

Perceptions of patients on the utility or futility of end-of-life treatment

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Background and objectives: Definitions of medical futility, offered by healthcare professionals, bioethicists and other experts, have been rigorously debated by many investigators, but the perceptions of patients of futility have been explored only by a few. Patients were allowed to discuss their concerns about end-of-life care, so that their ideas about treatment futility or utility could be extrapolated by us.

Methods: In this cross-sectional study, in-depth, semistructured interviews were conducted with 30 elderly people who were receiving outpatient care in a large, urban Veterans Affairs medical centre in the US. Each of their healthcare providers was also interviewed. Participants were asked to consider four terms commonly used in advance directive forms (ie, life-sustaining treatment, terminal condition, state of permanent unconsciousness and decision-making capacity) and to discuss what these terms meant to them. Audiotapes of the open-ended interviews were transcribed and responses were coded and categorised by constant comparison, a commonly used qualitative method.

Results: The following four factors were taken into account by the participants when discussing end-of-life interventions and outcomes: (1) expected quality of life; (2) emotional and financial costs of treatment; (3) likelihood of treatment success; and (4) expected effect on longevity.

Conclusions: Although the terms "utility" or "futility" were not generally used by the participants, segments of speech indicating their perceptions of these terms were identified. Treatment was not always discussed in the same way by patients and providers, but seemed to reflect the same four concerns. Therefore, it may be fruitful for providers to focus on these concerns when discussing end-of-life treatment options with their patients.

Healthcare professionals, legal consultants and bioethicists generally agree with the notion that physicians are not obliged to provide care that is medically futile, but there is vigorous debate on how futile treatment should be assessed and about who has the qualifications and the right to determine the criteria on which the utility or futility of a treatment should be judged.^{1,2}

Although some experts believe that a definition of medical futility is essential,^{3,4} others argue that futility is too ambiguous and pejorative a term to be useful.^{5–7} Rather than offering a dictionary definition of the term, the Veterans Administration has recommended that efforts be made to specify the clinical situations under which it would be appropriate to withhold or withdraw diagnostic or therapeutic modalities.⁸ Examples of such situations include, when the patient will never leave the intensive care unit, when there is clear and convincing evidence that there will be no improved outcome and when a patient is elderly and has a disease affecting three or more organ systems. More recently, in a report called *Challenges and change*, the Veterans Administration⁹ (p 6) indicated that the "definition of care that will not be provided" should include "that which is outside the limits of professional standards, that which is negligent, and that which compromises the physician's integrity".

Experts, however, are not the only stakeholders in efforts to define medical futility or to decide whether to institute, withhold or withdraw treatment, particularly the types of treatment that can be interpreted as either life-sustaining or death-prolonging interventions.¹⁰ Patients and family members or surrogate decision makers are also stakeholders in such decisions.¹¹ Given that futility is an ambiguous term, it may be helpful for experts participating in the debate to know what these stakeholders understand the term to mean.¹²

In our study, we conducted qualitative interviews with a cross-sectional sample of elderly patients at a Veterans Administration medical centre in the US to explore how the patients themselves define or perceive four different concepts related to end-of-life care: life-sustaining treatment, terminal condition, state of permanent unconsciousness and decision-making capacity. We chose these concepts because they are commonly used in advance directives (eg, living wills and durable powers of attorney for healthcare) and because patients should understand them before making decisions about the care they would like to receive in the future.^{13,14} We chose in-depth interviews because we wanted patients to be able to tell us, in their own words and without prompting, what types of end-of-life treatment they would consider to be acceptable, useful and warranted. From these discussions, we were able to extrapolate patients' perceptions of utility and futility. We also interviewed the healthcare providers of the patients to determine whether the issues that the patients chose to discuss varied greatly from the issues that their providers considered to be important. We chose primary care providers for our study because healthcare administrators and researchers have suggested that discussions about advance directives be conducted in the primary care setting when patients have time to think about their medical care preferences and discuss their wishes with their family or a proxy.^{14–16}

METHODS

Setting and participants

With the approval of the Veterans Administration Pittsburgh Healthcare System and University of Pittsburgh Institutional Review Boards, we recruited study participants between April 2000 and October 2002 from a large, urban, outpatient

Abbreviation: QOL, quality of life

primary care clinic in the Veterans Administration Pittsburgh Healthcare System. Physicians, certified registered nurse practitioners and physician assistants were eligible for participation if they were primary care providers at the clinic. Patients were eligible if they were ≥ 60 years, ambulatory, able to speak and read English, residing in the community, receiving outpatient care from the Veterans Administration, not cognitively impaired and not acutely ill (ie, not hospitalised or in obvious distress).

