

# Elderly Patients' Preferences for Long-term Life Support

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**Objective:** To study elderly patients' preferences regarding mechanical ventilation and tube feeding and to compare their preferences for short-term use with their preferences for long-term use of these life support interventions.

**Design:** Interviews with patients by clinicians during routine office visits.

**Setting:** Hospital-based, primary care geriatrics clinic in downtown Denver, Colo.

**Patients:** Two hundred eighty-seven elderly persons (mean age, 77 years; range, 60-99 years).

**Main Outcome Measures:** Preferences to use or withhold: (1) short-term mechanical ventilation; (2) long-

term mechanical ventilation; (3) short-term tube feeding; and (4) long-term tube feeding.

**Results:** Of the total sample, 253 patients (88%) would prefer short-term mechanical ventilation if the chance of recovering was reasonably good but only 11 (3.5%) would prefer long-term mechanical ventilation. One hundred eighty-nine (65%) would prefer short-term tube feeding, but only 13 (4.5%) would prefer long-term tube feeding in the setting of significant cognitive impairment.

**Conclusions:** Most elderly persons opt for short-term mechanical ventilation or tube feeding if the chance of recovering is reasonably good. Only a small minority would opt for long-term mechanical ventilation or tube feeding.

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CLINICIANS WHO care for elderly patients recognize the importance of advance directives. Specifically, clinicians need to know how their patients view cardiopulmonary resuscitation (CPR), mechanical ventilation, and tube feedings. Views about other life support care, such as dialysis and emergency surgery, are also important. However, it is the use of CPR, mechanical ventilation, and tube feedings that most frequently concerns geriatricians, their patients, and their patients' families.

We have been impressed by the difference between what elderly patients spontaneously express as their preferences and some of the preferences reported in the medical literature. The medical literature suggests that a significant minority of elderly patients would opt for extended life-support care, such as tube feedings and prolonged mechanical ventilation<sup>1-14</sup> (**Table 1**). In contrast, we had not yet heard (prior to our study) any elderly patient spontaneously express a preference for long-term tube feeding or me-

chanical ventilation. Furthermore, we had not yet seen a written advanced directive expressing a preference for long-term tube feeding or mechanical ventilation. The goal of our study was to determine elderly patients' preferences for short-term and long-term use of tube feeding and mechanical ventilation.

## RESULTS

**Table 2** shows the characteristics of the 287 patients who participated. **Table 3** shows the percentages of patients opting for short-term and long-term tube feeding and mechanical ventilation. Of the 253 who said that they would want short-term mechanical ventilation if their chance of recovering was reasonably good, a significant minority (approximately 20%) had stated that they "would not want to be kept alive by machines" when we first began discussing advance directives. They changed their minds when they understood that the duration of mechanical ventilation would be brief and that their chance of recovering was reasonably good.

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## SUBJECTS AND METHODS

Between August 1, 1991, and July 31, 1992, we interviewed 287 elderly patients from our geriatrics clinic in downtown Denver, Colo. Our goal was to interview all consecutive patients from 1 geriatrician's (D.J.M.) part-time practice during this 12-month period. Of the 371 consecutive outpatients, 84 were ineligible because of dementia, a language barrier, or acute medical problems that precluded a discussion about advance directives. During the first part of the interview, we focused on our patients' preferences regarding CPR. We have reported the results of those interviews elsewhere.<sup>15</sup> A geriatrician (D.J.M.), a geriatric nurse practitioner (S.S.), and 10 medical residents performed the interviews regarding preferences for CPR. At the end of those interviews, either the geriatrician or the geriatric nurse practitioner talked with each patient about their preferences for tube feedings and mechanical ventilation.

Our discussions about their preferences for tube feedings and mechanical ventilation did not follow a written script. However, the content was relatively uniform. When discussing mechanical ventilation, we asked patients to imagine a situation where they became very short of breath and presented to the emergency department. We explained that the problem may be secondary to several illnesses, including pneumonia, asthma, or congestive heart failure. We made a clear distinction between these scenarios and the scenarios regarding cardiac arrest that we had discussed earlier in the interviews. We asked the patients to imagine that they would have a reasonably good chance of recovering (we estimated 20%-50%) if they were on a "breathing machine" for a few days. After asking the patients if they would want mechanical ventilation for the short term (ie, several days to a week), we asked the patients to imagine that they were not improving after several days and would need prolonged mechanical ventilation. Then we asked if they would want it long term, but did not specify the duration.

We used a similar approach in discussing tube feedings. We asked patients to imagine situations (eg, advanced dementia, Parkinson disease, and strokes) in which the patients or their caregivers were unable to feed them by mouth. We then described tube feedings and explained that this would be one way of maintaining nutrition in someone who could not eat. When determining their preferences for short-term feeding, we asked them to focus on situations in which their ability to swallow changed abruptly, such as with a stroke. The general time frame we referred to for short-term use was 1 to 2 weeks. When asking about their preferences for long-term tube feeding, we asked them to focus on those conditions that were progressive, such as dementia, strokes without recovery of function, and Parkinson disease.

