



Recommended Policy Guidelines Regarding Medical Futility

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Executive Summary

In these recommended policy guidelines, the Center for Practical Bioethics and the Kansas City Regional Ethics Committee Consortium address the difficult problem of medical futility. Our goal was to help patients, their families, healthcare providers, and consultants become more effective in discussing end-of-life issues and the limits of medical intervention.

The Center and the Consortium are well suited to undertake this work and bring to it a strong history of support for patients' rights, sensitivity to the needs of healthcare providers, and a willingness to listen and respond to the concerns of diverse populations within the wider community. The project included a series of focus groups to engage the community and a task force of the Consortium to reflect on current practice. Their combined outcomes would

- establish a coherent philosophical, ethical and spiritual foundation,
- provide model guidelines,
- design a communications process,
- recognize and acknowledge diversity, and
- promote reasonable discussion in the community.

The guidelines recognize that while physicians are not obligated to provide futile treatment for their patients, they are obligated to act compassionately and professionally toward the patient's surrogate and family to ensure that the patient's well-being remains the focus of everyone's concern.

Active Listening

Members of the focus groups recognized the specific moral and professional obligations of healthcare providers to make treatment decisions and voiced the following concerns:

- Will my wishes, religious beliefs, and family be respected, and will it be a shared decision?
- Will I have the right to determine what quality of life means for me?
- In conflict resolution, will the clinical team listen to my family, clarify when necessary, and allow my family time to work things out?

The focus groups are described in Part One of this document and full summaries of each group are provided in Appendix A.

Guidelines for Cases Involving Medical Futility

Members of the task force, similarly convinced of the intimate link between culture and values, made communicating with the patient or the patient's surrogate and family the linchpin of their recommendations. In Part Two of the document, they identified the structural and relationship problems that must be addressed, the ethical principles that apply, and the functional definitions that help clarify the discussion.

Assessments of medical futility are the result of a process based on clinical judgment and the patient's known goals and wishes. Therefore, the guidelines for cases involving medical futility consist of several steps beginning with the assessment of the benefits and burdens of further medical treatment, communication, and consultation (steps 1, 2, and 3). Ideally, the process will culminate in a plan of care focused on palliative treatment (step 6).

Intermediary steps are needed in difficult cases. Where there is no consensus, two paths may be taken. First, the patient's right to refuse medical treatment is always to be honored. The process

is more likely to breakdown, however, when the patient or patient's surrogate insists, against medical advice, that "everything should be done" (step 4). In such cases, further consultation with the ethics committee is recommended (step 3), and in very conflicted cases, it may be necessary to engage the service of a trained bioethics mediator (step 5). If the conflict proves intractable, the physicians/clinical team will continue to care for the patient while helping the patient or patient's family find a new venue of care.

A schematic presentation of these medical futility procedures is charted on page 21.

Conclusion

The Center for Practical Bioethics and the Kansas City Regional Ethics Committee Consortium believe that most cases involving medical futility will be resolved without the need for bioethics mediation and without the rupture of the patient-doctor relationship that requires the physician to transfer the patient into the care of another.

We recognize, however, that the problems identified in this document have become problems of trust, not for a few patients but for many people who find it difficult to negotiate the intricacies of healthcare in these complicated times.

This situation calls us to examine the philosophical, ethical, and spiritual underpinnings of our system. We welcome this opportunity and offer this document as part of the larger discourse on the goals and limits of medicine, the benefits of palliative care, and the ways we can communicate effectively and respectfully with one another.

Recommended Policy Guidelines Regarding Medical Futility

Kansas City Regional Ethics Committee Consortium of the Center for Practical Bioethics

Prologue

Popular culture, as gleaned from TV shows, the popular press, and the internet, often portrays life-sustaining medical treatment as something magical. Whatever is broken, damaged, or in need of repair can be restored to good working order in relatively little time. Medical culture, on the other hand, often finds itself trying new treatment modalities with ambiguous or uncertain outcomes in a valiant but unpredictable effort to restore the patient to health or prolong life.

In reality, in some cases, no improvement in the patient's condition is possible: the patient is dying, and unwarranted treatments may be ineffective or even make the patient's condition worse. Sometimes a proposed treatment can effect a change in some bodily function of the patient that is being monitored (e.g., blood pressure, heart beat), but that same treatment may impose too great a burden on the patient to warrant its continued use. In such cases, it may be time to withdraw the unwarranted treatments and embrace a treatment plan focused on palliative or comfort care.

Recognizing this point in time can be difficult. Patients or their surrogates and families, and even healthcare providers, are often reluctant to move from curative to palliative care. Redirecting care is resisted because it appears that we are "giving up" or "ceasing to care." The Center for Practical Bioethics and the Kansas City Regional Ethics Committee Consortium have prepared these Medical Futility Guidelines to help clarify when the redirection of medical treatment is indicated and how patients or their surrogates, families, and physicians can continue to care for the patient even when further curative treatment is thought to be "futile."

The Center for Practical Bioethics and the Kansas City Regional Ethics Committee Consortium have previously prepared over a dozen guidelines on issues related to clinical and organizational ethics. Most recently, we reviewed and updated our Guidelines for Withholding/Withdrawing Life-Sustaining Treatment (August 2004). That document refers to medical futility, but does not address it directly. Based on our discussions then, and on a review of changes in the way medical futility is viewed in the literature, the Center resolved to produce a guidelines document dealing exclusively with the determination and communication of medical futility.

The Center and the Consortium are well suited to undertake this work and bring to it a strong history of support for patients' rights, a sensitivity to the needs of healthcare providers, and a willingness to listen and respond to the concerns of diverse populations within the wider community. Among these voices are many who often experience disparities in health and healthcare: cultural and ethnic minorities, the indigent, immigrants, persons who are elderly, persons with disabilities, and persons in rural communities. Including these voices is central to our methodology and purpose.

Background and Scope

Earlier efforts to craft medical futility guidelines are well known. They include the Houston Multi-Institution Collaborative Policy on Medical Futility (Halevy and Brody 1996) and the Medical Futility Guidelines of South Florida (2000). Despite these constructive measures, the onerous issue of medical futility continues to challenge healthcare institutions, providers, and ethics committees,

perhaps because these measures fail to reflect on the spectrum of public uneasiness regarding the difficult questions surrounding medical futility and limits to medical intervention.

The present document incorporates insights from extensive and engaged discussions with dedicated clinicians and with representative groups in our community. A task force of Center staff and healthcare professionals labored intensively in small groups and with frequent feedback from hospital ethics committee members to define the problem, to understand its effect on healthcare providers and the communities they serve, and to find common ground. Members of the task force also met with, and facilitated a variety of community and faith-based focus groups.

