advance directive of any kind. The family wants all life-prolonging treatments **continued**.
7. The patient left no oral or written advance directive. There are no known family members or friends.
8. If you were the patient described above, which of the following do you think the ethics consultant should recommend?

The possible recommendations

- A. Continue routine nursing care but discontinue all treatments necessary for prolonging life.
 - B. Continue fluid and nutrition through artificial means as well as routine nursing care, but do not provide any additional treatments necessary for prolonging life.
 - C. Continue fluid and nutrition through artificial means as well as routine nursing care, and in addition provide only the following treatments should they become necessary for prolonging life (circle as many as may apply): antibiotics, acute care hospitalization, blood transfusions, transfer to intensive care unit, dialysis, minor surgery, major surgery, artificial respiration, cardiopulmonary resuscitation, organ transplantation, other (specify).
 - D. Provide all possible treatments necessary for prolonging life.
 - E. Other (specify).
-

Respondents who had experience making recommendations about limiting treatment ($n = 61$) differed from those who had no such experience ($n = 56$) in that the former were younger ($p = .006$), more likely to be a doctor or nurse (74 percent versus 40 percent, $p = .0004$), more likely to have a written treatment directive (62 percent versus 22 percent, $p < .0001$) or proxy directive (69 percent versus 31 percent, $p < .0001$), less likely to live in Canada (33 percent versus 59 percent), and less likely to think an ethics consultant should recommend life-sustaining treatment for them if they were in PVS (23 percent versus 48 percent, $p = .004$).

RECOMMENDATIONS OF RESPONDENTS

Table 3 shows the comparative responses to the eight case vignettes as well as the proportion of agreeing pairs for each vignette.¹⁴ The similarity of responses from the entire samples in the two studies is readily apparent. The overall *kappa* for the first seven vignettes in the 2003 data is 0.21. (The analogous *kappa* for the earlier study was 0.17.) Both are indications of very poor agreement.

Nonetheless, compared with the data from 1991, agreement on recommendations for certain vignettes has increased modestly. Vignette one continues to show a strong consensus as to the appropriate recommendation (defined as proportion of agreeing pairs of $> .50$). This time, however, the proportion of agreeing pairs exceeded .50 for two additional vignettes (five and seven), with a greater percentage of respondents recommending withdrawal of life-prolonging treatment. Of note, the proportion of agreeing pairs did not increase at all and remains very low for both vignettes in which the patient wanted to be kept alive as long as possible (three and four), as well as for vignette six, in which the patient's wishes were not known and the family wanted to continue all life-prolonging treatment. Agreement was also low for the two vignettes in which there was a conflict between the wishes of the patient and the wishes of the patient's family.

While virtually all of the respondents offered specific treatment recommendations for vignettes one and five, approximately 20 percent of respondents selected option E, "Other (specify)," for at least one of the other vignettes. The most common write-in entries among the 212 associated with option E responses were suggestions to resolve the conflict through discussion (35 percent of entries), to delay the treatment decision (19 percent), to attempt to change the family's views (10 percent), or to seek legal counsel (9 percent). A few write-in comments (4 percent) suggested that ethics consultants should not make recommendations.

An additional 380 comments were received in response to the request that respondents explain or qualify their comments. These most commonly pertained to the patients' wishes (24 percent), the family's wishes (21 percent), fu-

TABLE 2 Comparison of Demographic Characteristics of Respondents

Characteristic	1991		2003	
	<i>n</i>	%	<i>n</i>	%
Sex				
Male	71	61	46	42
Female	46	39	63	58
Country of residence				
United States	80	70	83	76
Canada	34	30	26	24
Age in years				
≤ 40	33	28	31	28
41-60	69	58	57	52
> 60	16	14	22	20
Religion				
Catholic	30	26	18	25
Protestant	40	34	32	45
Jewish	14	12	13	18
Agnostic/atheist/other	32	28	8	11
Professional background*				
Physician	45	38	30	27
Nurse or other clinical	20	17	25	23
Philosopher/ethicist	48	41	28	25
Theologian or minister	28	24	6	5
Administrator/other	32	26	12	11
Attorney	7	6	9	8

* Percentages exceed 100 due to overlap.

tility (14 percent), cost (12 percent), or the best interests of the patient (10 percent). Less than 1 percent of comments suggested that food and fluid are basic care that should not be stopped.

FACTORS THAT INFLUENCE RESPONSES

Only one characteristic, personal preference for life-prolonging treatment in PVS, was significantly related to the intensity of LPT score (respondents who would want an ethics consultant to recommend more intensive life-prolonging treatment for themselves in PVS were more likely to recommend it for a hypothetical patient in PVS, $p = .01$). The intensity of LPT score was not associated with age, sex, country of residence, religion, or having an advance directive.

While the intensity of LPT score did not differ between respondents who had experience making recommendations to limit treatment and those who had no such experience, the two groups did sometimes differ significantly in their responses to individual vignettes, and the outliers generally fell into the latter group. For example, 100 percent of the respondents who had experience making recommendations to limit treatment selected option A in response to the first vignette, compared with 87 percent of those who had no such experience ($p = .03$).

