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# Physician Willingness to Withhold Tube Feeding After *Cruzan*: An Empirical Study

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In *Cruzan v. Harmon*,[2] the Missouri Supreme Court declined to let Nancy Cruzan's father discontinue her tube feedings.[3] The court insisted on clear and convincing evidence of her wishes and was unsatisfied that proof of

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2. 760 S.W.2d 408 (Mo. 1988), *aff'd sub nom.* Cruzan v. Director, Mo. Dep't of Health, 110 S. Ct. 2841 (1990).

3. *Id.* at 426.

this kind had been presented in her case.[4] In addition, it refused to defer to her family[5] or to consider her "quality of life."[6] On June 25, 1990, the United States Supreme Court affirmed the Missouri Supreme Court's decision.[7] Since *Cruzan*, public demand for living wills has exploded.

In the spring of 1991, we began a study to explore how the *Cruzan* decision and the heightened awareness of living wills had affected medical decision-making. We were curious and uncertain about the probable impact of living wills in a clinical setting. We were particularly interested in comparing the strength of living wills to that of family preferences. To study these questions, we mailed to all Missouri family physicians a questionnaire which explored the circumstances under which they would recommend tube feeding for a hypothetical elderly patient with severe neurological impairment.

The results of this study yielded four insights into the uneasy coexistence of law and medicine in the field of death and dying. First, *Cruzan* appears to have measurably altered family and physician decision-making. Both physicians and families are less willing to initiate heroic measures in the aftermath of *Cruzan*. Physicians also stated that they now ask for better evidence of their patients' wishes. Second, *Cruzan* has not stopped physicians from recommending against tube feeding when patient wishes are unknown. Nearly half of the physicians were willing to withhold tube feeding from our elderly patient. Two-thirds of these physicians were willing to withhold tube feeding even if the patient had no living will notwithstanding the doubts cast by *Cruzan* on the legality of doing so. Third, physicians were evenly divided in their deference to a living will of uncertain applicability. Fourth, families could readily influence physician recommendations even though family members lack legal standing in Missouri to make these decisions.

## I. METHODOLOGY

In May 1991, all 631 members of the Missouri Academy of Family Physicians were mailed a questionnaire asking specific questions about the impact of the *Cruzan* opinion on their practice and also about their attitudes towards living wills. The questionnaire then asked whether they would administer tube feedings to an elderly man with severe neurological impairment under several hypothetical situations.

All of the questionnaires asked the physician to assume that the patient had executed a living will, a copy of which was provided on the reverse side

4. *Id.* at 424.
5. *Id.* at 426.
6. *Id.* at 422.
7. Cruzan v. Director, Mo. Dep't of Health, 110 S. Ct. 2841 (1990).

of the questionnaire. The text of the living will was taken from a form widely distributed in Missouri and Kansas by the Midwest Bioethics Center and the Kansas City Metropolitan Bar Association.[8] This living will form was drafted to comply with the statutes of Missouri and Kansas. As a result, it is explicitly limited to terminal conditions. Although the back side of the Midwest Bioethics Center form provided for expansion of the scope of consent by the patient, we did not use that portion of the form. For half of the questionnaires, however, the respondents were informed that the patient had supplemented this "standard" living will to specifically include nutrition and hydration.[9]

The physicians were then asked whether they would recommend tube feeding for an elderly patient with severe neurological impairment. They were given the following information about the patient:

> One week ago you admitted a previously healthy 89-year-old retired farmer with sudden aphasia[10] and dense right hemiparesis.[11] CT scan shows a left-hemisphere infarct.[12] He is unable to swallow and is on maintenance

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8. The text read as follows:

> If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians who have personally examined me, one of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining procedures would serve only to artificially prolong the dying process, and I am unable to participate in decisions regarding my medical treatment, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort.

9. The language for this portion of the living will read: "I consider artificial nutrition and hydration (nutrition and fluid given through a tube in the vein, nose, or stomach) as just another method of 'artificially prolonging the dying process.'"

10. Aphasia is defined as "impaired or absent comprehension of or communication by speech, writing or signs, due to dysfunction of brain centers in the dominant hemisphere." STEDMAN'S MEDICAL DICTIONARY 104 (25th ed. 1990).

11. Hemiparesis is defined as "paralysis affecting one side of the body." *Id.* at 695. A dense hemiparesis refers to a total paralysis of one side of the body.

12. Infarct is defined as "an area of necrosis resulting from a sudden

> IV fluids. His neurologic status has not changed since admission except that he is more alert; however, he is unable to communicate. You tell the family that a decision needs to be made about a feeding tube and that you expect his aphasia and hemiparesis will not improve significantly but that you will not be able to give an accurate prognosis for 6-8 more weeks.