The study was approved by the institutional review board of Presbyterian-St Luke's Medical Center, Denver.

ing. Our study suggests that 3.5% to 4.5% of elderly patients would opt for long-term life support.

Our results differ significantly from other results reported in the medical literature. Several studies using various methods (eg, vignettes, in-depth interviews, and other survey tools) have suggested that the percentage of elderly patients opting for long-term tube feeding varies from 25% to 53%.<sup>2,3,7,9,10,12</sup> We believe the following factors explain most of the difference in results.

First, we explored patients' preferences in the setting of a routine clinic visit with a primary care provider (geriatrician or nurse practitioner). We assume that the trust resulting from an ongoing relationship between clinician and patient influences the expression of preferences. What patients tell a survey researcher, particularly a researcher they have met only once, may be quite different than what they tell a primary care physician. However, a study by Finucane et al<sup>1</sup> suggests that the primary care physician's influence may not be as great as it seemed to be in our study. In their study, primary care physicians interviewed their own patients. Eight (24%) of 34 elderly patients said they would want a feeding tube if they developed Alzheimer disease and could no longer feed themselves.<sup>1</sup> The wording of the scripted question used by Finucane et al suggests that there is no drawback to long-term tube feeding. This may explain why a higher percentage of their patients opted for tube feeding.

Second, we did not follow a script. This informal approach allowed the clinician to clarify misperceptions and explain the therapies and outcomes in terms that individual patients could understand. Structured surveys may not allow enough latitude to clarify misperceptions. A scripted question, such as the one Kayser-Jones<sup>9</sup> used to begin a lengthy interview, may lead to a higher percentage of patients opting for tube feeding. In their study, 53% of patients in long-term care settings opted for tube feedings when their preferences were elicited with a scripted question.

Third, our focus on long-term use of tube feeding implied that we were considering scenarios where the patients had advanced neurodegenerative diseases. Often we would say, "Imagine that you were in a condition where you couldn't recognize or talk with those you love." Our results are more consistent with results from studies focusing on preferences in the setting of advanced dementia where patients are no longer able to recognize or talk with others. For example, Danis et al<sup>4</sup> reported that 16% of 126 nursing home residents would want tube feedings if they were permanently unconscious. Emanuel et al<sup>5</sup> reported that 11% of 100 patients would want artificial nutrition if they had dementia. In contrast, Ouslander et al<sup>7</sup> reported that 34 (50%) of 68 ambulatory nondemented elderly patients would opt for tube feeding if they had dementia. In a vignette Ouslander et al presented to their patients, they stated, "This disease is making you lose more and more of your mental and physical abilities. Right now you can't even walk anymore. You can still recognize people and talk to them."<sup>7</sup> Our experience and the literature suggest that the degree of dementia being considered influences patients' preferences. Similarly, the duration of life support influences preferences. Schneiderman et al<sup>8</sup> reported that duration

## COMMENT

Our goal was to determine the percentage of elderly patients who would opt for short-term and long-term life support, specifically mechanical ventilation and tube feed-

**Table 1. Summary of Studies Reporting Percentage of Elderly Patients Who Would Opt for Tube Feeding**

| Investigators                       | Study Population                                 | Setting                                    | Interviewer                              | Scripted Interview | Opting for Tube Feeding, %             |
|-------------------------------------|--------------------------------------------------|--------------------------------------------|------------------------------------------|--------------------|----------------------------------------|
| Finucane et al <sup>1</sup>         | 34 elderly patients                              | Outpatient clinic                          | Primary care physician                   | Yes                | 24                                     |
| Gerety et al <sup>2</sup>           | 52 veterans                                      | Nursing home                               | Geriatricians not familiar with subjects | Yes                | 25-38, depending on condition          |
| Hare et al <sup>3</sup>             | 50 adults (mean age, 44 y)                       | Family practice outpatient clinic          | Research assistants                      | Yes                | 28                                     |
| Danis et al <sup>4</sup>            | 126 elderly patients                             | Nursing home                               | Research assistants                      | Yes                | 6 (if patient permanently unconscious) |
| Emanuel et al <sup>5</sup>          | 405 outpatients, 102 general public              | Outpatient clinic and telephone            | Research assistants                      | Yes                | 8-11, depending on condition           |
| Malloy et al <sup>6</sup>           | 201 elderly patients                             | Community                                  | Research assistants                      | Yes                | 11-28, depending on presentation       |
| Ouslander et al <sup>7</sup>        | 68 elderly patients                              | Adult day care center and residential area | Research assistants                      | Yes                | 50                                     |
| Schneiderman et al <sup>8</sup>     | 104 outpatients with limited life expectancy     | Outpatient clinic                          | Research assistants                      | Yes                | 22                                     |
| Kayser-Jones <sup>9</sup>           | 103 elderly patients                             | Nursing homes                              | Research assistants                      | Yes                | 53                                     |
| Everhart and Pearlman <sup>10</sup> | 30 veterans                                      | Intensive care unit                        | Researcher                               | Yes                | 28-40, depending on condition          |
| Danis et al <sup>11</sup>           | 2536 elderly patients                            | Outpatient clinics                         | Research assistants                      | Yes                | 43                                     |
| Reilly et al <sup>12</sup>          | 218 elderly patients                             | Community                                  | Research assistants                      | Yes                | 27-44, depending on condition          |
| Sonnenblick et al <sup>13</sup>     | 108 offspring of terminally ill elderly patients | Hospital                                   | Physicians                               | Yes                | 66                                     |
| O'Brien et al <sup>14</sup>         | 379 elderly patients                             | Nursing homes                              | Research assistants                      | Yes                | 33                                     |

