The Attitudes of Patients With Advanced AIDS Toward Use of the Medical Futility Rationale in Decisions to Forgo Mechanical Ventilation

J. Randall Curtis, MD, MPH; Donald L. Patrick, PhD, MSPH; Ellen S. Caldwell, MS; Ann C. Collier, MD

Background: The medical futility rationale asserts that physicians need not offer their patients therapies that have zero or close to zero probability of success. The rationale is controversial, but it is used in practice.

Objective: To examine the attitudes of patients with advanced acquired immunodeficiency syndrome (AIDS) toward the medical futility rationale as it might apply to their medical care.

Methods: We conducted a cross-sectional study with interviewer-administered questionnaires. Fifty-seven patients with advanced AIDS (C3 stage AIDS and a CD4 cell count <100/µL) were recruited from academic and private clinics.

Main Outcome Measure: Whether patients believe it is acceptable for physicians to withhold mechanical ventilation, without offering it, if physicians determine the intervention is futile.

Results: Sixty-one percent of patients (n=35) believed that it was definitely acceptable for their physician to not offer mechanical ventilation if the physician judged this intervention to be futile, and 26% (n=15) believed this was probably acceptable. Less than 10% of patients (n=5) said not offering therapy judged futile was definitely not acceptable. Patients who were less likely to prefer mechanical ventilation in different hypothetical health states were significantly more likely to accept decisions on the basis of futility (P=.003). Health-related quality of life, patient satisfaction with medical care, and patient-clinician communication about end-of-life care were not associated with attitudes toward medical futility.

Conclusions: Although the majority of patients with advanced AIDS accept the medical futility rationale, a substantial minority do not. Acceptance of this rationale was associated with wanting less life-sustaining treatment. Physicians invoking the medical futility rationale and hospitals using policies incorporating the medical futility rationale should take into account this diversity in the attitudes toward medical futility.

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Patient autonomy in decisions about medical care has been a part of medical ethics for centuries, but during the 1960s and 1970s autonomy became the predominant ethical principle guiding medical decision making. The medical futility rationale states that physicians may decide not to offer certain therapies in circumstances in which the therapy has zero or near zero probability of success. This rationale gained popularity in the 1980s, in part because of the rapid growth of medical technology and concerns that physicians should not be forced to use technology in situations in which its use was considered futile. Many medical organizations have written statements supporting use of the medical futility rationale in withholding or withdrawing medical therapies, including the American Medical Association, the American Thoracic Society, and the Society for Critical Care Medicine. Furthermore, some hospitals have written the medical futility rationale into their do not resuscitate order policies. However, use of this rationale remains controversial; some physicians and ethicists have argued that the medical futility rationale is impossible to apply in a consistent manner and is in direct contradiction to the principle of patient autonomy.

See also pages 1565 and 1690

The medical futility rationale is frequently invoked in decisions about whether a high-risk surgical candidate should be taken to the operating room or whether a patient should be provided an
PATIENTS AND METHODS

We recruited 57 patients with acquired immunodeficiency syndrome (AIDS) and their primary care clinicians into a prospective cohort study. Enrollment criteria for patients included a prior AIDS-defining illness and a post CD4 cell count of less than 100/µL. Patients were excluded if they could not speak English, if they had a diagnosis of dementia, or if they had been seeing their primary care clinician for less than 3 months. All interviews were conducted between August 1, 1996, and January 31, 1997.

PATIENTS AND INTERVIEWS

Patient recruitment has been described previously.13 In brief, advertisements were placed with community-based organizations, university and private clinics, and an AIDS Clinical Trials Unit, and letters describing the study were sent to community physicians. Letters and advertisements described the focus of the study as "patient-doctor communication" and did not mention the end-of-life emphasis. The University of Washington Human Subjects Committee approved all procedures, and patients provided written informed consent.

Study staff conducted structured interviews with patients at study enrollment. Interviewers were experienced with research interviews, were trained by the investigators, and were supervised for their first 2 interviews. Interviewers were provided with systematic explanations for items about the medical futility questionnaire and offered these explanations only if the subject had questions. All interviews took place in quiet settings with only the interviewer and patient present; patients read the questionnaire along with the interviewer and the interviewer recorded the patients' responses.