We began by inviting all 45 primary care providers in the outpatient clinic to participate in the study and enrolled the first 30 who responded. After interviewing each provider, we checked the Veterans Administration's computerised patient record system to identify patients who met the eligibility requirements and were scheduled to see the provider within 2 months. As these pre-identified patients arrived for their appointments, we invited them to participate in an anonymous interview about advance directives and end-of-life care. We explained that the interview would take about 1 h and would take place immediately after the clinic appointment. Of the 94 patients who were approached, 31 expressed an interest in participating. Of the 31 patients, 1 was subsequently excluded because of cognitive impairment.¹⁷ Those who were approached but chose not to participate gave various reasons, including other scheduled appointments, time constraints, transportation issues, the presence of family members and physical limitations.

Data collection

Participants were individually interviewed in a private area by one of three doctoral-level professionals with degrees in medicine, medical sociology, or rhetoric and health communication. After the participants provided informed consent and sociodemographic data, the interviewer started the audiorecorder and began the semistructured interview, which consisted of open-ended questions on four terms: life-sustaining treatment, terminal condition, state of permanent unconsciousness and decision-making capacity.

Regarding the first term, the interviewer began by asking two major questions: "Can you tell me what the term 'life-sustaining treatment' means to you?" and "Can you tell me why you think of it in that way?" Probing questions, which helped the interviewer move from the first major question to the second, included items such as, "What words or pictures come into your mind when I say this term?" The interviewer continued with the same questions about the three other terms. Finally, the interviewer asked, "If you were in a room full of medical students or trainees, what one thing would you want them to know about how to best talk to patients about end-of-life care?"

Data transcription and analysis

The audiotaped interviews were transcribed, imported into Ethnograph (Qualis Research, Denver, Colorado, USA) and coded. We then examined the transcripts by using methods of grounded theory¹⁸ and constant comparison, to discern themes or categories of responses.¹⁹ As we read and reviewed the transcripts of the 30 patients and each of their providers, we found that, although we had not introduced the subject of medical futility, the participants tended to discuss this subject in the context of their perceptions of decision making at the end of life. More specifically, their understanding about futility emerged as a core theme in their discussions on end-of-life treatment.

The standardised unit of analysis that we used was a text unit called a conversational turn. For purposes of analysing responses to the open-ended question, we counted a single turn as a text unit in which one person spoke for a period, regardless of the length of time. Because medical futility

encompasses several subcategories, we sometimes assigned multiple codes for a given text unit. Categorising the text units of the interviews in terms of subjects or themes allowed us to discern the patterns of responses expressed by the patients and the providers.

We continued to examine the data until the categories were theoretically saturated.²⁰ When there were no further changes to the coding scheme, we tested its reliability by randomly selecting 20% of the transcripts, coding them independently, comparing the results and refining the coding rules until we obtained $\kappa > 0.70$ agreement, a statistical method of inter-rater agreement.²¹

RESULTS

The sample population

Of the 30 patients in the study, 28 (93%) were men, 27 (90%) were white and only 4 (13%) had not completed at least a high-school education. These characteristics are typical of the overall Veterans Administration population in the US and Puerto Rico, where 95.2% are men, 88.7% are white and about 12% of male veterans have not completed high school.²² The patients ranged in age from 60 to 81 years, with a mean of 70.5 years. Regarding religious preferences, 3 had no preference, 15 were Roman Catholic, 9 were of various Protestant denominations, 2 were Jewish and 1 was agnostic. Most (24) patients were retired, and most (17) were married or living with a partner.