of life support strongly influences patients' preferences. Although we did not specify the duration of life support in days or weeks, we did confirm that major differences in duration (short-term vs long-term) strongly influences patients' preferences.

Fourth, preferences expressed by ambulatory elderly persons in an outpatient setting may differ from those expressed by elderly persons in long-term care settings. Residents in long-term care facilities may be more likely to accept a life with significant disabilities because they have already had to adjust to a loss of independence.

Fifth, our population of patients was relatively homogeneous. Most patients were white and either Protestant or Catholic. The results may be significantly different for a population of Orthodox Jews or for fundamentalist Christians who are African American or Hispanic.<sup>16-18</sup>

Sixth, our discussion of tube feeding and mechanical ventilation followed a scripted interview regarding CPR. We do not know what effect this sequence had on our patients' preferences regarding tube feedings and mechanical ventilation, but we suspect it had some.

Finally, biases of the clinicians can influence preferences of the patients. If clinicians favor long-term tube feeding for themselves, they are likely to present this option in a more positive light than if they do not. Malloy et al<sup>6</sup> reported that 11% of community-dwelling elderly persons would opt for tube feeding if this option was presented negatively, and 28% would opt for it if presented positively. Clinicians can express biases in many ways, such as with facial expressions and other body language, time spent with the patient, and attention to other medical concerns.<sup>19</sup>

We admit that we are biased. We do not believe that long-term tube feeding serves the best interest of our patients who are severely demented. We believe that hos-

pice care is the best approach for our severely demented patients who develop an acute, life-threatening illness.

This admission raises 4 key questions. Where do the biases originate? Should clinicians have biases? Should clinicians share biases with their patients? And finally, do the biases unduly influence patients' preference?

Where do our biases originate? If our biases originate from prejudices we may have had about severely demented people, we should be suspicious of our biases and do everything possible to minimize their effects. If, on the other hand, our biases originate from discussions with many elderly patients or experience with many dying patients, we should not discount the value of our clinical biases. We believe our biases originate from 2 sources. One is clinical experience. The other is communitywide discussions about guidelines for appropriate end-of-life care. The Colorado Collective for Medical Decisions (formerly GUIDe, a consortium to develop guidelines for appropriate end-of-life care)<sup>20,21</sup> is sponsoring these discussions, which have confirmed that only a small minority of elderly patients would want long-term tube feedings.

Should clinicians have biases about long-term life support, such as tube feedings? Recent critiques about tube feeding suggest that clinicians should be critical.<sup>22,23</sup> Tube feedings may not increase survival<sup>24</sup> and may actually increase medical complications, such as aspiration pneumonia.<sup>25,26</sup> They may reduce the quality of life for people with terminal diseases.<sup>27</sup> In one study, restraints were used in 53% of the patients to keep the tube in place.<sup>28</sup> When patients understand the likelihood that restraints may be required to keep the tube in place, many opt to forgo this intervention.<sup>14</sup> Feeding tubes may discourage human contact (eg, feeding someone with a spoon), thus encouraging more "antisocial" forms of eating.<sup>23</sup> Families may find the psychological and financial

**Table 2. Characteristics of the 287 Patients Who Were Interviewed**

| Characteristic          | Value        |
|-------------------------|--------------|
| Mean $\pm$ SD age, y    | 77 $\pm$ 7.0 |
| Sex                     |              |
| Female                  | 65           |
| Male                    | 35           |
| Race or ethnic group, % |              |
| White                   | 84           |
| Black                   | 8            |
| Hispanic                | 6            |
| Other                   | 2            |
| Living alone, %         | 52           |
| Religion, %*            |              |
| Protestant              | 62           |
| Catholic                | 23           |
| Jewish                  | 2            |
| Other                   | 9            |
| Agnostic                | 3            |
| Education, %†           |              |
| Grades 1-8              | 15           |
| Grades 9-12             | 51           |
| College                 | 29           |
| Graduate school         | 5            |
| Income, %               |              |
| <\$11,000               | 63           |
| \$11,000-\$25,000       | 23           |
| >\$25,000               | 14           |

\*Percentages do not total 100 because of rounding.