Accordingly, Part One of our document is an account of the shared concerns or "common ground," regarding the issue of medical futility as expressed throughout our twelve focus group meetings. Situating and acknowledging these collective concerns prior to the actual policy guidelines underscores our firm belief that these voices from our community are not ancillary but central to the discussion and resolution of this difficult issue. Detailed summaries of the groups are contained in Appendix A.

Part Two describes the policy guidelines that emerged from our many and varied discussions. These guidelines have been prepared for ethics committees, medical staffs, governing committees, and other healthcare administrators and providers. Our goal is to help them develop, review, or update their organizations' medical futility policies and engage in discussion with patients and their families about care that offers little chance of cure.

Although each case of medical futility is unique and involves different patients and surrogates, family members, physicians, nurses, and other caregivers, the basic issues and consequent conflict of values are likely to be fairly constant across time. The challenge, as we learned from our many discussions among the task force, consortium

members, and community focus groups, is to know when a further curative treatment offers too little benefit and how best to make these decisions together with patients, surrogates, and families.

Medical futility can be assessed in two distinct though interacting ways. It can be determined in terms of the physiologic effects of treatment on patients; or it can be determined in terms of the toll it takes on patient values. In both cases, however, the assessment is never unilateral, and in every instance, consultation, informed consent, support, communication, pain management, and continued personal care are essential.

Part One

Community-based Focus Groups

I can't be found in myself, I discover myself in others.

That much is clear.

And, I suspect that I also love and care for myself in others.

—Hugh Prather, as (quoted by a focus group member in a subsequent email)

Introduction

Insights from the medical futility focus groups are a vital component in these recommended policy guidelines. This first part highlights shared questions raised by our diverse groups in meetings held throughout the Kansas City Region, including Lexington and Columbia, Missouri, and Lawrence, Kansas.

With the exception of two hospital-based palliative care teams, the focus groups represent populations that tend to be marginalized in our region's healthcare system: African-Americans, Latinos, the indigent, immigrants, Vietnamese, the elderly, persons with disabilities, faith groups, and persons in rural health settings. The following groups played a key role in making these groups possible. Without their willingness to collaborate and assist us as liaisons, some at least of the many

voices of our community would not have been heard.

Boone Hospital Center's Palliative Care Team, Columbia, Missouri

Boone Hospital's Palliative Care Team includes medical and nursing professionals as well as social workers, clergy, physical and occupational therapists, and pharmacists. Its fundamental aim is to relieve pain and suffering and associated symptoms for patients who cannot be cured. It provides ongoing patient and family support, and educational programs for hospital staff and the broader community.

Boone Hospital Center, 1600 East Broadway, Columbia, MO 65201.

Cristo Rey, Kansas City, Missouri

The Cristo Rey Network describes its vision as enabling "rigorous college prep education within the grasp of urban young people so that they may achieve their potential and build a better world." Its mission is to "bring quality, Catholic, college preparatory education to urban communities with limited educational options." The Network assists young people who have limited educational options, many of whom are African Americans or recent immigrants. Services also include academic assistance, counseling, and work study programs.

Cristo Rey Kansas City High School, 211 West Linwood, Kansas City, MO 64111.

El Centro, Inc. Kansas City, Kansas

El Centro provides a wide range of services for Latino immigrant families and their communities. Its mission is to "create and sustain educational, social and economic opportunities for families." El Centro's services include childcare, tutoring, family intervention, job placement, financial and home buying literacy, rental housing, housing rehabilitation, and services for seniors.

El Centro, Inc., 650 Minnesota Avenue, Kansas City, KS 66101

Greater Kansas City Interfaith Council Kansas City, Missouri

The Greater Kansas City Interfaith Council describes its mission as bringing about "a sustainable, pervasive culture of knowledge, respect, appreciation and trust amongst people of all faiths and religious traditions in the greater Kansas City community." It does this through interfaith dialogue, resource development, interaction among faith leaders, and community education. It is made up of faith leaders from various religious and spiritual traditions.

Greater Kansas City Interfaith Council, Box 10332, Kansas City, MO 64171

Heartland Senior Health Heartland Health

The Senior Health program at Heartland Health provides a variety of services aimed at improving the health of seniors in the community. Its benefits include educational updates on health information, ongoing speaker events, assistance with community resources, programs to enhance physical health and fitness, an annual Senior Olympics, an AARP sponsored safe driving course, and health screening.

Heartland Senior Health, Heartland's Plaza 1, 802 North Riverside Road, St. Joseph, MO 64506.

Lafayette Regional Health Center Lexington, Missouri

Lafayette Regional provides compassionate and cost-effective healthcare to Lafayette County residents and surrounding rural communities. A member of the HCA Midwest Health System, Lafayette addresses the need for integrated healthcare with those who live in more rural settings, and places special emphasis on pain management.

Lafayette Regional Health Center, 1500 State Street, Lexington, Missouri 64067.

**Lawrence Memorial Hospital
Palliative Care Team, Lawrence, Kansas**

Lawrence Memorial's Palliative Care Team provides the best in comfort care, pain and symptom management, and emotional support for patients for whom there is no cure. It also offers a sustained support system for patients' families. In addition, team members educate hospital staff regarding pain and symptom management and issues surrounding bereavement and grief. The team includes physicians, nurses, social workers, and a chaplain.

Lawrence Memorial Hospital, 325 Maine Street, Lawrence, KS 66044.

**Mattie Rhodes Center
Kansas City Missouri**

Also known as the Mattie Rhodes Counseling and Art Center, Mattie Rhodes offers family and community support to the growing Latino population in the Kansas City region. It also serves recent Latino immigrants and their families. (The annual national growth rate of Latinos is about 57 percent; the rate in the Kansas City metropolitan area is about 130 percent.) Mattie Rhodes provides "professional social services, mental health counseling and art experiences in a bilingual, culturally sensitive environment."

Mattie Rhodes Counseling and Art Center, 1740 Jefferson, Kansas City, MO 64108.

**Samuel U. Rodgers Community
Health Center, Kansas City, Missouri**

This community health center seeks to ensure that quality and compassionate healthcare and useful health-related information is provided to the poor and underserved in rural and urban communities. Patients come from diverse ethnic backgrounds and especially represent African Americans and migrant communities. Programs include comprehensive outpatient services, school-based health clinics, substance abuse treatment, adult day care, foster care, medical case management, and interpretation and transportation services.

Samuel U. Rodgers Health Center, 825 Euclid, Kansas City, MO 64124.

