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Journal

JOURNAL OF CLINICAL ETHICS, 4(1)

ISSN

1046-7890

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Publication Date

1993-03-01

DOI

10.1086/jce199304109

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Establishing Advance Medical Directives with Demented Patients: A Pilot Study

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Introduction

Specific planning for the contingencies of future severe illness is particularly important in the care of patients with mild or moderate dementia. Many of these patients will suffer progressive cognitive impairment during a period of otherwise good physical health. When severe illness develops, the dementia may have advanced to a point where meaningful, patient-based decision making is impossible. Without advance directives, the physician and family must face the tragic

dilemma of determining how much suffering from intercurrent illness and its treatment the patient will undergo in order to continue a life already burdened with severe cognitive impairment. Furthermore, the recent *Cruzan* decision permits substantial state intrusion into this decision-making process. The US Supreme Court, while affirming a constitutional right to refuse life-sustaining treatment, allowed to stand a Missouri state law that requires "clear and convincing evidence" of an incapacitated person's specific wishes about withdrawal of life-sustaining treatment before that treatment may be withdrawn. The decision also allowed Missouri to ignore a family's substituted judgment in such cases.¹

Data show that although physicians and patients alike believe that advance planning is important,² actual plans were rarely discussed between the two parties before the PSDA.³ Nursing home residents with dementia are less likely than nondemented residents to be involved in plans about future life-support treatment.⁴

We undertook this small pilot study to see whether being asked specific questions about hypothetical future severe illness is measurably burdensome to outpatients with early dementia of the Alzheimer's type (DAT). We also measured the consistency of patients' replies and made a judgment about their capability in making the decisions.

Subjects

Subjects were selected from a group of patients enrolled in an Alzheimer's disease support group at Francis Scott Key Medical Center in Baltimore. All had been diagnosed with DAT by an attending neurologist using standard criteria, and some were enrolled in a trial of drug therapy for dementia. Anticipating approval by the institutional review board (IRB), we discussed the study with several patient-caregiver dyads. The IRB unexpectedly limited us to six patients, and we enrolled the first six for whom study was convenient. The patients' mean age was seventy-four, and four of the patients were male.

Methods

One of us conducted all of the interviews in the patients' homes. Each interview began with patient and caregiver together. The caregiver was asked a series of questions about the patient's health. The patient was asked the same series of questions about his own health. Next, the patient was asked a series of progressively more directed questions about his dementia and its likely prognosis (Table 1).

After excusing the caregiver, the interviewer described to the patient three types of therapy (CPR, mechanical ventilation, and feeding tube) and hypothetical situations in which each might be required to sustain life (heart attack, severe pneumonia, and automobile accident with

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This article was submitted to The Journal of Clinical Ethics in May 1991 and was accepted for publication in December 1991.

Table 1
Sequence of Questions to Determine Demented Patients' Knowledge of
the Prognosis of Dementia
(Asked with Caregiver Present)

What is the particular reason that has led you to be seen in [the geriatric neurologist's] clinic?
 [If reply inappropriate] Have you noticed any problem with your memory?
 [If patient denies any memory problem, skip to next section.]
 How long have you had this condition/problem?
 During this time, has it gotten better, stayed about the same, or gotten worse?
 In the future, do you think this condition/problem/illness will be better, stay the same, or get worse?
 What do you think is the worst it will progress to?

Table 2
Questions about Adverse Emotional Effects Asked after the Interview

Did this discussion make you worry more about your health?
 Did it make you feel let down by your doctors?
 Did it make you feel sad or worried?
 Do you think it is a good idea for doctors to talk to their patients about these things?
 Do you think it was a good idea for us to talk to you today about this subject?

facial trauma, respectively). The patient was asked whether he would accept each of these treatments (always, usually, rarely, or never) in each of two scenarios: (1) on the day of the interview, and (2) at a time when "you could no longer recognize your family or friends . . . because of stroke, Alzheimer's disease, a car accident, or some other disease." A Mini-Mental State examination (MMS) was administered.⁵ The mean score was 17. (Scores below 24 are associated with dementia.⁶) At the conclusion of each interview, the interviewer made a subjective clinical judgment about whether the patient's decision seemed meaningful, based on the patient's apparent comprehension and reasonableness during the discussion. The interview was repeated two weeks and four weeks after the initial interview.