Of the 30 primary care providers who participated, 19 were physicians, 10 were nurse practitioners and 1 was a physician assistant. In all, 19 were women, 26 were white, 2 were African-American and 2 were Asian or Pacific Islanders. They ranged in age from 30 to 60 years, with a mean of 41.4 years. Regarding religious preferences, 7 had no preference, 9 were Roman Catholic, 9 were of various Protestant denominations, 2 were Jewish, 2 were Hindu and 1 refused to answer. Most (25) providers were employed full time, and most (22) were married or living with a partner.

Interview analysis

When we asked the 30 patients and each of their providers to tell us what the advance directive terms meant to them, their definitions ranged from general to specific, and their examples ranged from abstract (eg, based on hypothetical situations) to highly personalised and contextualised (eg, based on previous experiences with healthcare, with end-of-life care of their loved ones and with life in general). Specific language in the accounts of the patients and providers suggested the concepts of utility and futility, and from this language and the context in which it was used we were able to extrapolate the participants' views and definitions of these terms. For example, the following phrases suggested futility, even though the word itself was not mentioned: "that's a vegetable", "not what I consider life", "corpse lying there taking up space", "nothing to look forward to", "that doesn't solve anything", "no point" and "a waste of time and money".

Both groups of participants tended to define end-of-life care in terms of whether outcomes were in conformity with particular values and goals. Providers also tended to make the assessment on the basis of medical data, at least on the surface. Both groups tended to take four factors into account when discussing whether a treatment was acceptable and whether it should be implemented: (1) effect on quality of life (QOL); (2) emotional, financial and other costs; (3) likelihood of success; and (4) effect on length of life. As we discuss each of these categories, we provide direct quotations from a variety of patients. Although space limitations prevent us from providing quotations from healthcare professionals, we indicate the number of cases in which they covered the same topics.

Expected effect of treatment on QOL

This outcome was discussed most often, with QOL mentioned, without prompting, by 17 patients and 21 providers. In most cases, treatment was roughly defined as futile if it would keep a particular patient alive but would not allow the patient to function at a level that he or she would personally find acceptable.

Although QOL pertains to all aspects of human life, including a person's physical, social, emotional and spiritual well-being, the relevance of each aspect varies from person to person. One patient, for example, made this argument:

[Quality of life is] not laying in bed staring at the ceiling all 24 hours a day and have a tube running into you feeding you and a tube running out of you going to the bathroom. I mean that's not quality of life, that's a vegetable. That's not much of a life. Can't get up and go to a movie or watch television or no dancing.... I like my freedom. You know, being able to go for a ride and whatever. Go to work. I enjoy going to work.

But another patient made this argument:

Now what is that quality of life? Doesn't necessarily need to be physical only. Physically and mentally. I cannot be physically capable of doing things, but mentally my mind is still good. I can read. I have my sight and so on.

Many patients feared that someone else would decide on their behalf what was an acceptable QOL. This was seen in the following statement:

I think in some cases when people get put on machines, that very often it's [a matter of a family member not wanting] to lose my mommy or my daddy or my child. And in those cases, you're sustaining the life signs [but] not really what I consider life, because there's no quality to it. And in those cases, I think you're doing it for yourself more than for the person who is in question.

Most patients and healthcare providers believed that decisions on whether to attempt or forgo the initiation of interventions to sustain life include value judgements about what constitutes an acceptable QOL. Many gave examples to show that life-sustaining treatments that some patients would gladly endure would be rejected by them or by others, further suggesting that people value different aspects of QOL.

Emotional, financial and other costs of treatment

We found that 24 patients and 13 providers judged treatment in terms of costs such as being dependent on loved ones for care, loss of productivity, loss of financial savings, or the presence of pain and suffering.

On the one hand, patients were particularly concerned about becoming a burden to their family members if they were seriously ill or incapacitated. On the other hand, many did not think that their family members would be a burden to them under similar circumstances. One elderly male patient, for example, described the following reactions to a case in which a father was placed on life-support systems and was visited often by his daughter:

Leave somebody else to enjoy their life. Why take the pleasure away from them? I can't see that.... [The father] will last 5 or 10 more years. Here is a young lady out here. She loves her father and she is going to sit there for 5 or

10 more years and suffer when all they have to do is take him on his way and let her live.