**The Whole Person, Inc.
Kansas City, Missouri**

This private, nonresidential corporation provides independent living services to residents throughout Kansas and Missouri. It provides a "variety of community-based, consumer-driven services to people with disabilities to promote consumer control and choice of services, self-direction, empowerment, independence, self-reliance, self-help, self-advocacy, and integration into the community." Its programs include services for the physically disabled, the frail and elderly, and the deaf and their families. The Whole Person also provides community education.

The Whole Person, Inc., 114 West Gregory Blvd., Suite 430, Kansas City, MO 64114.

Vietnamese-American Community, Inc.

This community association serves the nearly 15,000 Vietnamese who live in the Kansas City metro area. It promotes an appreciation of Vietnamese culture through language classes and cultural education and helps Vietnamese and their families, including recent immigrants, to adjust to and integrate into both the regional culture and the broader American culture.

Vietnamese-American Community, Inc., 6612 Independence Avenue, Kansas City, MO 64125.

As each of these organizations represents a unique population, each of our focus groups expressed a unique set of concerns. Nonetheless, despite the diversity of the groups, our meetings also revealed a core of shared interests that we urge all healthcare institutions and professionals to consult when crafting their futility guidelines. We also encourage readers to review the individual summaries from each group in Appendix A.

Format of the Meetings

After proper introductions to each other and to the futility project, each focus group was asked to consider a hypothetical case study that had been especially constructed to evoke questions regarding medical futility.

Patient and family names and other contextual matters were varied to ensure the relevance of the case study to the members of each group. For example, we used Vietnamese names when we met with Vietnamese persons and changed the context to reflect the concerns of people with disabilities when we met with them.

We also took care to translate medical terminology into language more accessible to

lay people. Uncle Oly (Fig. 1) was our original case study. Uncle Octavio (Fig. 2) is the same case adapted for use in our Latino groups. It also demonstrates the translation of medical terms into more accessible language.

Four key questions were used to guide the discussion (Fig. 3). The first two questions allowed participants to describe their feelings or *concerns* and to express their opinions about

Figure 1.—Uncle Oly

Olag Svenson is an eighty-six year-old gentleman who has lived at Happy Valley nursing home for the last three years. Olag and his brother Sven emigrated to this country from their native Sweden. The brothers each settled on adjoining farms in the plains states. Olag remained a life-long bachelor, though he often said he was married to his fiddle and spent many happy hours jammin' with friends and family. Sven married and had two children, Olag's niece and nephew.

Five years ago Olag suffered a stroke which left him with a moderate hemiparesis, a noticeable speech disarticulation and the occasional need for a wheelchair. Recovering from his stroke was difficult and left him unable to play the fiddle or perform his daily life activities. Olag moved in with his brother Sven and his family. His niece Samantha and his nephew John, now grown children with their own families, had developed a fond affection for their uncle despite his rather stubborn and contrary persona.

Three years ago Olag moved to Happy Valley nursing home when Sven, his only living relative, died unexpectedly. Sven's wife, burdened by her own health needs, was unable to care for Olag; besides they didn't really get along that well anyhow. Since arriving at Happy Valley, Olag's age has begun to take a more obvious toll. His recent memory has deteriorated though past memory remains relatively vivid. He often believes he is still back in the "old country" and frequently reverts to his native Swedish during conversation.

The personnel at the nursing home find Olag to be a "challenging" resident. Olag has never had much use for physicians and rarely sought health care as a younger man. He frequently refers to the medical and nursing staff as "monumental fools." Rare visits from Samantha and John (both live several hours away) seem to spark a more affable attitude but only briefly.

Two weeks ago the nursing home experienced an outbreak of influenza. Olag suffered a more serious bout than others and required more rigorous nursing care and support than the nursing home could provide, so he was sent to the hospital. Though he has recovered significantly, he still has frequent and severe coughing episodes which interfere with his ability to breathe. He remains on oxygen and now spends most of his time in bed coughing. His appetite has deteriorated and he has lost nearly 20 lbs (current weight 110 lbs). The hospital is expecting to discharge him but the nursing home is reluctant to take him back.

A chest x-ray yesterday revealed a loculated abscess in the lower lobe of his right lung. The medical staff has recommended that Olag have the abscess surgically removed. It is highly unlikely that Olag's condition will improve without the surgery. If not performed he will likely suffer a course of continued inanition (starvation). Furthermore, if the abscess were to rupture, a severe systemic infection would seem highly likely.

On the other hand, Olag is a very high-risk surgical candidate. His frailty would make intra-operative stability very tenuous. He could die on the operating table or in the recovery process.

The hospital has contacted John who said "they should do whatever Uncle Oly wants." Samantha became rather hysterical and said "I simply could not make that kind of decision for Uncle Oly."

Figure 2.—Uncle Octavio

Octavio Fuentes is eighty-six years-old. He and his brother Benito came to this country from Mexico. They worked and lived on a farm. Octavio never married, but he often said he was married to his Mariachi violin. He spent many happy hours playing music with friends and family. His brother Benito married and had two children: Eva and Emiliano.

Five years ago, Octavio suffered a stroke. The stroke made it hard for him to move his left arm and leg. It is difficult to understand him when he speaks, and he sometimes needs a wheelchair. He can no longer play the Mariachi violin, and even dressing himself can be hard. Octavio moved in with his brother Benito and his family. His niece Eva and his nephew Emiliano, now grown children with their own families, had developed a fond affection for their rather rough and stubborn uncle.

Three years ago, Octavio moved to Happy Valley nursing home when his brother Benito died suddenly. Benito's wife was not able to care for Octavio. Since he moved to Happy Valley, Octavio's health has been failing. "He seems to be older than he ever was," Eva says, on one of her visits. Octavio's recent memory is not so good, but he remembers his childhood and his brother. He often believes he is still back in Mexico, and he often speaks Spanish on the rare occasions when he talks.

The people who care for Octavio at the nursing home find it hard to help him. He has never liked doctors and almost never took any medicine as a younger man. He calls the doctors and the nurses "big fools." Visits from Eva and Emiliano (both live several hours away) seem to make him happy, but the good mood never lasts.

Two weeks ago, the nursing home was hit by an outbreak of flu. Octavio suffered a higher fever than others. The doctor sent him to the hospital. He recovered from the flu, but he still has frequent and severe coughing that interferes with his ability to breathe. He remains on oxygen and now spends most of his time in bed. He has stopped eating, and he has lost nearly 20 lbs. He weighs about 110 lbs. The hospital is expecting to send him "home," but the nursing home does not want to take the sick man back.

A chest x-ray yesterday showed an abscess in the lower part of his right lung. The medical staff has recommended that Octavio have the abscess surgically removed. Octavio will not improve without the surgery. Furthermore, if the abscess breaks open, he may suffer a severe infection throughout his body.