ITEM DEVELOPMENT

We have described the use of focus groups of persons with C3 stage AIDS as defined by the Centers for Disease Control and Prevention14 to develop a list of the barriers and facilitators regarding the patient-clinician communication about end-of-life care.14 An additional goal of these focus groups was to gain experience in asking patients about the medical futility rationale. During these focus groups, we found that patients had difficulty understanding this rationale unless it was framed under the circumstances of "end-stage AIDS with less than 3 months to live" and described a specific treatment that would be withheld. The groups' experience led to the formulation of questions used in this study. In addition, in reference to the question about mechanical ventilation, we also asked about cardiopulmonary resuscitation. The results for cardiopulmonary resuscitation were essentially the same as those for mechanical ventilation (data not shown). All questions were pilot-tested with 5 patients with advanced AIDS followed by cognitive debriefing to ensure that they understood the questions.

We modified a previously existing measure of preferences for life-sustaining treatments in different health states15 to develop a treatment preference score, as described previously.13 For this treatment preference score, we asked patients and clinicians whether the patient would choose to receive mechanical ventilation in 4 different health states relevant to end-stage human immunodeficiency virus (HIV) disease: (1) persistent vegetative state or coma, (2) severe dementia, (3) permanent and constant pain, or (4) being confined to bed and dependent on others for daily self-care. The answer choices for receiving the treatment in each health state were "definitely no," "probably no," "probably yes," and "definitely yes"; these responses were given a score of 1 to 4, respectively, to create a treatment preference scale ranging from 4 to 16. To measure satisfaction with care, we used 6 items from an HIV-specific instrument developed by Wilson and colleagues (Ira Wilson, MD, MSc, written communication, May 10, 1995). To measure health status, we used the HIV Patient Assessed Report of Status and Experience (HIV-PARSE), which was developed and validated for the measurement of health-related quality of life (HRQL) in patients with HIV infection and AIDS.16 The HIV-PARSE is a multidimensional scale with 8 domains and 30 items. To determine whether there had been patient-clinician communication about end-of-life care, we asked patients the following question: "Have you discussed with your doctor, in a face-to-face discussion, the kinds of treatments you would want if you became too sick to speak for yourself?" To measure the quality of patient-clinician communication about end-of-life care, we used a measure validated in a previous report from this study.13 We examined for an association between attitudes toward medical futility and both the occurrence and the quality of this communication. Interview questions used in this study are available from the authors on request.

STATISTICAL ANALYSIS

Treatment preferences, HRQL, satisfaction with care, and quality of communication were each expressed as ordinal scales. To examine for an association between attitudes toward medical futility and these variables we used the Kruskal-Wallis 1-way analysis of variance. To test for an association between the occurrence of any communication about end-of-life care and attitudes toward medical futility, we used χ² analysis. Two-tailed P<.05 was used to determine statistical significance.
The medical futility rationale represents a controversial approach to medical decision making in the setting in which clinicians determine that a medical intervention has a zero or near zero probability of a successful outcome. While empiric research has shown that there are only a small number of circumstances for which physicians can say that there is a less than 1% chance of a successful outcome, medical futility nonetheless represents an important issue for the medical community because it addresses a cornerstone of medical decision making in the intensive care unit. In a previous study from our institution, we examined the use of the medical futility rationale in do not resuscitate orders and found evidence of misconceptions about medical futility on the part of medical residents. However, throughout the medical futility debate there has not been any empiric research examining what patients with advanced disease think about this rationale. In the current study, we demonstrated that the majority of patients with advanced AIDS accept the medical futility rationale when used by their own primary care clinician.

We found no association between HRQL and patients’ attitudes toward medical futility. There have been contradictory reports about the effect of quality of life on patients’ preferences for life-sustaining treatment. There are a number of studies demonstrating that if patients are presented with hypothetical scenarios depicting a very poor quality of life, they would prefer less life-sustaining treatment than they want in their current health situation. However, when investigators have measured patients’ current quality of life, there has been little or no association between current quality of life and preferences for intensive care or other life-sustaining treatments. Our data suggest that while treatment preferences predict attitudes toward medical futility, current disease-specific HRQL was not strongly associated with either preferences or attitudes.