After each interview, we asked the patient and caregiver a series of questions about their reactions to

the discussion (Table 2), and we asked each caregiver whether she thought the discussion had any ill effect on the patient. Each caregiver was contacted by telephone five days after the interview and was again asked if she thought the patient had suffered any adverse effects as a result of the discussions. The interviews and follow-up were repeated two and four weeks after the initial interview.

Results

Awareness of Illness and Prognosis

Three patients (*B*, *D*, and *F*, in Table 2) with mean MMS scores over three interviews of 21, 22, and 16, respectively, acknowledged serious memory impairment and expected this condition to progress. Two patients (*A* and *E*) with mean MMS scores of 18 and 15 acknowledged memory loss but did not expect further deterioration. Patient *C*

denied any memory problem. His mean MMS score was 10.

Adverse Effects

Three caregivers predicted that their patients might be upset by discussing these issues. At the conclusion of all interviews, however, there were no measurable adverse effects. All patients denied feeling "worried," "sad," or "let down" by their doctor. No adverse reactions were identified by caregivers at the exit interview or at the five-day-follow-up telephone calls. Three patients and three caregivers spontaneously reported enjoying the process. All patients and all caregivers thought it was "a good idea for doctors to talk to their patients about these things," but none reported ever having had such a discussion. No patient and only one caregiver recalled having discussed medical treatment previously. All patients and subjects thought "it was a good idea . . . to talk . . . today about this subject."

Consistency and Meaningfulness of Decisions

Table 3 shows data about the three interviews for each of the six patients. Patients *A* and *B* each had three consistent interviews, all judged to have been meaningful by the interviewer. Patients *C*, *D*, and *E* were inconsistent and/or judged not to have provided meaningful responses at one of the interviews. Patient *F* had responses that were considered meaningful in a single interview, followed by two incoherent interviews.

Patients were generally more likely to say they would refuse life-sustaining therapy if they were to become severely impaired than in their current situation.

Discussion

In this small study, we used very gross measures to look for

evidence of adverse effect: we asked the patients and we asked their caregivers. No important adverse effects were reported. Perhaps more compelling, no patient or caregiver declined any of the repeat interviews, although it would have been quite simple not to re-invite the interviewer into the home for these subsequent interviews. While not part of our study design, three patients and three caregivers were documented to have remarked spontaneously that they had enjoyed or benefited from the discussions.

Our study is limited in several respects. It is small. No controls were done, and we do not know how consistent the responses of nondemented patients would be if they were asked these questions repeatedly. Interviews were conducted in the patients' homes, rather than in the clinic. If these issues were raised by a patient's physician at a routine clinic visit, adverse effects might result. No such adverse effects were seen, however, when nondemented outpatients were asked similar questions.⁷

There is no definitive objective test that a clinician can apply to determine a patient's decision-making capacity. A hierarchy of tests has been proposed, ranging from a simple assent (for example, the patient does not resist as a blood pressure cuff is applied) to a thorough analysis of the patient's comprehension.⁸ Roth, Meisel, and Lidy have observed:

The search for a single test of competency is a search for the Holy Grail. Unless it is recognized that there is no magical definition of competency to make decisions about treatment, the search for an acceptable test will never end. . . . Judgments [about competence] reflect social considerations and societal biases as much as they reflect matters of law and medicine.⁹

We used a test that is common in practice: we asked the patient, discussed the replies, and made a global judgment. The consistency

Table 3
Patient Replies about Treatment Preferences

Patient	MMS Score	Patient Replies ^a					
		Current Situation ^b			Severe Impairment ^c		
		CPR	Vent	Tube	CPR	Vent	Tube
Patient A							
Visit 1	17	A	A	A	N	N	N
Visit 2	18	A	U	U	N	N	N
Visit 3	19	A	U	U/R	N	N	N
Patient B							
Visit 1	23	U	U	R	N	N	N
Visit 2	20	R	R	U	N	N	N
Visit 3	20	U	R	R	R	R	R
Patient C							
Visit 1	11	N	N	N	N	N	N
Visit 2	8	N	R	R	D	D	N
Visit 3 ^d	11	U	R	N	N	N	N
Patient D							
Visit 1	23	U	R	R	R	R	R
Visit 2	22	U	U/R	U	U	N	U
Visit 3	--	U	U/R	U/R	N	N	N
Patient E							
Visit 1	15	U	U	A	A	N	A
Visit 2	14	U	U	U	R	R	R
Visit 3 ^e	17	A	U	U	A	A	A
Patient F							
Visit 1	19	R	R	R	N	N	N
Visit 2 ^f	15	U/R	U/R	U/R	DK	DK	DK
Visit 3 ^g	13	UN	UN	UN	UN	UN	UN

^a A = always accept; U = usually accept; R = rarely accept; N = never accept; D = defer to family; DK = don't know; UN = unable to reply coherently.