On the other hand, Octavio is not strong, so the operation is risky. He could die on the operating table or in the recovery process. He continues not eating. He might starve.

The hospital has contacted Emiliano who said "do whatever Uncle Octavio wants." Eva cried like her heart would break and said "I simply cannot make that decision for Uncle Octavio."

Figure 3.—Questions for Discussion

- A. What is it about this case that concerns you? (Concerns)
- B. Do you believe this is a case of medical futility?
How do you define medical futility?
What do you believe should go into determining futile treatment? (Futility)
- C. How should determinations of futility be communicated? (Communication)
- D. How should situations of conflict be resolved? (Conflict Resolution)

futility, that is, how it is defined and by whom. The third and fourth questions were procedural questions dealing with *communication* and *conflict resolution*.

These questions go to the heart of our document and recommendations. We have therefore used them as the organizing element in our summaries (see Appendix 1). They also provide the framework for our identification of core interests and common ground.

Finding Common Ground

Despite the diverse populations represented in the various focus groups, quite a few concerns and questions were common to all groups. Respect for patients as persons appeared as the underlying principle guiding participants' decisions, and they also clearly affirmed the premise that providers have specific professional and moral obligations. The task force recognizes the congruence of these elements with the principles and values that underlay its articulation of recommended guidelines.

Respect for patients as persons entails that they will determine their own quality of life, be treated equally with other persons, never viewed or treated as objects or discriminated against because of age, gender, disabilities, poverty, culture, ethnicity, religion, or social usefulness. In addition, caregivers will respect patients' values, see that they have a sound support system, and allow them to die with dignity.

Providers have specific professional and moral obligations to

- relieve the patient's pain and suffering,
- provide the best possible comfort care,
- encourage advance care planning with patients and family members,
- communicate clearly, honestly, and compassionately with patients, surrogates, and family members, and

- assure patients, surrogates, and family members that comfort care is never futile.

Along with this correspondence in fundamental principles and values, certain themes resounded throughout the discussions in response to each of the four questions in Figure 3. Here are those themes, posed in the form of questions from the community (as would-be patients) to healthcare providers.

Concerns

- Will I as a patient be the primary decision maker?
- If I am not capable, will someone who knows me well speak for me?
- Will the clinical team respect and involve my family?
- Will the clinical team be sensitive to my religious beliefs?
- Are providers aware of their own biases regarding color, ethnicity, race, age, disabilities, religion, socioeconomic status, and gender?
- Will the clinical team encourage my family to discuss advance planning before my condition gets worse?
- Will my family avoid self-interest and decide on the basis of what I would want?
- Will the healthcare institution educate the community about these issues?

"Will the clinical team ensure my family that comfort care is never futile and that I will never be abandoned?"

Futility

- Will I be free from treatment intervention that harms me excessively and provides no benefit?

- Do families and providers realize that values are implicit in any determination of medical futility?
- Are not considerations of medical effectiveness and medical benefit critical?
- Given that quality of life is especially critical, am I not the sole determiner of my own quality of life?
- Will the judgment of medical futility result from a shared decision?
- Although there is always room for hope, shouldn't hope also be reasonable?

"Guidelines should include (1) a statement that medically futile treatment will not be offered; (2) a statement as to who makes the determination of futility; and (3) a clear description regarding redirecting treatment to palliative care and hospice."

-African-American Focus Group

Communication

- Will the attending physician or my primary care physician be assigned responsibility for communication among all parties?
- Will providers and the clinical team discuss what we (my family and I) think would "characterize" a good death?
- Will providers avoid sending mixed messages and refrain from offering ineffective treatment options?
- Will physicians be sensitive and respectful to my cultural background and beliefs?
- Will finances and resources be honestly and sensitively discussed with my family?

- Will my family and I exercise our duty to be informed and ask questions of providers and the clinical team?
- Is the ethics committee an invaluable resource in communication?
- Do institutional guidelines on medical futility underscore the need for proper communication?
- Will the clinical team empower the family to make its own decision, or will it impose its agenda on the family?

Conflict resolution

- Will my own determination of my quality of life be the decisive factor?
- Will institutional guidelines on medical futility help guide both the family's and the institution's decisions?
- Do these guidelines include a clear statement that medically futile treatment will not be offered; statements regarding institutional and public education; and measures regarding treatment redirection to palliative care and hospice?
- Do these guidelines avoid being strictly "from the medical perspective," and do they promote respectful dialogue and collaboration with my family?
- Will the clinical team listen to my family, clarify when necessary, and allow my family time to work things out?
- Is the ethics committee recognized as a valuable resource for guidance?

Commentary

Our focus group meetings generated profound lessons. The most noteworthy message is that the splendid variety of voices from diverse populations, particularly those that tend to be underestimated, unheard, or ignored in our health system, do

indeed manifest mutual concerns. Diversity does not mean difference. With so much emphasis now on cultural sensitivity and awareness, often expressed as "cultural competence," recognition of diversity can be a tribute to inclusion rather than exclusion. We see this in intercultural studies: Discernment of disparities also encourages an appreciation of the humanity we all embrace.

Our meetings underscored the intimate link between culture and values. Cultures and subcultures have distinct worldviews and ways of understanding "self," the role of family, familial and social obligations, religion and spirituality, what it means to be healthy, what represents a good life, what constitutes a good death, and the role of health providers throughout this entire spectrum of life and death. This connection between culture and values is a particularly patent premise in our pluralistic society, and certainly evident among the patient population in the United States.

Yet, despite their diverse views and beliefs — whether African American, Latino, Vietnamese, disabled, elderly, faith-based, or rural — our participants also echoed the unadorned truth that we embrace a shared humanity. They affirmed as much in their fears about our healthcare system and whether our healthcare providers will honor their professional and moral duties to relieve pain and suffering, to comfort, to enhance family support, and to treat all patients with respect and dignity.

Allaying such fears requires that health professionals become, in a word, communicators. Communication is the most fundamental human dimension. It lies at the root of all efforts at cultural sensitivity. Furthermore, genuine communication exists in a naturally symbiotic relationship with sustained connectedness. Our focus groups clearly pose this challenge to healthcare professionals, a challenge that is all the more daunting given our fragmented and disconnected health system: How can we more properly communicate and work in ways that enable our patients to remain connected, connected to their system of support, their loved ones, and to the healthcare team?

What role does medicine play in forging these connections? Medicine lies at the intersection of the sciences and the humanities. And because it directly seeks to relieve pain and suffering, it continues to be, at least in principle, the most humane of the sciences. Is medicine today humane?