The respondents were then asked whether they would recommend tube feeding and whether they would change that recommendation under different factual assumptions.[13] The variations included assumptions about the family's wishes (either "pushing for" or "pushing against" a feeding tube), the absence of a living will, the timing vis-a-vis the *Cruzan* decision, a change in the age of the patient (48 instead of 89), and a one-year period of feeding without clinical change.

Seventy-two percent (72%) of the physicians responded.[14] The significance of differences between groups of physicians were determined using the chi-square statistic.[15] SPSS Version 4.0[16] was used to analyze the data.

## II. RESULTS

The responses indicate that *Cruzan* has significantly affected the environment in which decisions about life-sustaining treatment are made. More than half of the respondents (51%) reported that patients and their families resist trials of heroic therapy more often now than they did before *Cruzan*. Many physicians were also less aggressive in their treatment recommendations after *Cruzan*. In response to our questions about tube feeding for an elderly patient with severe neurological impairment, twenty-two percent (22%) of the physicians who opposed tube feedings said they would have recommended tube feedings prior to *Cruzan*. Both findings are consistent with widely expressed fears that people would resist the initiation of life-sustaining procedures out of suspicion that the treatments could not

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insufficiency of arterial or venous blood supply." *Id.* at 779. Necrosis is "death of one or more cells, or of a portion of tissue or organ." *Id.* at 1026.

13. The responses indicated whether the physician favored tube feeding, intravenous fluids or neither. They were dichotomized to "recommends feeding tube" versus "recommends no feeding tube."

14. This figure was calculated after excluding 18 physicians who were part of the pilot study.

15. This is a statistical test used to measure the significance of differences in responses.

16. This is a computer software program that performs data analysis.

thereafter be stopped.[17] Over fifty-five percent (55%) of the physicians also reported that they now ask for clearer evidence of patients' wishes than they did before *Cruzan.*

The impact of living wills was more difficult to assess. Fifty-nine percent (59%) of the physicians said living wills are very useful in the care of their patients; thirty-one percent (31%) felt that they are somewhat useful; and ten percent (10%) concluded they are not useful.[18] Despite this strong endorsement of living wills in the abstract, the actual impact of the living will forms used in our hypothetical case study was more modest. When asked whether they would recommend tube feedings for an elderly patient with neurological impairment and a living will, only forty-seven percent (47%) of the physicians opposed tube feedings. Not surprisingly, the opposition to tube feeding was higher among physicians who received the living will specifically refusing nutrition and hydration (53%) than among those who received the standard living will (42%; p=.02). When the physicians who had initially opposed tube feeding were asked what they would recommend in the absence of either type of living will, thirty-three (33%) changed their recommendations. Physicians who received the standard living will were less likely to change their recommendations than physicians who received the specific living will (26% v. 40%; $p < 0.05$).

The influence of family preferences was more dramatic. When physicians were asked what they would recommend if the family *opposed* feeding tubes, forty-two percent (42%) of the physicians who initially recommended tube feedings changed their recommendations. Family preferences were more influential among physicians who received questionnaires containing the standard living will than among those who received the specific living will (49% vs. 31%; $p < 0.01$).

Families who *favored* tube feedings were even more influential than families who opposed them. When asked what they would do if the family favored tube feeding, sixty-six percent (66%) of those physicians who had

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17. *E.g., Cruzan,* 110 S. Ct. at 2870 (Brennan, J., dissenting); *Cruzan,* 760 S.W.2d at 440 (Higgins, J., dissenting); L. Gregory Pawlson, *Impact of the* Cruzan *Case on Medical Practice,* 19 L. MED. & HEALTH CARE 69, 71 (1991); Ellen C. Weiss, *The Effect of the Treatment Setting on the Decision-Making Process: Acute Care Hospitals and Emergency Services,* 19 L. MED. & HEALTH CARE 66, 67-68 (1991).

18. Those physicians who said living wills were very useful were only slightly less likely to recommend feeding tubes than those physicians who said living wills were somewhat useful or not useful (51% vs. 55%). Thus, the group of physicians who least valued living wills were not, as one might have suspected, significantly more resistant to the idea of withholding life-sustaining care.

initially opposed tube feeding said they would now recommend it.[19] Once again, deference to family pressures varied with the kind of living will received. More physicians who received the standard living will changed their recommendation in response to family requests than did those who received the specific living will (75% vs. 57%; $p < 0.01$).

The differences in responses between urban and rural physicians and between male and female physicians were not statistically significant. Other findings of the study, such as the influence of changes in patient age and prognosis, are contained in the full study as published in the *Journal of the American Geriatrics Society*.[20] In addition, the full study contains information about the most common comments written on the questionnaires.