Although patients' wishes were the most commonly cited factor in responses to the request that respondents explain or qualify their recommendations, overall, the responses did not reflect strict adherence to patients' wishes. Only 59 percent of the respondents consistently recommended withdrawal of life-prolonging treatment in cases involving a PVS patient who did not want such treatment (vignettes one and two). For cases involving a PVS patient whose prior wishes were to be

TABLE 3 Comparison of Responses to the Variations in the Case (1991/2003)

Variation #	N	N	2003	A: Routine care only		B: Fluid + nutrition		C: Additional treatments		D: Everything possible		E: Other (specify)		Proportion of agreeing pairs	
				1991	2003	1991	2003	1991	2003	1991	2003	1991	2003	1991	2003
1	115	104		93	94	5	4	1	0	0	1	1	1	0.87	0.89
2	116	103	No LPT	3	4	38	28	36	36	6	18	16	14	0.30	0.43
3	114	103	All LPT	50	59	24	20	6	4	0	4	20	13	0.34	0.27
4	116	103	All LPT	20	17	37	36	26	21	3	12	14	12	0.26	0.24
5	115	104	Unknown	68	79	20	10	3	1	0	2	9	2	0.50	0.68
6	112	103	Unknown	12	11	43	28	24	31	2	10	19	20	0.29	0.24
7	115	102	Unknown	56	68	22	16	10	3	0	3	13	11	0.38	0.51
8	114	101	Personal preference ³	83	75	10	13	2	3	0	2	4	7	0.71	0.59

NOTES

1. PVS patient's wish for life-prolonging treatment (LPT) as expressed in an advance directive.
2. Wishes of the PVS patient's family regarding LPT for the patient.
3. The LPT the respondent thinks an ethics consultant should recommend if the respondent were in PVS.

kept alive as long as possible (vignettes three and four), only 10 percent of the respondents consistently recommended providing all necessary life-prolonging treatment. Still, patients' wishes had a major impact on the responses. Comparing pairs of vignettes that varied only with respect to patients' wishes, about 81 percent of the respondents changed their recommendations between vignettes one and four, and 76 percent changed between vignettes two and three.

The strong influence of family's wishes is also apparent. Comparing paired vignettes that varied only with respect to family's wishes, 33 percent of our respondents changed their recommendations between vignettes one and two; 32 percent changed between vignettes three and four, and 65 percent changed between vignettes five and six.

Finally, respondents seemed significantly influenced by resource allocation and/or futility concerns. The vast majority of respondents (82 percent) did not recommend providing the PVS patient with all possible treatments necessary for prolonging life even when both the patient and the family wanted the patient kept alive as long as possible.

LIMITATIONS

The findings of this study are limited in several respects. Although our response rate of 64 percent is respectable for a survey study, our respondents were self-selected in that they were all registrants at the same professional meeting. In addition, not all respondents had acted as ethics consultants either independently or as a member of an ethics committee. Therefore, our results may not be generalizable to all ethics consultants.

As in the earlier study, responses to simplified hypothetical cases may not accurately reflect actual behavior. A more detailed account of the patient's case might have resulted in different choices for some of the respondents. The request for a single "recommendation" after each vignette, along with the forced choice between options, does not reflect the usual process of ethics consultation. Our inclusion of an "other" category among the options, and our request to "explain or qualify" each response, allowed the respondents to voice any reservations they might have had about the framing of the questions; however, few did.

DISCUSSION

This study demonstrates wide variability in what ethics consultants say they would recommend for specific hypothetical cases involving a PVS patient. Compared to the 1991 study, the results are strikingly similar overall. Although in a few cases agreement has increased modestly, consensus is still largely lacking.

To better understand the variability of the responses we observed, we examined several well-known consensus statements and guidelines published in the interval between the two studies, and attempted to determine the extent to which responses in this study were consistent with those guidelines.¹⁵ We found that, for difficult cases such as those described in vignettes two through seven of this study, the guidelines were generally too nonspecific and nonprescriptive to suggest a particular best course of action. For example, the Royal College of Physicians suggests that "decisions not to intervene by cardio-pulmonary resuscitation or to prescribe antibiotics, dialysis and insulin *can* [emphasis added] be taken clinically, in the best interests of the patient, after full discussion with those concerned."¹⁶ Similarly, the Multi-Society Task Force on PVS encourages physicians to "work closely with the family to determine the appropriate level of medical treatment," but stops short of saying what should be done in case of conflict.¹⁷

We also examined several published guidelines, consensus statements, and standards on ethics consultation to see how they might inform our discussion.¹⁸ Almost all caution ethics consultants against imposing their own personal moral views on others. For example, Fox and Arnold assert, "Certainly, many normative aspects of clinical practice remain controversial, and it is important not to overestimate the extent of prevailing consensus on ethical issues. For many situations there is a range of ethically acceptable alternatives."¹⁹ In a similar vein, the ASBH *Core Competencies* document explicitly rejects an "authoritarian approach," in which the ethics consultant displaces the appropriate moral decision maker and/or excludes relevant parties

from the decision-making process, in favor of an "ethics facilitation approach," which involves "the building of morally acceptable shared commitments or understandings."²⁰