The following guidelines offer a way for us to address the difficult problem of medical futility in order to help restore medicine's humaneness. Furthermore, only by attending to the diverse yet unified voices in our community can healthcare professionals more fully exercise their humanity. By being "present" to our patients, by listening to what they say and to what they do not say, by embodying compassion, by committing ourselves to relieve pain and suffering, by assuring our patients that we will "be" with them to the end and will never abandon them, we take a vital and necessary step toward cultivating trust, without which our healthcare is in itself futile.

Part Two

Recommended Policy Guidelines Regarding Medical Futility

I. Purpose/Rationale/Goals

- A. Establish a coherent philosophical, ethical, and spiritual foundation to help patients, families, providers, and consultants (e.g., ethics committees) become more effective in discussions of futility.
- B. Provide model guidelines that may be used to inform institutional policy and facilitate discussions of futile treatment, including but not limited to withholding/withdrawing life-sustaining treatment policies and policies outlining opportunities for palliative care, that is, for treatment redirection.
- C. Design a communications process that will help patients, their surrogates, families, and healthcare providers engage in appropriate ongoing discussions about the patient's diagnosis,

the patient's goals and expectations, medical options, and goals of treatment.

D. Recognize and acknowledge in practice the variety of ways that cultural diversity affects the process of decision making in clinical contexts and the way patients, surrogates, families, and healthcare providers communicate with one another.

E. Promote reasonable and fair dialogue in the community about the limits of medicine and the benefits of palliative care.

II. Problems to Be Addressed

A. Structural Difficulties

1. The fragmentation of care that characterizes the delivery of healthcare as it is currently structured makes it difficult for patients and their families to know when "physiological" futility has been reached and when the goals of treatment should be redirected. For example, the increasing use of hospitalists, shorter hospital stays, transfers of patients to other care settings, and consultations with medical specialists may result in a patient's receiving care and information from persons other than an attending physician or primary care doctor. Such persons may have only partial knowledge about a patient's condition and goals of care.
2. Access to information through the internet and other media, although it has significant positive benefits, also heightens the risk of misinformation. Patients, surrogates, or families may hear about and confuse experimental treatments with therapeutic options, or wonder if perhaps their physicians are receiving incentives to limit care.

B. Patient/Provider Relationships

1. An erosion of the doctor-patient relationship also makes assessing futility more difficult. When patients, their surrogates, and family members believe that the determination of futility is being used as a reason to withhold

beneficial treatment from an individual, they understandably begin to question their providers.

2. Providers, on the other hand, may overlook signs that a patient or the patient's surrogate and family have reached a qualitative or normative determination of futility. They may believe that the family is still expecting them to restore the patient's health, and that the family will reject any suggestion about treatment redirection.
3. Value conflicts between healthcare professionals, patients, their surrogates and families may also result from diverse cultural perspectives and differing levels of knowledge or education.

C. Communication Issues

1. In the absence of sufficient, open, and honest disclosure, patients and their surrogates and families find it difficult to initiate or participate in discussions about medical futility. The power differential between clinicians and patients exacerbates this difficulty. Many patients hesitate to question the course of treatment when they have been taught to believe that "the doctor knows best."
2. Providers do not always communicate diagnoses and prognoses clearly, in language that can be understood, and with future eventualities foretold as cogently as possible. As the clinical situation changes, patients and their families or surrogates are not always fully informed, and the implications of such changes for weighing the risks and benefits of treatment are often not discussed.
3. The need to redirect treatment may be discussed with the patient and family before, or in the absence of, a consideration of the patient's values and goals of care. Such conversations lack context and may lead to the perception that families and providers have different goals of care. If the

patient's goals of care are not examined and adjusted frequently, the patient, surrogate, and family will be suspicious of change, and providers will have difficulty understanding or explaining how treatment can be redirected to best serve the patient's needs when further curative treatment is no longer beneficial.

4. Discussing all treatment options, including, for example, experimental treatments that are not medically appropriate for a particular patient, frequently confuses the discussion of patient care and prevents agreement on the notion of futility. In such cases, patients, their surrogates and families may focus on the inappropriate treatment as though it were a feasible option, rather than on the benefits and burden of the treatment.

D. False Hopes

1. Although hope is always beneficial, false or unrealistic hopes can prolong the patient's suffering and the dying process. This problem has several guises. We noted in the prologue that popular culture often focuses unrealistic expectations on the power of medical technology. An uncritical faith in modern medicine combined with our culture's denial of death may explain or contribute to a patient's, surrogate's, or family's plea "to do everything possible."
2. Other cultural and religious beliefs, for example, a belief in fate, or particular views of divine intervention, may also encourage some patients, surrogates, or families to persist in aggressive curative measures when these treatments are no longer of benefit to the patient.

III. Identification of Principles/Values

All persons, regardless of their physical or mental diagnosis or condition, or their racial, ethnic, social, religious, or financial status, have intrinsic value and personal dignity and deserve respect and compassion. The following are the primary ethical principles to be taken into account in situations involving medical futility.

The Principle of Respect for Autonomy

Patients have the right to be self-ordering and to make treatment decisions that will affect the course of their lives. This right is the patient's right of self-determination or autonomy. The proper exercise of autonomy presumes that patients are adequately informed and have the capacity to make healthcare decisions, including the right to refuse any medical treatment. The principle of autonomy also supports the right of patients to make advance directives and to delegate decision-making authority to a surrogate or proxy.

When the patient is no longer able to speak for him or herself, the surrogate decision maker bears the same authority as the patient.

Doctors and nurses, and indeed all healthcare providers, have a moral obligation to involve the patient in his or her healthcare decisions, to see that he or she is adequately informed, and to recognize and honor the right of the patient's surrogate to speak for the patient in all matters relating to the patient's health and goals of care.

However, within the cultural world of the patient, the exercise of autonomy is not an absolute right. The patient's right to be autonomous does not impose a duty or obligation on a healthcare professional to provide treatment deemed to be medically futile. Such a demand would necessarily conflict with the professional's personal or professional ethics.

The Principles of Beneficence and Nonmaleficence

The obligation to promote the well-being of the patient is basic to the patient/provider relationship. The obligation to promote the patient's well-being involves identifying the possible benefits and burdens from the patient's perspective. Likewise, providers must avoid or minimize any harm to patients. It follows that providers have to give sufficient information to patients, surrogates, and families so that they can make informed decisions.

Physicians have no medical, legal, or moral obligation to provide treatment that in their professional judgment will not benefit the patient or that will subject the patient to more harm than benefit. Nor are physicians obliged to offer patients every available treatment. Only treatments that can reasonably be expected to benefit the patient should be proposed during treatment planning discussions. Treatment decisions should be made based on current medical knowledge and experience.