## III. LIMITATIONS

The study has several potential limitations. First, our findings are based on what physicians said they would do, rather than on what they did. A previous study found a strong correlation between predicted and actual action,[21] but this correlation has not been tested for life-sustaining treatments. Second, caution must be exercised in generalizing these findings to other forms of life-sustaining treatments. Even though most courts[22] and medical ethicists[23] treat tube feedings as a form of medical care which may be withheld in appropriate circumstances, some physicians[24] and the Missouri

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19. Even the physicians who had based their decision to withhold tube feeding entirely on the living will were willing to administer tube feeding if the family insisted. Sixty-nine percent favored a feeding tube under these circumstances.

20. Ely et al., *supra* note 1.

21. J.R. Kirwan et al., *Clinical Judgment in Rheumatoid Arthritis: I. Rheumatologists' Opinions and the Development of 'Paper Patients,'* 42 ANNALS RHEUMATIC DISEASES 644, 645 (1983).

22. ALAN MEISEL, THE RIGHT TO DIE § 5.10 (1989).

23. *See, e.g.*, THE HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING (1987); Bernard Lo & Laurie Dornbrand, *Guiding the Hand That Feeds: Caring for the Demented Elderly*, 311 NEW ENG. J. MED. 402 (1984); Robert Steinbrook & Bernard Lo, *Artificial Feeding-Solid Ground Not a Slippery Slope*, 318 NEW ENG. J. MED. 286 (1988).

24. *E.g.*, PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL AND LEGAL ISSUE IN TREATMENT DECISIONS 90, 190 (1983); Diane

Supreme Court[25] seem to disagree, and the Missouri legislature has treated tube feeding inconsistently.[26] Finally, our findings may not be generalizable to states other than Missouri or to specialties other than family practice. Because the rules upheld by the U.S. Supreme Court in *Cruzan* were those of Missouri, the case may be more influential here than in other states. In addition, family practitioners may be more likely to involve family members in a treatment decision and less likely to treat aggressively than other specialists.[27]

## IV. DISCUSSION

### A. *The Influence of* Cruzan

The Missouri Supreme Court felt that insistence on strong evidence of patients' wishes was a reasonable way of minimizing erroneous decisions to end life-sustaining care.[28] To this extent, the judges will find comfort in one of our findings. Over fifty-five percent (55%) of the physicians reported that they ask for clearer evidence of patients' previously expressed wishes after *Cruzan* than they had before. However, they do not always insist on such evidence before withholding tube feeding. In our scenario, the physicians had no information about the patient's unwritten instructions, yet two-thirds of the physicians who recommended against tube feeding said they would have done so even if the patient had no living will.

On the other hand, the dissenters in both the United States Supreme Court[29] and the Missouri Supreme Court[30] predicted that the difficult burden

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L. Redleaf et al., *The California Natural Death Act: An Empirical Study of Physicians' Practices*, 31 STAN. L. REV. 913, 932-33 (1979).

25. *Cruzan*, 760 S.W.2d at 412, 423.

26. *Compare* MO. REV. STAT § 459.010.3 (1986) (statutory definition of "death-prolonging procedures" excludes artificial nutrition and hydration) *with* MO. REV. STAT. § 404.820 (1991 Supp.) (durable power of attorney statute permits withholding of artificial nutrition and hydration but only if the patient specifically grants that power and subject to special requirements).

27. Efrem Alemayehu et al., *Variability In Physicians' Decisions on Caring for Chronically Ill Elderly Patients: An International Study*, 144 CANADIAN MED. ASS'N J. 1133, 1138 (1991); Terry A. Travis et al., *The Attitudes of Physicians Toward Prolonging Life*, 5 INT'L J. PSYCHIATRY MED. 17, 21 (1974).

28. *Cruzan*, 760 S.W.2d at 424.

29. *Cruzan*, 110 S. Ct. at 2870 (Brennan, J., dissenting).

30. *Cruzan*, 760 S.W.2d at 440 (Higgins, J., dissenting).

of proof placed on families who wish to terminate life-sustaining medical care would discourage the initiation of heroic care.[31] Regrettably, this prediction was well-founded. Over half of our respondents reported that patients and their families are resisting trials of heroic therapy more often now than they had before *Cruzan*. The bright side of this finding is that patients and their families may now be more willing to voice their objections to aggressive care. The dark side is that they feel the necessity to decline trials of heroic measures. In the months after *Cruzan* it was rare to attend a conference on death and dying without hearing anecdotes about ill-advised refusals to initiate even short term heroic measures. More than ever, patients and families now fear that they will be unable to stop treatment once it has begun.