We also found no significant association between patient satisfaction with care or patient-clinician communication about end-of-life care and patients’ attitudes toward medical futility. There are a number of possible explanations for this lack of association. Most importantly, this is a small study and the lack of an association may be due to a low power to show small but clinically important differences. Our purpose in this study was not to identify all factors associated with attitudes toward medical futility, but rather to identify the major

**Table 1** shows the demographic characteristics of the patients in our sample. Patients were predominantly white, gay or bisexual men, and representative of the demographics of HIV infection in the Seattle area. The majority of patients (n = 50 [88%]) had a diagnosis of AIDS 12 or more months prior to study enrollment. The following question regarding a decision to forego mechanical ventilation was presented to the 57 patients:

Imagine that you have end-stage AIDS and your doctor thinks you have less than 3 months left. Suppose you have been admitted to the hospital with severe pneumonia and you’re having difficulty breathing. Your doctor feels that if you went on life support—such as a mechanical ventilator, which breathes for you—you’d be very unlikely to get off the life support machine alive. Is it ok for your doctor to keep you comfortable and let you die without offering the life support machine?

The distribution of the patients’ responses to the question was (1) definitely no, 5 (9%), (2) probably no, 2 (4%), (3) probably yes, 15 (26%), and (4) definitely yes, 35 (61%).

To better understand the factors associated with patients’ responses, we examined whether acceptance of medical futility was associated with patients’ treatment preferences, HRQL, satisfaction with care, and patient-clinician communication about end-of-life care. Of these factors, only treatment preferences were significantly associated with patient attitudes toward medical futility (Table 2). Patients who were less willing to undergo mechanical ventilation in the health states of coma, permanent intractable pain, dependence for activities of daily living, and dementia (lower treatment preference scores) were more accepting of the medical futility rationale (higher medical futility score) (Table 2). There was no relationship between patients’ attitudes toward medical futility and either HRQL or their satisfaction with care, although there was a trend toward an association between higher satisfaction with care and being more accepting of the medical futility rationale (P = .08). There was no association between patients’ attitudes toward medical futility and either the patients’ report of the occurrence of patient-clinician communication about end-of-life care (data not shown) or the patients’ report of the quality of patient-clinician communication about end-of-life care (Table 2).

**Table 1. Sociodemographic Characteristics of 57 Patients With Advanced AIDS Enrolled in the Study**

<table>
<thead>
<tr>
<th>Demographics</th>
<th>No. (%)</th>
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<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5 (9)</td>
</tr>
<tr>
<td>Male</td>
<td>52 (91)</td>
</tr>
<tr>
<td>Median age, y</td>
<td>39</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>37 (65)</td>
</tr>
<tr>
<td>African American</td>
<td>9 (16)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>6 (11)</td>
</tr>
<tr>
<td>Native American</td>
<td>3 (5)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Time since AIDS diagnosis, mo</td>
<td></td>
</tr>
<tr>
<td>&lt;6</td>
<td>3 (5)</td>
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<tr>
<td>6-12</td>
<td>2 (4)</td>
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<tr>
<td>12-24</td>
<td>14 (25)</td>
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<tr>
<td>&gt;24</td>
<td>36 (63)</td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (4)</td>
</tr>
</tbody>
</table>

* AIDS indicates acquired immunodeficiency syndrome; HIV, human immunodeficiency virus.

**RESULTS**

**COMMENT**

The medical futility rationale represents a controversial approach to medical decision making in the setting in which clinicians determine that a medical intervention has a zero or near zero probability of a successful outcome. While empiric research has shown that there are only a small number of circumstances for which physicians can say that there is a less than 1% chance of a successful outcome, medical futility nonetheless represents an important issue for the medical community because it addresses a cornerstone of medical decision making in the intensive care unit. In a previous study from our institution, we examined the use of the medical futility rationale in do not resuscitate orders and found evidence of misconceptions about medical futility on the part of medical residents. However, throughout the medical futility debate there has not been any empiric research examining what patients with advanced disease think about this rationale. In the current study, we demonstrated that the majority of patients with advanced AIDS accept the medical futility rationale when used by their own primary care clinician.