As physicians have a duty to provide only medically appropriate and beneficial treatments, so patients and their surrogates and families have a similar obligation to demand treatments only if they are medically appropriate and beneficial. This principle may, however, be understood both strictly and permissively. Both physicians and patients may sometimes willfully and knowingly choose treatments that have only marginal medical benefit to enable the patient and family to fulfill personal goals or values. For example, a patient may choose to undergo cardiopulmonary resuscitation, hoping to live a few days to see a grandchild born.

Patients, surrogates, and families should listen to what healthcare providers are saying and seek clarity when they do not understand what is being said to them. Healthcare providers should also listen to patients, surrogates, and their families and work with them to determine a course of action based on the patient's values and goals of care or best interest.

It is always in the patient's best interest to have full communication among all parties (i.e., among providers, patients, surrogates, and families) when treatment decisions are being made.

The Principle of Justice

Decisions about life-sustaining treatment should be based on clinical judgment and the patient's known goals and wishes, not on considerations of race, ethnicity, religion, physical or mental disabilities, or socioeconomic status. The principle of justice requires that like cases be treated alike.

The ability to afford medical care must not determine judgments about futility, nor should the character, condition, or social status of the patient. Clinicians should not label a treatment "medically" futile if the real objection to the treatment is its excessive cost.

The cost of medical treatment and the patient's character, abilities, and social status have no role in determining physiologic futility. However, in determinations of qualitative or normative futility, the patient's age, quality of life, family circumstances, and costs can help patients, their surrogates, families, and providers determine the relationship between the medical treatment's effectiveness and its benefits and burdens to the patient.

Healthcare policymakers, hospital and nursing home administrators, and health systems personnel are ethically obligated to consider the needs of populations of patients and to provide that which best serves the commonweal. Society, guided by such professionals, then chooses how to allocate scarce resources. Physicians may use their knowledge and expertise to help guide society's choice, but they must not usurp the role of society or attempt to supply such reasoning to individual cases. The well-being of the patient is the physician's primary and only duty when making clinical judgments.

When curative interventions or treatments to prolong life are deemed to be "physiologically or medically" futile and/or inconsistent with the patient's goals and values, the best use of resources will be to concentrate on relieving the patient's pain and suffering, enhancing communication with family and friends, and providing psychological, social, and spiritual support.

IV. Definitions

The following functional definitions apply within the context of these guidelines:

1. *Best interest decisions*: the method used by surrogate decision makers to determine what

is best for a patient whose preferences are not known; a decision based on what reasonable persons would choose for themselves under similar circumstances.

2. *Decisional capacity*: the ability of a patient to make a specific decision; that is, the ability to understand relevant information, to reflect on it, and to communicate (verbally or nonverbally) decisions or preferences to providers. Decisional capacity is assessed relative to a particular topic or decision, and may come and go in the clinical environment.

3. *Family*: one or more relatives or intimate friends.

4. *Goals of care*: the hoped for or anticipated outcomes of medical treatment. The first goal of care is usually to prevent illness or trauma; the second, to restore health. But as illness progresses, other goals may be added and in time become more significant to the patient, for example, to relieve suffering, to improve the patient's quality of life, to prolong life, to have a good death.

5. *Mediation*: bioethics mediation is a relatively new application of the field of mediation and dispute resolution which has long been used in labor, human resources disputes, and other fields. In this application, a trained mediator who combines clinical knowledge and ethical reasoning with the tools of the mediation process becomes a neutral third party to level the playing field and help people search for common ground.

6. *Medically futile treatment*: any intervention that, on the basis of current medical knowledge and experience, holds no reasonable promise for contributing to the patient's well-being or of achieving agreed-on goals of care. Synonyms to "futile," such as ineffective, medically inappropriate, or nonbeneficial, are sometimes used. An ineffective treatment is one that may prolong a physiological function without contributing to the restoration of health. A nonbeneficial treatment is one that does not contribute to the patient's well-being. If either of these conditions occurs, the treatment is medically inappropriate or futile.

7. *Normative, evaluative, or qualitative futility*: interventions that either the patient, surrogate, family, or clinical team deems to be inconsistent with the patient's goals and values.

8. *Life-sustaining treatment*: interventions judged likely to be effective in prolonging bodily functions.

9. *Palliative care*: a range of treatments intended to provide relief of pain and suffering, control symptoms, reduce anxiety, and provide comprehensive support to patients. Such care is sometimes referred to as "comfort" care — care that serves to relieve or alleviate pain and suffering without attempting to cure.

10. *Persistent vegetative state*: a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of hypothalamic and brain-stem autonomic functions.

11. *Physiological or quantitative futility*: interventions deemed to be unable to achieve an intended medical (i.e., somatic) goal.

12. *Substituted judgment*: a method of decision making used by surrogate decision makers who know the patient well enough to determine what he or she would decide; a decision by a surrogate based on the expressed preferences of the patient.

13. *Surrogate*: an agent or agents who act on behalf of a person who lacks capacity to participate in a particular decision. An appropriate surrogate may be (1) identified by the patient (e.g., in a healthcare treatment directive, living will, or durable power of attorney); (2) appointed by a court (e.g., a guardian); or (3) the adult who is most involved with the patient and most knowledgeable about the patient's personal values and preferences.

14. *Terminal illness*: an illness that can be expected to cause the patient to die; an irreversible and unrelenting condition for which there is no known cure.

V. Working Assumptions

1. The term “medical futility,” though disputed, remains useful.
2. Designations of “medical futility” are context-dependent. Such decisions are relative to circumstances and assume certain value judgments.
3. Guidelines should focus more on what will be done than on what will *not* be done. That is, care will always be provided, including palliative or comfort care.
4. Hope is an attitude that can be maintained and encouraged even in situations of medical futility.
5. Decisions regarding medical futility should be collaborative, involving all members of the treatment team. They should not be unilateral decisions.
6. Although institutions have varying patterns of organization and leadership, communicating and resolving medical futility require that a member of the clinical team, usually but not always an attending physician or primary care doctor, be designated to assume leadership for communication with the patient's surrogate and family, and for continuity of care.
7. Although clinical caregivers are not obligated to violate their own professional and moral integrity, when faced with moral conflict, they are obligated to involve others in the discussion and seek resolution.
8. The healthcare institution is responsible for conducting educational efforts to inform and educate staff, administration, and the community regarding medical futility issues. Cultural sensitivity and competence will help ensure that these educational efforts respond to the needs of various cultural groups.
9. These guidelines operate within the larger framework of institutional policies and should be congruent with similar policies of withholding/withdrawing life support and other end-of-life decisions.