Even physicians are less aggressive about initiating care than they were before *Cruzan*. In our hypothetical scenario, forty-seven percent (47%) opposed tube feeding. Of them twenty-two percent (22%) said they would have recommended tube feeding before *Cruzan*. This finding surprised us. In *Cruzan*, the Missouri Supreme Court had insisted that tube feeding be continued for a 30-year-old woman in a persistent vegetative state absence clear and convincing evidences of her wishes. In the view of the court, the state's "unqualified" interest in preserving human life required continued feeding because her artificial hydration and nutrition were not "oppressively burdensome" to her[32] and because the evidence of her wishes was not sufficiently reliable.[33] After this decision, we had suspected that physicians would feel more obliged to administer nutrition and hydration than they had before. Our data suggest a contrary response. Only three percent (3%) of the physicians who favored tube feeding on our facts would have opposed it before *Cruzan*, while twenty-two percent (22%) of those who opposed tube feeding on our facts would have recommended it before *Cruzan*.

There are at least two plausible explanations why physicians might be more inclined to withhold tube feedings after *Cruzan*.[34] First, the increased

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31. Ethicists had also predicted this result. *See supra* note 17.

32. *Cruzan*, 760 S.W.2d at 423-24.

33. *Id.* at 424.

34. In addition, the failure of *Cruzan* to prompt more aggressive care in our scenario may be explained by factual differences between our scenario and the facts of *Cruzan*. Our scenario was different in two important respects; our patient had a much shorter life expectancy than Nancy Cruzan and his tube feeding had not yet started. Indeed, forty-five percent (45%) of the physicians who opposed tube feeding for our 89-year-old patient would have recommended treatment if the patient had been 48 years old. These factual differences may explain why *Cruzan* did not generate more aggressive care in our case. But it would not account for the *increased* tendency to oppose life support

reluctance of our respondents to initiate tube feeding after *Cruzan* could be based on changes in their attitudes toward living wills. After *Cruzan* our respondents may perceive themselves to be more deferential to living wills than they were before. The likelihood that this was an important factor is weakened by the small percentage (33%) of physicians whose opposition to tube feeding was premised on the living wills.

Second, physicians may fear that treatments which are commenced will have to be continued indefinitely. This explanation for their increased opposition to tube feeding is both intuitively convincing and alarming. As the President's Commission observed in 1982, a "troubling wrong occurs when a treatment that might save a life or improve health is not started because the health care personnel are afraid that they will find it very difficult to stop treatment if, as is fairly likely, it proves to be of little benefit and greatly burdens the patient."[35]

Similar reluctance to try heroic measures could occur in any state perceived by its citizens to place undue restrictions on the discontinuance of life support. As a result, judges and legislators in states which place the most stringent limits on the withdrawing of medical care, such as Missouri, New York[36], and Oklahoma,[37] should recognize the real risk that well-intended safeguards could have harmful consequences which outweigh the expected benefits.

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after *Cruzan*. For that finding, another explanation is necessary.

35. PRESIDENT'S COMM'N, *supra* note 24, at 75.

36. *See In re* O'Connor, 531 N.E.2d 607, 613 (N.Y. 1988) (precluding discontinuance of treatment without clear and convincing evidence of specific patient preferences).

37. *See* OKLA. STAT. ANN. tit. 63, § 3004.3-5 (West 1990 Supp.) The statute only permits withholding of nutrition and hydration if (1) the patient is competent and will die of some other cause before death by starvation or dehydration; or (2) the nutrition "will itself cause severe, untractable and long-lasting pain . . . or hydration is not medically possible;" or (3) the patient left clear and convincing instructions *after* contracting "a specific illness or injury" based on information sufficient to constitute informed consent. *Id.* Ohio and Washington also appear to place special limits on decisions about nutrition and hydration. *See* OHIO REV. CODE ANN. § 2133.08-.09 (Page's 1991 Supp.) (in the absence of a living will, nutrition and hydration may only be withheld from terminal patients who have been in a permanent unconscious state for twelve months and only with an order from probate court); *In re* Grant, 747 P.2d 445, 451 (Wash. 1987), *modified*, 757 P.2d 534 (Wash. 1988) (5-4 against authorizing parents to forego artificial nutrition and hydration for terminally-ill child).

Regrettably, the Missouri Supreme Court may have further exacerbated this result by suggesting that it might be more defensible to withhold tube feeding than to withdraw it.[38] The court noted that the continuation of tube feeding is less invasive than the initial placement of the tube and then concluded that tube feeding was not "oppressively burdensome" to Ms. Cruzan.[39] This language may give the distinction between withholding and withdrawing more legal and clinical weight than it deserves.[40] Although placing a feeding tube is more invasive than the continuation of tube feeding, the difference will rarely be sufficient to justify the withholding of a feeding tube in one case but not the other. Instead, as others have amply noted,[41] recognition of a distinction between failure to initiate a treatment and failure to continue will often discourage the initiation of appropriate heroic care.