Similarly, another patient feared becoming a burden to his fiancée if he were in a state of permanent unconsciousness:

She would probably feel that she had to come visit me and everything when I wouldn't even know that she was there. So she's better off [if] she comes to the cemetery and visits and at least she can plant flowers there. She can't do anything when I'm laying in bed, you know in the vegetable state.... I'm in no hurry for [death] to come. But when my time comes I do want to go.

Alternatively, another patient expressed this belief:

Well, there are people who are bedridden for one reason or another. But they still contribute to a family. Just like in a lot of ways I think Alzheimer's patients do. They're still there. They're still alive. They're still human beings. Because they don't have the memories they used to have doesn't make them any less human. Or that we love them less.

Many feared becoming a financial burden if they were hospitalised:

Well, they had me on ... a resuscitator or [whatever] they call the machines today. But I don't think it should be done. Because you're just a burden to your family. I ain't got no money coming in when I'm laying there And I'm costing my family money.

In contrast, other patients feared that their family would suffer financially if they died. Thus, they would find utility in specific treatments, even if it compromised their QOL. In one case, for example, the husband was willing to endure endless life-sustaining procedures because his wife would cease to receive his pension when he died. In another case, the patient said:

I know I have a lot of pain. Sometimes I wish I were dead because of my pain.... Then I think of my [family].... I might still be good for something. Staying alive I can help my grandchildren out.

Although most healthcare providers emphasised the importance of pain management, some patients worried that pain medications would not be available to ensure that they could live or die comfortably.

The likelihood of treatment success

Nine patients and 12 providers judged treatment in terms of the likelihood that it would have a positive physiological benefit or improve the chances of recovery, cure, survival, independence or comfort. Thus, their language suggested that they would see utility in treatments that would help them reach these goals, and most patients agreed that they should be given a realistic estimate of their chances of reaching these goals.

Some patients perceived the likelihood of success in terms of whether there was any hope for improvement. For example, in reference to his mother, a patient stated:

Well, my mother who is 95 now is in the nursing home. I have seen some of the patients in this vegetative condition

who are in a fetal position and they have to feed them with a syringe and squirt food into their mouth. I can't see where that does anybody any good just to have almost a corpse lying there taking up space and money and there is no hope of them ever recovering from that.

Another patient discussed hope for improvement with some treatment measures but not with others:

If I only need oxygen, okay, and not a defibrillator or any drastic measures to keep me alive,...okay, I'd go along with that. I don't want to go to anything too drastic, like the breathing machine that breathes for you, the ventilator, and things like that. If there is no hope for me to get better,...then I would like to have it end.

With more lofty goals, some patients discussed hope in terms of a cure. In reference to his wife, one patient stated:

She no longer was able to ... do anything at all, couldn't get out of a chair, couldn't sign her name, had a hard time speaking because she couldn't get her words out even though she could think, but she couldn't get them out. Her eyesight was failing. Her heart was giving her problems and she was in pain.... The tumor was growing, but it was pushing. Everything was being pushed out of her head. Eventually if you can't think and can't move and can't do, you are done. At that age when they say there is no hope, the tumor cannot be stopped, we cannot remove it, we cannot operate, we can't give her any more radiation, we can't do anything except wait for her to die—that is nothing to look forward to. You would want to go right then.

References to the likelihood of treatment success were also phrased in terms of probability or chance of an outcome. For example, one patient said that he would not want to be placed on resuscitators and similar equipment unless "there's a chance that [he] could come out of it". One provider said that he tries to give some indication of the likelihood of success by discussing research that shows a patient's chance of surviving for 1 year.

Expected effect of treatment on length of life

Eight patients and 12 providers discussed treatment in terms of the length of life to be secured. None discussed examples of treatments, the effect of which would potentially shorten the length of life. Instead, all focused on treatments that would sustain or prolong life.

Patients generally associated efforts to sustain life with having healthcare providers use machines to aid certain bodily functions. Many patients recognised the utility of using medical equipment on a short-term basis to increase long-term survival. For example, one stated that life-sustaining treatment is acceptable as a "temporary means ... whether it be ... intravenous or some [way to be fed] because I can't eat by myself". Yet, few patients were in favour of using medical equipment on a long-term or permanent basis. For example, one discussed the following scenario:

Have you done everything you can? Is there anything else that you can do? And if the answer is I've done everything and nothing will work, ... [then to keep someone alive by having] the machines keep going ... I think it's just sustaining existence. That doesn't solve anything.