VI. Recognizing Medical Futility

Determining medical futility for an individual patient is the result of a process. It may begin when an attending physician or other member of the clinical team becomes concerned that one or more medical treatments are no longer effective for this patient. This determination, namely, that to begin or continue a particular treatment is physiologically futile, is primarily a medical and professional judgment usually made by the physician/clinical team on the basis of current medical practice and experience.

Alternatively, the process may begin when the patient or patient's surrogate or family indicates to the attending physician or other members of the care team that further treatment would be inconsistent with the patient's goals and values and is therefore unwanted or too burdensome. In this case, the patient, surrogate or family, is expressing a judgment of qualitative or normative futility. Guidelines related to medical futility should clearly note that either the patient or the physician can initiate a discussion about the futility of further treatment.

The distinction between physiologic and normative futility helps delineate the roles of patients and physicians in the decision-making process. However, this distinction is not absolute. Patients and their advocates often understand and make judgments about physiologic futility, and physicians who know and value their patients will have considered their patients' values and ways of life, and examined their own personal values. Consensus is reached when medical expertise and the patient's goals and wishes come together for the well-being of the patient.

Thus, a judgment of medical futility is never made unilaterally. If it is initiated by physicians, corroboration of the judgment should be sought among other physicians and members of the care team; consultation with a palliative care specialist or team may be especially helpful. If initiated by the patient, a similar effort should be undertaken to determine the patient's or surrogate's capacity to make this decision.

Treatments that may become physiologically futile include but are not limited to cardiopulmonary resuscitation (CPR), artificially supplied nutrition (enteral or parenteral), mechanical ventilation, dialysis, pacemakers, insulin, and broad spectrum antibiotic therapy or prophylaxis when the probability of success is extremely low.

General clinical markers that may indicate physiological futility include but are not limited to a diagnosis of brain death (i.e., a total and irreversible loss of brain function), a diagnosis of persistent (or permanent) vegetative state, and/or treatments that merely prolong the dying process. In addition, there is a growing body of literature about specific interventions for specific populations of patients, for example, CPR, artificial nutrition and hydration, dialysis, and treatments for congestive heart failure. But, with the exception of brain death, clinical markers, statistical probabilities, and anecdotal analogies, while helpful, should not be the sole determinants of futility.

VII. Guidelines for Cases Involving Medical Futility

Step 1: Assessing the benefits and burdens of further medical treatment

Anyone on the clinical team or the patient, the patient's surrogate, or family may request an assessment of futility. The family or the care team may have discussed the patient's prognosis informally, before a formal assessment is requested, but care should be taken to prevent premature, inconsiderate, or "hearsay" notions of futility from disturbing a patient's or family's trust in the clinical team. Futility assessments should involve

- consultation with others, especially consultation with the hospital's palliative care team; and
- consultation with a patient advocate, chaplain or spiritual advisor, social worker, or other facilitator who has not been directly involved in providing patient care.

During the assessment, treatments begun should be maintained.

Step 2: Communicating with the patient or the patient's surrogate and family

Communications regarding futility should be led by the patient's attending physician or another designated person on the care team. Other members of the care team may attend, but every effort should be made to avoid an authoritarian or paternalistic approach. The agenda should include the

- patient's apparent values and goals of care,
- perceived futility and potential burden of further medical treatments,
- feasibility or desirability of beginning a time-limited trial of certain interventions,
- meaning and availability of palliative care,
- physicians' promise not to abandon the patient.

Begin the conversation by revisiting the goals of care, the patient's diagnosis and prognosis, and any changes in his or her condition that have led to this crossroad. The conversation should also clearly distinguish between the effects of a medical treatment and its benefits to the patient. The care team will

- explain as clearly as possible the medical basis for their recommendation to withhold or withdraw medical treatment and begin a course of palliative care.
- share the value judgments that have informed their recommendation.
- ask the patient's surrogate or family member to share the values that have guided the patient's life, and ask them how the patient would decide these difficult issues.
- talk to the patient, surrogate, or family about possible options, and let them know that a time-limited trial (e.g., 24 to 48 hours) may help determine if a particular treatment might benefit the patient.

- explain that if no benefit is apparent in the allotted time, the medical treatment will be withdrawn.
- assure the patient or family that they are not abandoning the patient and will continue to do all that is possible to relieve the patient's pain and suffering.

If the care team and the patient or patient's surrogate and family agree on the futility of further treatment, a new plan of care should be determined, which may include

- a time-limited trial of some potentially beneficial treatment,
- the withdrawal or withholding of treatments deemed to be futile, and
- a meeting of the providers and the patient/surrogate/family with the palliative care specialist/team to initiate planning for treatment redirection and hospice referral if desired.

When this point has been reached, go to Step 6.

Step 3: Consulting with the ethics committee

If the patient/surrogate/family and the care team are not able to reach consensus, a consultation with the ethics committee may provide guidance and promote additional dialogue leading to consensus. Ethics committees do not determine futility, but they encourage decision makers to recognize any underlying conflicts of value that may be preventing them from acting together on the patient's behalf.

During this procedural step, treatments begun should be maintained.

- Anyone on the clinical team or the patient, the patient's surrogate, or family may request an ethics consultation.
- Consultation interviews may occur with the patient, surrogate or family, and clinicians, separately or together.

- Ethics consultations should be documented in the patient's medical record, but documentation procedures may vary according to institutional policies and procedures.

If consensus is reached regarding the futility of further medical treatment, the patient/surrogate/family, and the attending physician/care team should meet with the palliative care specialist/team to determine a plan for palliative care. Go to Step 6.

If consensus is not reached, resolution of the conflict may still be possible. Go to step 4.

Step 4: Procedures in the absence of consensus

When the attending physician/clinical team has not reached a determination of physiological futility, but the patient or the patient's surrogate has reached a qualitative determination of futility, respect for the dignity of the patient and constitutional law requires that the clinical team honor the patient's right to refuse any medical treatment. The attending physician and care team will refer the patient to the palliative care specialist/team and meet with this team to assure that the patient's treatment is properly redirected. The patient may be discharged to palliative care, home care, and/or referred to hospice. Go to Step 6.

However, if the clinical team views continued curative care to be futile, but the patient or patient's surrogate or family insists that treatment not be withheld or withdrawn, and that everything possible needs to be done to prolong the life of the patient, the attending physician/clinical team must act compassionately and professionally toward the patient's family so that the patient's well-being remains the focus of everyone's concern.

The patient may request transfer to the care of another physician. If so, the attending physician/clinical care team will help the patient or the patient's surrogate or family find a new venue of care, whether within the hospital, or in another facility.

During the transfer of care to another physician or clinical team, care begun should be maintained.