### *B. The Influence of a Statutory Living Will*

The United States Supreme Court's decision in *Cruzan* dramatically increased public interest in living wills. In its aftermath, the Society for the

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38. *Cruzan*, 760 S.W.2d at 422-24.

39. *Id.*

40. Most courts have rejected the distinction between not starting treatment and stopping treatment. *E.g.*, Satz v. Perlmutter, 362 So .2d 160, 163 (Fla. Ct. App. 1978), *aff'd*, 379 So. 2d 359 (Fla. 1980); Brophy v. New England Sinai Hosp., Inc., 497 N.E.2d 626, 637-38 (Mass. 1986); McKay v. Bergstedt, 801 P.2d 617, 625 (Nev. 1990); *In re* Conroy, 486 A.2d 1209, 1234 (N.J. 1985); *Grant*, 747 P.2d at 452; *see also* MEISEL, *supra* note 22, § 4.4 (collecting cases). *Contra Cruzan*, 760 S.W.2d at 422-24 (noting that the continuation of tube feeding is less invasive than the initial placement of the tube and concluding that tube feeding was not "oppressively burdensome to Nancy); Workman's Circle Home & Infirmary for the Aged v. Fink, 514 N.Y.S.2d 893, 896 (Sup. Ct. 1987) (permitting withholding of gastronomy but not intravenous feeding because the latter was "more passive and less intrusive"). *Cf. In re* Riddlemoser, 564 A.2d 812, 816 n.5 (Md. 1989) (noting that withholding and withdrawing care are "separate and distinct," but not relying upon the distinction). The distinction is most likely to be material when the initiation of treatment would impose a materially greater burden on the patient than continuation of an existing treatment. *See Cruzan*, 760 S.W.2d at 422-23; *Workmen's Circle*, 514 N.Y.S.2d at 895-96.

41. *Brophy*, 497 N.E.2d at 638; *In re* Conroy, 486 A.2d at 1234; PRESIDENT'S COMM'N, *supra* note 24, at 61-62, 73-77; Joanne Lynn & James F. Childress, *Must Patients Always Be Given Food and Water?*, HASTINGS CENTER REP., Oct. 1983, at 17, 19-20.

Right to Die experienced a 500% increase in living will requests.[42] In Missouri, the Midwest Bioethics Center witnessed an explosion in requests for living will forms. We were interested in studying the clinical impact on a realistic borderline case of preprinted living wills like the one widely distributed in Missouri by the Midwest Bioethics Center.

Overall, forty-seven percent (47%) of the physicians said they would oppose a feeding tube if the patient had executed the living will in our study. When these physicians were asked what they would have recommended in the absence of a living will, thirty-three percent (33%) changed their recommendation. Thus, one-third of the physicians who recommended against tube feedings had based their decision entirely on the patient's living will, and they comprise one-sixth of the total respondents. Not surprisingly, those physicians who received the living will which specifically included nutrition and hydration were both more likely to oppose tube feeding than those with the standard living will (53% vs. 42%; p=0.02) and also more likely to change their recommendation in the absence of a living will (40% v. 26%; $p<0.05$).

One possible explanation for the modest impact of the living wills is that the physicians did not believe that the patient was terminally ill as required by the language of the living will.[43] The patient in our scenario could have lived for months and perhaps even years. As a result, some physicians (4%) commented that the living will was inapplicable because the patient was not terminally ill.

In addition, the standard living will did not specify whether artificial nutrition and hydration were to be withheld. Under the Missouri living will statute, "death-prolonging procedures" do not include the administration of artificial nutrition and hydration.[44] Although we did not use the living will form provided by the Missouri statute, some physicians may have concluded that the language of our living will should be interpreted to exclude artificial nutrition and hydration.

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42. *Concern for Dying*, SOCIETY FOR THE RIGHT TO DIE NEWSLETTER (New York, N.Y.), Fall 1990, at 1. Between the Court's June 25, 1990 decision and mid-October 1990, that organization had filled more than 400,000 requests for forms of living will and durable power of attorney. *Id.* At that time, demand was reportedly still growing. *Id.*

43. While the Missouri living will statute defines "terminal" conditions to be those resulting in death in a "short-time" regardless of the application of medical procedures, our living will did not use an explicit time limitation. MO. REV. STAT. § 459.010.6 (1986).

44. MO. REV. STAT. § 459.010(3) (1986). However, the *Cruzan* decisions place no limit on oral or written instructions which extend beyond the terms of the living will statute.