†Only the highest level attained is shown.

burden associated with tube feedings excessive.<sup>29</sup> For various reasons, physicians,<sup>30-32</sup> nurses,<sup>33</sup> ethics committee members,<sup>34</sup> and surrogate decision-makers<sup>35</sup> may consider tube feedings inappropriate for patients with advanced dementia and other progressive diseases. Biases against tube feeding for certain patients are justifiable.

Should clinicians share their biases with their patients when trying to elicit their patients' preferences about life support? Recently, Quill and Brody<sup>36</sup> shed new light on the pendulum that has swung from the paternalism prevalent in the 1950s to the emphasis on patient autonomy prevalent today. In the model they refer to as "independent choice," clinicians do not share their biases; they simply present options to the patient or surrogate decision-maker. In the model they refer to as "enhanced autonomy," clinicians do share their biases. Quill and Brody claim that we patronize our patients when we assume they cannot deal with our biases.<sup>36</sup> Our clinical experience supports the claim that clinicians actually enhance patient autonomy (and discover what patients truly want) when they share their biases with patients.

Did our biases unduly influence our patients' preferences? We tried to minimize the effects of our biases. If our biases had been evident, it is unlikely that 88% of our patients would have expressed a desire for short-term mechanical ventilation. As noted before, many patients opting for short-term mechanical ventilation or tube feeding started the conversation with the assertion that they "would not want to be kept alive with machines."

In summary, our results differ significantly from results of other studies because we, as primary care clini-

**Table 3. No. (%) of 287 Elderly Patients in an Outpatient Practice Who Opt for Short-term and Long-term Life Support**

| Response  | Short-term Mechanical Ventilation | Short-term Tube Feeding | Long-term Mechanical Ventilation | Long-term Tube Feeding |
|-----------|-----------------------------------|-------------------------|----------------------------------|------------------------|
| Yes       | 253 (88.1)                        | 189 (65.0)              | 11 (3.5)                         | 13 (4.5)               |
| No        | 29 (10.1)                         | 95 (33.6)               | 273 (95.1)                       | 270 (94.1)             |
| Undecided | 5 (1.8)                           | 3 (1.0)                 | 3 (1.0)                          | 4 (1.4)                |

cians who may have expressed biases during informal interviews with our patients, explored our patients' preferences about long-term life support.

Our study has 3 important limitations. First, these data are relatively old. The interviews occurred from 1991 to 1992. Considering how quickly the field of bioethics has progressed and how much attention has been given to advance directives in the last decade, one must ask if data from 1991 are pertinent in 1998. We believe they are. Our results are consistent with this decade's trend toward more appropriate palliative care, which has been encouraged by the results of the SUPPORT study<sup>37</sup> and the debates on physician-assisted suicide. Furthermore, recent studies confirm that only a very small minority of patients (<4%) would want everything done to prolong life.<sup>38,39</sup>

Second, our population of patients was fairly homogeneous. Our results may not apply to a population of elderly patients with a higher percentage of minorities.

Finally, our biases may have influenced our patients' preferences more than we recognize. As noted above, we believe that the expression of some bias may improve communication and enhance patient autonomy. We tried to minimize the effects of our biases. However, we must admit that the biases of one of the investigators (D.J.M.) are strong enough<sup>40-42</sup> that they may have influenced results in ways that neither the clinicians nor the patients could perceive.

The majority of elderly patients favor life support interventions when there is a reasonably good chance that the intervention will return them to their previous level of function. Only a small minority would want prolonged life support interventions when there is little or no chance of the intervention improving their health.

Many elderly patients with strokes, Parkinson disease, Alzheimer disease, and other dementias are unable to feed themselves. Eventually they are unable to be fed by others. Frequently these patients spend the rest of their lives in nursing homes, fed through gastric tubes. Many do not recognize family members or other caregivers. Our study suggests that the vast majority of elderly patients would want to avoid this outcome. They would rather be treated without prolonged tube feeding or mechanical ventilation. If other clinician-investigators confirm that only a small minority (<5%) of patients would want long-term life support, we should reconsider the presumption in favor of life support for patients with advanced dementia or other terminal diseases. According to the patients we serve, palliative care is appropriate for those who are not able to breathe on their own or are not able to be fed by others.

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