Indeed, all of the guidelines stress the centrality of the ethics consultant's role in building consensus. For example, Fletcher and Siegler talk about the goal of ethics consultation to foster "a fair and inclusive decision-making process" and "to facilitate resolution of conflicts in a respectful atmosphere with attention to the interests, rights, and responsibilities of those involved."²¹ The American Medical Association report on ethics consultation states categorically, "Where there is a dispute, the consultation role is one of negotiation and resolution."²² And the Veterans Health Administration's national guidance on ethics consultation suggests that ethics consultants should "facilitate moral deliberation" to help the decision maker or makers determine which option is best among the various options that are ethically justifiable.²³

Thorough elicitation and discussion of the participants' perspectives — and efforts to facilitate a solution that is acceptable to all — are essential to the ethics consultation process. Because clinical cases are so complex, and because the process of ethics consultation is as important as the outcome, it is generally inappropriate for ethics consultants to make specific clinical recommendations that are based only on a brief summary of a case. The best ethics consultants learn from experience that ethics consultation cases are rarely as straightforward as they may initially seem.

Most of the respondents in this study were willing to respond to a request for a recommendation of an "ethically correct" treatment decision even though only minimal case information was presented. In every vignette, respondents had the option to select "E, Other (speci-fy)," but most selected one of the specific treatment options instead. Relatively few pointed out the need to collect additional information, identify the appropriate decision maker, or engage the healthcare team and the family in moral deliberation.

While it is unreasonable to expect that all ethics consultants' responses to clinical vignettes will be the same, it is reasonable to expect that their responses will reflect widely accepted standards. Such standards suggest that ethics consultation is not primarily about prescribing ethical actions, but facilitating an ethical decision-making process. Future research might attempt to assess the use of a systematic approach that includes key steps, such as confirming the adequacy and accuracy of information, identifying the appropriate decision maker, clarifying the full range of ethically justifiable options, and engaging the participants in discussion.²⁴

While consultants' responses to this study may differ from their behavior in actual practice, the current study suggests a continued need to clarify and apply standards for ethics consultation, particularly with regard to the role, nature, and effect of ethics consultants' recommendations; how to identify the appropriate decision maker; and the limits to the decision maker's authority.

DISCLAIMER

The views expressed in this article do not reflect the views of the Department of Veterans Affairs or of the United States government.

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NOTES

1. E. Fox and C. Stocking, "Ethics Consultants' Recommendations for Life-Prolonging Treatment of Patients in a Persistent Vegetative State," *Journal of the American Medical Association* 270 (December 1993): 2578-82.

2. Ibid.

3. Ibid.

4. Multi-Society Task Force on PVS, "Medical aspects of the persistent vegetative state — first of two parts," *New England Journal of Medicine* 330 (1994): 1499-508; Multi-Society Task Force on PVS, "Medical aspects of the persistent vegetative state — second of two parts," *New England Journal of Medicine* 330 (1994): 1572-9.

5. http://www.aan.com/professionals/practice/pdfs/pdf_1995_thru_1998/1995.45.1015.pdf.

6. British Medical Association Medical Ethics Committee, *BMA guidelines on treatment decisions for patients in a persistent vegetative state* (London: British Medical Association, 1994).

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8. J.C. Fletcher and M. Siegler, "What Are the Goals of Ethics Consultation? A Consensus Statement," *The Journal of Clinical Ethics* 7, no. 2 (Summer 1996): 122-6.

9. E. Fox and R.M. Arnold, "Evaluating Outcomes in Ethics Consultation Research," *The Journal of Clinical Ethics* 7 (1996): 127-38.

10. http://www.ama-assn.org/ama1/pub/upload/mm/369/ceja_3i97.pdf, accessed 15 October 2006.

11. Society for Health and Human Values — Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation, *Core Competencies for Health Care Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998); M.P. Aulisio, R.M. Arnold, and S.J. Youngner, "Health Care Ethics Consultation: Nature, Goals, and Competencies: A Position Paper from the Society for Health and Human Values — Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation," *Annals of Internal Medicine* 133, no. 1 (July 2000): 59-69.

12. <http://www.ethics.va.gov/integratedethics.asp>, accessed 22 March 2007.

13. The corresponding variable in the 1993 study looked at recommendations made as an independent ethics consultant in the past three years.

14. As explained in our 1991 report, "The proportion of agreeing pairs statistic can be understood as follows. Let a randomly chosen respondent make a recommendation for variation 5. The chance that a second randomly selected respondent would agree with the first is 50%, because the proportion of agreeing pairs is 0.50 for that vignette. Although the proportion of agreeing pairs statistic does not adjust for chance agreement, it is clear that no consensus exists when there is only a 50/50 chance that two people will agree. See note 1 above, p. 2580.

15. See notes 4 through 7 above.

16. See note 7 above.

17. Multi-Society Task Force on PVS, "Medical aspects — second of two parts," see note 4 above.

18. See notes 8 through 12 above.

19. Fox and Arnold, see note 9 above.

20. See note 11 above.

21. See note 8 above.

22. See note 10 above.

23. See note 12 above.

24. See note 11 above.