Because of these uncertainties about the applicability of the living will to the facts of our scenario, the study may understate the number of physicians who would respect a fully applicable living will. The increased deference paid to the specific living will supports this hypothesis. On the other hand, the study instrument informed the physicians that the patient had a living will which was reprinted on the back of the questionnaire. In clinical settings, by contrast, physicians will often be unaware of the living will's existence at the time that a treatment decision has to be made.[45]

Although the impact of the living will in our study was modest, it is legally quite interesting. It illuminates the role which living wills may play in those common cases where the living will is either ambiguous or inapplicable. The most likely explanations for deference under these circumstances have interesting and quite different legal implications. First, those physicians who deferred to the living will may have viewed the patient's condition as "terminal." Second, these physicians may not have read the text of the living will, which was reprinted on the back side of the questionnaire, and, thus, may not have been aware that the living will was limited to conditions which would be terminal regardless of treatment. Third, these physicians may have assumed that the very existence of a living will revealed material information about the patient's values.

### 1. Ambiguities in Language of the Living Will

The applicability of the living will turned, *inter alia*, on whether the patient's condition was "terminal."[46] Both living wills defined "terminal" conditions to be those which would result in death "whether or not life-sustaining procedures are utilized." In the study scenario, as in many clinical cases, the life expectancy of the patient was uncertain. In one sense, all 89-year-old men are near death, but that does not necessarily make them "terminal." The patient's neurological injury had not impaired the patient's vital functions, except for the ingestion of food. Artificial feeding could conceivably have prolonged the patient's life for months or longer. However, the patient's poor health did increase the risk of diseases, like pneumonia, which could hasten death. Under these circumstances, reliance on the living will is a close call, especially in a state where evidence of patient wishes is supposed to be clear and convincing.

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45. Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 NEW ENG. J. MED. 882, 884 (1991) (advance directives were transferred from nursing home to hospital for only 25 of 71 hospitalizations).

46. It also turned on whether the living will was meant to apply to artificial nutrition and hydration. *See* text accompanying note 44, *supra*.

### 2. Ignorance of the Living Will's Terms

An alternative explanation for the deference shown to the living wills in our study is that the physicians did not read the terms of the living wills printed on the back side of the questionnaire.[47] While there is evidence that living wills often do not come to the attention of treating physicians in time to influence the treatment decision,[48] no one has studied how carefully health care providers examine the text of advance directives.[49] If physicians do not familiarize themselves with the actual contents of their patients' living wills, the movement toward greater use of living wills and toward more specific and more lengthy advance directives will face some difficult practical obstacles.[50] More study of physicians' practices is clearly in order.

### 3. Consciously Applying the Living Will Beyond its Terms

Finally, the physicians who were influenced by the living will may have viewed the directive as a broad statement of the patient's values, not just a set of specific instructions. They may have felt that the living will was meant to apply beyond its terms. As a result, they may have given it some weight when making their treatment recommendations. If so, their conduct has intuitive appeal, but creates the risk of discontinuing treatments that the patient would have wanted. Thus far, no court has ruled on the propriety of this expansive use of living wills. In order to decide whether to endorse it,

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47. The living will also required certification of a "terminal condition" by a second physician.

48. Danis et al., *supra* note 45, at 884 (advance directives were transferred from nursing home to hospital for only 25 of 71 hospitalizations).

49. The Danis Study cited in the prior footnote is not reassuring. In that study, the presence of an advance directive did not make care more consistent with the patient's previously expressed preferences.

50. *E.g.*, Omnibus Budget Reconciliation Act of 1990, 42 U.S.C. §§ 1395 cc(f)(1), 1396a(a)(57)-(58), 1396a(w) (1990 Supp.) (these provisions are commonly known as the Patient Self-Determination Act and require notice to certain patients of their rights to give advance directives.); Linda L. Emanuel et al., *Advance Directives for Medical Care-A Case For Greater Use,* 324 NEW ENG. J. MED. 889, 895 (1991); Linda L. Emanuel & Ezekiel Emanuel, *The Medical Directive: A New Comprehensive Advance Care Document,* 261 JAMA 3288, 3289 (1989); Joan M. Gibson, *Reflecting on Values,* 51 OHIO ST. L.J. 451, 451-54 (1990) (advancing patient autonomy through completion of a "values history").

lawmakers will need to have a better idea of what patients would want done under these circumstances. Here too, more research is needed.[51]

In the interim, most courts will probably decline to authorize cessation of such treatments not covered by the living wills unless they receive evidence of oral instructions by the patient, or the patient has authorized a proxy to decide.[52] Therefore, patients who want their surrogates to have discretion in cases not covered by their specific instructions should provide this authority in their advance directives. The easiest way to do this is to supplement or replace their living wills with a durable power of attorney for health care decision-making[53] which authorizes their surrogate to make that decision in their behalf. Alternatively, patients who prefer greater control of the treatment decision could attempt to draft living wills which exhaustively state the circumstances in which they would like treatment withheld.[54] Another option is to supplement the individual's living will with a statement of the patient's values and of the factors which should be considered when making decisions