Most patients weighed considerations of length of life against those of QOL, as was evident in the following argument:

Putting you on a life support machine ain't nothing except you are going to be laying there for what 10 or 15 years maybe? That is just a waste of time and money.

Like the patients, the providers weighed longevity against QOL in their discussions of equipment designed to sustain life. Some emphasised the importance of doing everything that is in the patient's best interests while following a "wait and see" approach with regard to the prospects for recovery.

DISCUSSION

Our study population consisted of 30 elderly veterans and 30 primary care providers, each of whom was interviewed individually for about an hour. On the one hand, the generalisability of our findings to other populations is somewhat limited because of the small sample size, non-probability sampling technique, use of a single Veterans Administration clinic site and relative lack of gender, racial and ethnic diversity of the participants. On the other hand, however, the length of the interviews afforded participants the opportunity to provide in-depth information about their perspectives on end-of-life care, and the open-ended structure of the interviews allowed for participant-directed responses that have important implications for patient-provider communication on advance directives and life-sustaining treatment.

In our analysis of the interviews, we found that both the patients and the providers tended to take the following four factors into account when discussing end-of-life care: the effect on QOL; the emotional, financial and other costs; the likelihood of success; and the effect on length of life. Although the patients and the providers often had overlapping views on these four factors, patients thought that providers were more concerned with extending the length of life than with quality-based outcomes, and this led some patients to worry that providers would place a higher value on longevity than on other patient-care goals. Patients were more likely than providers to discuss end-of-life treatment as an acceptable means of assisting the body temporarily rather than on a long-term or permanent basis. Although providers were concerned with QOL, they also emphasised physiological considerations, including the probabilities of success or failure of end-of-life interventions. Indeed, in many cases, providers indicated that their most difficult decisions were those on struggling with conflicting QOL and physiological goals for treatment.

Whereas the providers tried to be more objective in their discussions of medical futility, the patients often presented lengthy narratives of their own experiences or the experiences of their friends and loved ones to illustrate their perceptions of futile treatment. We found variations in the perceptions of medical utility that were sometimes evident in whether the respondents referred to interventions that "prolong life" versus those that "prolong death". As one provider in our study pointed out, the term "life-sustaining treatment" is not neutral in this respect: "I just think when you say it ... you are giving people connotations about sort of prolonging a life in terms of their entire concept of life."

In our study, considerations about the past, present and future QOL were crucial to most patients' discussions of what treatments they considered to be acceptable. Rather than discussing cases in which different treatment options might be effective, patients often preferred to discuss outcomes that

they would find acceptable. This shows that end-of-life decisions generally entail value judgements.

Consistent with the literature, our findings show that medical futility does not have a single, universally recognisable and clinically applicable meaning.²³ As Ewer²⁴ points out, the concept of medical futility is problematic because it is almost impossible to identify patients whose medical condition makes additional therapeutic intervention unmistakably futile, especially with regard to specific goals of treatment. In practice, the concept of futility is applied broadly and often inappropriately or even detrimentally. Some patients and physicians worry, for example, that insurers will use the concept as an excuse to deny payment for costly but beneficial treatments. Some patients fear that physicians will use the concept as a reason to justify their failure to deliver all of the types of treatment that the patients and their family members request.⁷ As indicated in *Challenges and changes*, these fears are not unfounded:

It appears that in the past the term "futility" has most often been used in individual cases, on a one-on-one basis at the bedside, where the physician felt it necessary or appropriate not to discuss, not to offer, to withhold, to withdraw, or to deny a particular therapy for one or more reasons. This plan could occur even though the patient or surrogate had requested the therapy or asked that it be continued. The reasons included, but were not limited [to the following]: treatment was totally inappropriate, never tried before, previously tried but rarely or never successful; [the] results of treatment would produce negative quality of life, only preserve permanent unconsciousness, or fail to end total dependence on the intensive care unit (qualitative futility); etc.... Much of the foregoing rationale is based upon physician decisions or physician values. It is argued that this is a return to paternalism or subversion of patient autonomy, to the exclusion of patient values.⁹ (p 3)