^b Patient replies regarding their current situation.

^c Patient replies regarding scenario in which disabling, irreversible cognitive impairment develops.

^d Interviewer judged patient's decisions to be unreliable.

^e *Ibid.*

^f *Ibid.*

^g *Ibid.*

of a patient's replies when re-interviewed served as an external check. In this sense, we did not search for a "Holy Grail." We did not apply more extensive tests of competency, such as a more formal analysis of the patient's reasoning, for two reasons. We were unsure if the patients would be upset by a more thorough and challenging discussion, and we wanted our results to be clinically applicable.

In our small group of patients with dementia, patients *A* and *B* replied consistently to hypothetical questions about treatment, convinced the interviewer that their decisions were made rationally, and consistently refused treatment in the "severe impairment" scenario. Patients *C* and *D* also appeared reasonably consistent in their refusal of treatment with severe impairment.

In summary, asking patients with mild or moderate dementia to discuss plans for possible future illness did not lead to any serious adverse consequences in this pilot group of subjects. In some patients, the replies were clear, consistent, and convincing. We believe that it is especially important for physicians to talk with patients with dementia about advance directives, and that many demented patients will be capable of establishing valid, useful advance directives.

Acknowledgment

The authors acknowledge the invaluable assistance of Ellyn H. Boyd in preparing the manuscript for this article.

NOTES

1 *Cruzan v. Director, Missouri Department of Health*, 497 US, 111 L. Ed. 2nd 224, 100 S. Ct. 2841 (1990).

2 S. E. Bedell and T. L. Delbanco, "Choices about Cardiopulmonary Resuscitation in the Hospital: When Do Physicians Talk with Patients?" *New England Journal of Medicine* 310 (1984): 1090-93; B. Lo, G. A. McLeod, and G. Saika, "Patient Attitudes to Discussing Life-Sustaining Treatment," *Archives of Internal Medicine* 146 (1986): 1613-15; T. E. Finucane, J. M. Shumway, R. L. Powers, and R. M. D'Alessandri, "Planning with Elderly Outpatients for the Contingencies of Severe Illness: A Survey and Clinical Trial," *Journal of General Internal Medicine* 3 (1988): 322-25.

3 Bedell and Delbanco, "Choices"; Lo, McLeod, and Saika, "Patient Attitudes"; Finucane, Shumway, Powers, and Alessandri, "Planning"; A. L. Evans and B. A. Brody, "The Do-Not-Resuscitate Order in Teaching Hospitals," *Journal of the American Medical Association* 253 (1985): 2236-39.

4 T. E. Finucane and S. J. Denman, "Deciding about Resuscitation in a Nursing Home: Theory and Practice," *Journal of the American Geriatrics Society* 37 (1989): 684-88.

5 M. Folstein, S. E. Folstein, and P. R. McHugh, "The 'Mini-Mental State': A Practical Method for Grading the Cognitive State of Patients for the Clinician," *Journal of Psychiatric Research* 2 (1975): 189-98.

6 R. P. Roca, "Bedside Cognitive Examination," *Psychosomatics* 28 (1987): 71-

76.

7 Finucane, Shumway, Powers, and Alessandri, "Planning."

8 L. H. Roth, A. Meisel, and C. W. Lidz, "Tests of Competency to Consent to Treatment," *American Journal of Psychiatry* 134 (1977): 279-84; P. S. Appelbaum and T. Grisso "Assessing Patients' Capacity to

Consent to Treatment," *New England Journal of Medicine* 319 (1988): 1635-38; J. F. Drane, "Competency to Give an Informed Consent: A Model for Making Clinical Assessment," *Journal of the American Medical Association* 252 (1984): 925-27.

9 Roth, Meisel, and Lidz, "Tests of Competency," 283.

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