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51. No researcher has studied this specific issue, but some research is being done on the motivations and wishes of people who give advance directives. *See, e.g.*, Nancy Elder et al., *Community Attitudes and Knowledge About Advance Care Directives*, __ J. AM. BOARD FAM. PRACTICE (forthcoming Nov. 1992) (examining why people do or do not give advance directives); *cf.* Ashwini Sehgal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed*, 267 JAMA 59, 61 (1992) (39% of the patients with advance directive gave "no leeway" for overriding the directive if doing so were in their "best interests.").

52. Although the courts have been willing to extrapolate a patient's intentions from ambiguous or general language in advance directives, *see* MEISEL, *supra* note 22, § 12.10, this ordinarily occurs when the language of the advance directive is sufficiently ambiguous to encompass the treatment decision in question. Courts have also been willing to supplement written advance directives with evidence of oral instructions. *In re* Browning, 568 So. 2d 4, 15-17 (Fla. 1990) (living will not applicable to nonterminal patient, but oral evidence clear and convincing). But once the terms of the advance directive have been interpreted, the courts have not yet been asked to authorize the withholding of treatments which fall outside of the living will absent an oral directive by the patient.

53. See, e.g., MO. REV. STAT. §§ 404.800-.865 (Supp. 1991). For a related discussion on proxy health care decision-making power, see J. Daniel Patterson, Note, *The Proxy Puzzle & The Durable Power of Attorney for Health Care Act*, 57 MO. L. REV. 935 (1992).

54. Emanuel et al., *supra* note 50; Emanuel & Emanuel, *supra* note 50.

for the patient.[55] Regrettably, these value statements may not satisfy courts which insist on clear and convincing proof of the patient's wishes regarding a specific treatment decision. In those jurisdictions, a durable power of attorney is the surest way to avoid the risks of omission which are inherent in the execution of a living will.

### *C. Family Preferences*

In our study, physicians readily deferred to family wishes. Forty-two percent (42%) of the physicians who initially recommended tube feedings said that they would have withheld the feedings at the family's request. The physicians who initially opposed tube feeding were even more deferential to the family's wishes. Sixty-six percent (66%) of physicians said they would comply with a family's request to administer tube feedings. In both cases, the family's preferences were more influential among physicians who had received the standard living will than among those who had received the specific living will.[56] The dominant role of the family was also reflected in the comments of the respondents, most of whom emphasized the importance of the family's wishes. For example, physicians responded, "I go 99% with what the family wants."

As a practical matter these findings are not surprising. In the absence of binding patient preferences, a physician's deference to reasonable family wishes is consistent with medical custom,[57] ethical consensus[58] and public opinion.[59] Indeed, most physicians will follow the family's instructions even

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55. *See* Gibson, *supra* note 50, at 452-54; Pam Lambert et al., *The Values History: An Innovation in Medical Surrogate Decision-making*, 18 L. MED. & HEALTH CARE 202, 210-11 (1990); Sehgal et al., *supra* note 51, at 62-63.

56. Interestingly, the physicians who favored tube feedings despite the specific living will also demonstrated a greater willingness to resist family pressures to withhold tube feedings. Their resistance to both the living will and family preferences may reflect strong personal opposition to the withholding of artificial nutrition and hydration.

57. Arnold Relman, *The Saikewicz Decision: Judges as Physicians*, 298 NEW ENG. J. MED. 508, 508 (1978).

58. *See* PRESIDENT'S COMM'N, *supra* note 24, at 126-28; THE HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING, *supra* note 23.

59. *E.g.*, *In re* Jobes, 529 A.2d 434, 447 n.11 (N.J. 1987) (citing N.Y. TIMES, Dec. 2, 1986, at C10); Earl Ubell, *Should Death Be A Patient's Choice*, PARADE MAG., Feb. 9, 1992, at 24, 26.

when they conflict with the patient's previously expressed wishes.[60] In our study, this deference is particularly easy to understand because the physicians may have harbored doubts about both the applicability of living wills and about the patients' best interests.

As a legal matter, however, these findings are more interesting. While many states either authorize family decision-making or give serious consideration to family wishes, many others, including Missouri, have yet to authorize informal family decision-making.[61] In *Cruzan*, the Missouri Supreme Court refused to grant the patient's father and guardian the power to refuse life-sustaining treatment without a formal delegation of power by the patient.[62] As a result, deference to families who seek the termination of life-sustaining treatments is not yet sanctioned by the law of Missouri.