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We also found no significant association between patient satisfaction with care or patient-clinician communication about end-of-life care and patients’ attitudes toward medical futility. There are a number of possible explanations for this lack of association. Most importantly, this is a small study and the lack of an association may be due to a low power to show small but clinically important differences. Our purpose in this study was not to identify all factors associated with attitudes toward medical futility, but rather to identify the major
factors associated with patients’ willingness to accept medical futility. In addition, because patient satisfaction with medical care is generally uniformly high and the quality of patient-clinician communication about end-of-life care may be uniformly low, it is also possible that there is not enough variability in these 2 factors to identify an association with attitudes toward medical futility.

Opponents of the medical futility rationale may argue that since the rationale should not be used in clinical practice, patients’ attitudes toward the rationale are irrelevant. However, the medical futility rationale is in clinical use and not likely to disappear. In addition, opponents of the rationale may use our data to argue that the medical futility rationale should not be used because a substantial minority of patients oppose its use in their care. We believe this interpretation of the data is incorrect because the medical futility rationale does not depend on uniform acceptance by patients. Conversely, proponents of the medical futility rationale may argue that patients’ attitudes toward the rationale do not matter because the point of the rationale is that, in some circumstances, physicians should be able to make decisions unilaterally without input from patients. However, if this rationale is to be used in the absence of a clear consensus in the medical community, it is critically important to know what patients likely to be in these circumstances think about the rationale. This knowledge should influence how clinicians approach patients and families when discussing end-of-life care and when taking a process-based approach to futility determinations, as recently recommended by the American Medical Association’s Council on Ethical and Judicial Affairs.

There are several important limitations to this study. First, as noted above, the sample size was small and important associations may have been missed. Second, these findings represent the attitudes of a sample of persons with advanced AIDS in the Pacific Northwest and may not be representative of patients with AIDS throughout the country because of geographic or cultural differences. In addition, further research will be necessary to determine whether these findings can be generally applied to patients with other diseases. Finally, given the fact that we are reporting results of a structured interview, it is difficult to be confident that individual patients interpreted the question about medical futility in an identical manner. In particular, we did not specify in the structured interview whether the patient would be told that mechanical ventilation would be withheld.

Invoking the medical futility rationale does not diminish the importance of communicating with patients and their families about medical care. Instead, invoking medical futility increases the importance of clear and sensitive communication with patients and their families. Therefore, it is important to understand that the majority of patients (61% [n=35]) with advanced AIDS accepted this rationale, but that 12% (n=7) did not. It is also helpful for clinicians to understand that patients are less likely to accept the medical futility rationale if they have a preference for more aggressive life-sustaining therapies at the end of life. Understanding their patients’ attitudes toward the medical futility rationale will allow clinicians to improve their communication with patients and families in settings in which life-sustaining therapies are futile.

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REFERENCES

Correction

In the article by Haffner et al titled “Reduced Coronary Events in Simvastatin-Treated Patients With Coronary Heart Disease and Diabetess or Impaired Fasting Glucose Levels: Subgroup Analysis in the Scandinavian Simvastatin Survival Study” in the December 13/27, 1999, issue of the ARCHIVES (1999;139: 2661-2667), 2 of the symbols in the key in Figure 5 were incorrectly labeled. The square should represent DM (diabetes mellitus) and the circle should represent NFG (normal fasting glucose). The figure is reprinted correctly here. The journal regrets the error.

Figure 5. Effects of simvastatin therapy on major coronary events by glucose status, stratified by level of lipid variables. DM indicates diabetes mellitus; IFS, impaired fasting glucose; NFG, normal fasting glucose; LDL-C, low-density lipoprotein cholesterol; HDL-C, high-density lipoprotein cholesterol; and TG, triglycerides. Error bars indicate SEM. To convert HDL-C and LDL-C from millimoles per liter to milligrams per deciliter, divide millimoles per liter by 0.02586. To convert TG from millimoles per liter to milligrams per deciliter, divide millimoles per liter by 0.01129.