Technically, the determination of futility ultimately lies with the physician.¹⁰⁻¹¹ According to the American Medical Association's²⁵ (Section E-2.035) *Code of ethics*, for example, "Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients." Yet, most disagreements over appropriate care occur in cases in which a critically ill patient has little chance for recovery, and the most difficult cases arise when patients or family members insist on additional interventions even though the physician believes that such care is futile and should not be provided. As more value is placed on the patient-physician partnership and joint decision making in the clinical context, physicians increasingly face the dilemma of how to interpret and respond to treatment choices of patients, as well as their perceptions of the value, or utility, of a treatment in the light of their own goals and values.²⁶ Withholding treatments that are futile (as defined by the physician) supports the ethical principles of both non-maleficence (do no harm) and beneficence (relieve suffering). But, some ethicists argue that invoking the principle of futility solely from the providers' perspective is in direct conflict with the principle of patient autonomy.

During recent decades, patients and their families have been increasingly participating in end-of-life decisions, both in the hospitals and in the courts.²⁷ Although there is no clear legal precedent in the US federal courts about withholding futile care against a patient's wishes, case law has been based in large part on the bioethical principles of autonomy and beneficence, and the state courts have usually ruled in favour of the patient, especially in cases regarding the withholding or withdrawal of unwanted life support.²⁸ For example, in

1986, the California Superior Court upheld the right of a mentally competent 28-year-old woman with tetraplegia, cystic fibrosis and degenerative arthritis to refuse oral feedings and have her nasogastric feeding tube removed.²⁹

In addition to case law, the principle of autonomy has been upheld by several organised committees formed to develop a policy related to death and dying. For example, in 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research³⁰ determined the following:

The voluntary choice of a competent and informed patient should determine whether or not life-sustaining therapy will be undertaken, just as such choices provide the basis for other decisions about medical treatment Health care professionals serve patients best by maintaining a presumption in favor of sustaining life, while recognizing that competent patients are entitled to choose to forego any treatments, including those that sustain life. (p 19)

Similarly, the Council on Ethical and Judicial Affairs of the American Medical Association³¹ declared:

The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail. The principle of patient autonomy requires that physicians respect the decision to forego life-sustaining treatment of a patient who possesses decision-making capacity. (Section E-2.20)

Although there is agreement that futile endeavours should not be carried out,³² there has been little guidance in identifying what is empirically futile.³³ In 1997, to remedy this problem, the Society of Critical Care Medicine's Ethics Committee proposed that a treatment be defined as futile only when it will not accomplish the intended goal.³⁴ The committee further stated that futility should not apply to the types of treatment that are often mislabelled as futile: treatments that are extremely unlikely to be beneficial, those that have beneficial effects but are extremely costly and those that are of uncertain or controversial benefit. In other words, the fact that a treatment may be "inadvisable, costly or a poor use of healthcare dollars" does not make it futile.³⁴ There may be a question about the efficacy of an intervention, in which case the debate rests on scientific evidence. But, if there is a question about the intervention's likely benefit in a specific scenario, then ethical decision making requires us to recognise both the providers' and the patients' various perceptions of benefit, as well as the goals and values on which these perceptions are based.³⁵⁻³⁶

Our research supports a growing body of literature that suggests that the discussion of end-of-life care should be viewed as a process, rather than an event, and that the preparation of advance directives should be viewed as an opportunity to clarify the healthcare preferences and goals of patients and their family members. Because of the lack of detailed patient-provider communication about advance care planning, living wills containing vague treatment instructions are likely to lead to different understandings of concepts such as life-sustaining treatment and lead to care that is inconsistent with the treatment goals of patients.³⁷⁻³⁹

Our results show that although patients do not necessarily label treatments as useful or futile, they have strong and definite notions of treatment outcomes that they do and do not want. It is vital, then, that healthcare providers ask their patients the appropriate questions so that the patients

themselves can become engaged in effective decision making about current and future treatment options. As so many factors affect end-of-life decision making, the goals of treatment must be clearly identified and well defined. Rather than labelling or mislabelling treatment options as useful or futile, healthcare providers must be clear and honest about the range of options, and must take the time and effort to explain each option in terms of the expected QOL, the emotional and other costs, the likelihood of success and the effect on longevity.

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