The extent of physicians' deference to families who pushed against tube feeding suggests that physicians either (1) are unaware of the bearing of *Cruzan* on this issue, (2) read *Cruzan* as applying only to the specific facts at issue in that case (*i.e.*, the cessation of ongoing tube feeding in a vegetative patient); or (3) are willing to run the legal risks of acquiescing in the wishes of the family. Physicians might be willing to accept the risks of deferring to the family if they personally believe that withholding tube feeding is the right thing to do but want family support for that action. Physicians may also perceive more risk of litigation in confronting families than in deferring to them.[63] In our study, the physicians who commented on the importance of

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60. Robert W. Blum, *Death and Decision Making Among Minnesota Physicians*, 65 MINN. MED. 499, 500 (1982); Redleaf, *supra* note 24, at 935-36 (nearly three-quarters would violate a patient's oral wishes; one-third would violate a binding written directive); Joel M. Zinberg, *Decisions For the Dying: An Empirical Study of Physicians' Responses to Advance Directives*, 13 VT. L. REV. 445, 478 (1989) (61% of Vermont interviewees and 74% in California would delay implementation of a living will pending family agreement).

61. Judith Areen, *Advance Directives Under State Law and Judicial Decisions*, 19 L. MED. & HEALTH CARE 91 (1991).

62. *Cruzan*, 760 S.W.2d at 425.

63. *See* Redleaf, *supra* note 24, at 936; Zinberg, *supra* note 60, at 477 (physician insistence on family support principally influenced by fear of liability). As a practical matter, only the patient's family or the patient's estate could bring a civil lawsuit after the treatment of a patient like the one in our scenario. When the family agrees on continued care, the risks of liability for continued treatment are minimal. There are no reported cases awarding damages against physicians who have disregarded an advance directive at the instigation of the family. The only analogous cases involved lawsuits against physicians who allegedly disregarded the wishes of a

family preferences were also more likely to remark on the legal risks associated with the treatment decision.

The legal implications change markedly if the living will is believed to govern the scenario. In that event, both law and current ethical consensus agree that the living will should be respected. However, sixty-nine percent (69%) of the physicians who based their recommendation to withhold tube feeding on the presence of a living will said they would change that recommendation if the family wanted more aggressive care. As a result, our findings are consistent with previous studies suggesting that physicians will not follow patient wishes unless the family agrees.[64] Nevertheless, caution should be exercised in generalizing from our findings. Our study presented the physicians with an ambiguous factual context where the decision-making was more complex than a simple choice between clear patient wishes and contrary family wishes. Under the circumstances presented in our scenario, the willingness of many physicians to change their recommendations may have been influenced by the uncertain authority of the living will and by the physicians' own ambivalence about the patient's best interests. Under these circumstances, family support may have been particularly important. Of course, fear of litigation by the families could play a role as well.

As a result, patients who do not wish to have their preferences overridden would be well advised to discuss their wishes with family members and formally designate a family member who is comfortable with those wishes as a proxy decision-maker.

## V. CONCLUSION

At the very least, the results of this study should make courts pause before grounding decisions about the withholding of medical care on assumptions about the instrumental role of judicial opinions in shaping provider conduct. Lay perceptions and misperceptions about the risks of

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*currently competent patient.* Neither suit succeeded in recovering compensatory damages. *See* Foster v. Tourtellotte, 704 F.2d 1109, 1110 (9th Cir. 1983) (when patient's wife and one of his three sons opposed removal of respirator, trial court's denial of compensatory damages not appealed); Ross v. Hilltop Rehabilitation Hosp., 676 F. Supp. 1528, 1534 (D. Colo. 1987) (patient's sister opposed discontinuation of gastrostomy feeding and threatened suit; federal civil rights suit by personal representative dismissed). Damages in these cases, like those in wrongful life cases, present difficult conceptual and policy issues. They would require a comparison between life and nonexistence.

64. *See supra* note 60. And a recent study suggests that many patients would want their wishes overridden if proxies believed that treatment would be in their best interests. Sehgal, *supra* note 51, at 61.

litigation and about the distinction between withholding and withdrawing treatment seem to be as influential as the actual holding of *Cruzan*.

In addition, the unanswered questions raised by our study point out the need for further research about the behavior of health care providers and about patients' expectations. How well do physicians familiarize themselves with the text of their patients' living wills? Do providers give effect to living wills beyond their terms and, if so, is this what patients would want? Are patients better served by discussing their wishes with family members than by signing a living will? What makes the distinction between withholding and withdrawing treatment so powerful in practice? The answers to these questions will help inform the ongoing debate about how best to regulate this controversial field.