If, however, the patient or the surrogate and family do not want to change physicians but continue to demand treatment that the clinical team has determined on the basis of current medical practice and experience to no longer benefit the patient, the case should go to mediation. Go to step 5.

During the transfer of care to another physician or while the case is in mediation, care begun should be maintained.

Step 5: Mediation, or further procedures in the absence of consensus

Bioethics mediation as a procedure for dealing with medical futility is a relatively new application of the field of mediation. The mediator will be a neutral third party who combines clinical knowledge, ethical reasoning, and skills of mediation to level the playing field and help all parties reach consensus.

The mediation process will show respect for each person's views and values and be strictly confidential. We stress the importance of having a trained mediator involved in the discussion. In some cases, the mediator may be a member of the ethics committee, but being on the ethics committee or having ethics training is not a substitute for training in healthcare mediation.

We recognize that bioethics mediation is a new service and may not be available in all healthcare organizations. This expertise should be sought in the larger community.

If the mediation results in a consensus that further treatment would be futile, then planning for treatment redirection or palliative care should begin immediately. Go to Step 6.

If, following mediation, the parties are still in disagreement, the following guidelines apply. Physicians are never morally obligated to provide

futile treatment because to do so would violate their professional and moral integrity. However, physicians are morally obligated to help arrange for the orderly transfer of the patient to another physician and/or healthcare institution.

- The patient, surrogate, or family must be clearly and compassionately told that no further treatment will be offered.
- The patient's surrogate or family may then arrange for a transfer of care. The attending physician/clinical team will assist them as much as possible. Return to step 4.
- If a transfer of care is not possible, legal resolution is always a last resort.

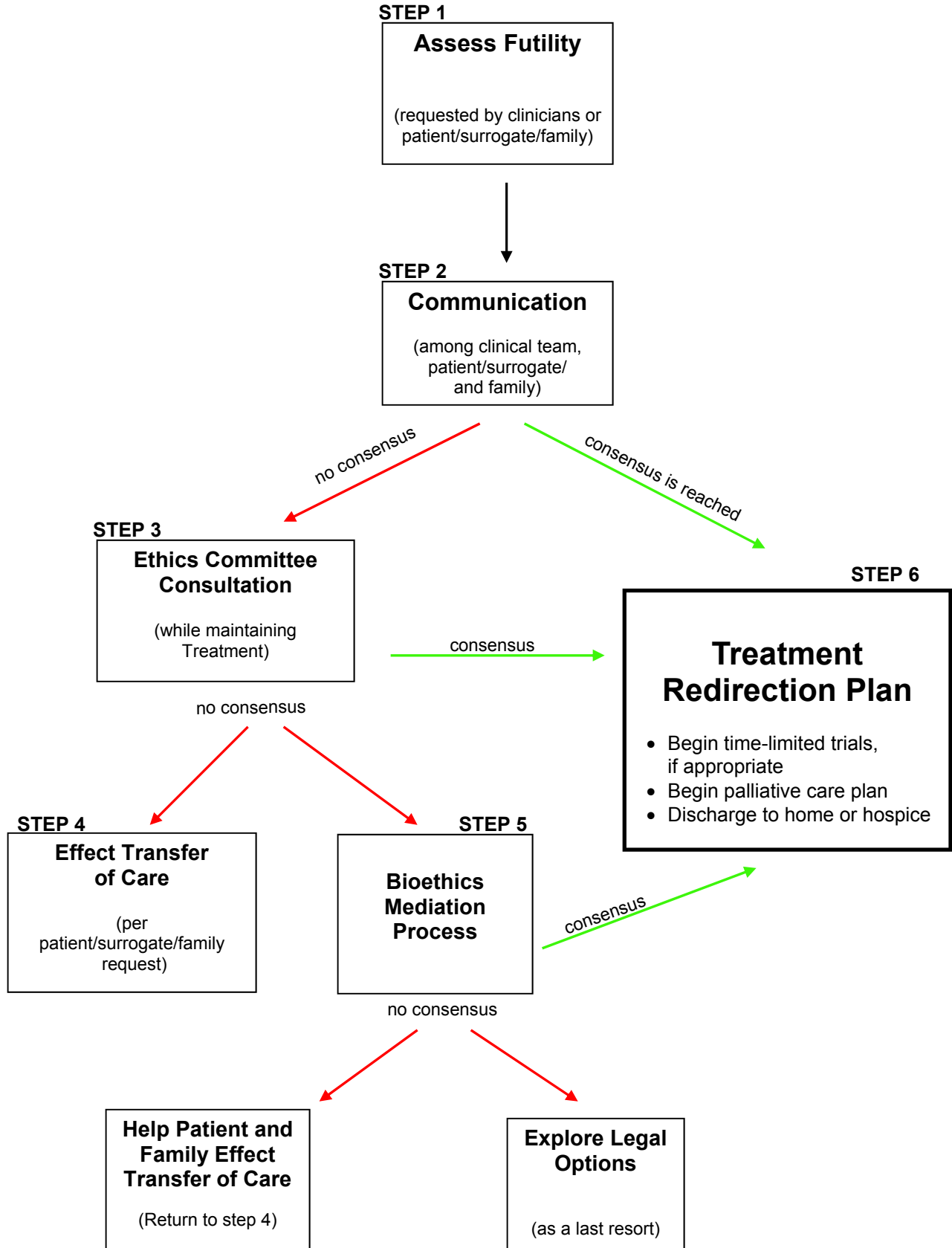
During mediation and until the patient's transfer is accomplished, care begun should be maintained.

Step 6: Initiate or continue palliative care

Palliative care minimizes patient suffering and should be provided across the continuum of care from a patient's diagnosis until the end of life. However, following a consensus regarding medical futility, the focus of patient care shifts entirely to palliation. Palliative care includes

- pain management and symptom control (e.g., air hunger, nausea, constipation, dry mouth),
- withdrawal of futile life-sustaining treatments, including artificial nutrition and hydration,
- decisions regarding cardiopulmonary resuscitation (CPR) and antibiotics,
- support for grief and bereavement, actual and anticipatory — for the patient, surrogate, and family, but also for the clinical team and other care providers,
- psychosocial and spiritual support, and
- referral to hospice or home care.

MEDICAL FUTILITY PROCEDURES



Conclusion

The Center for Practical Bioethics and the Kansas City Regional Ethics Committee Consortium believe that most cases involving medical futility will be resolved without the need for bioethics mediation and without the rupture of the patient-doctor relationship that requires the physician to transfer the patient into the care of another.

We recognize, however, that the problems identified in this document have become problems of trust, not for a few patients but for many people who find it difficult to negotiate the intricacies of healthcare in these complicated times.

This situation calls us to examine the philosophical, ethical, and spiritual underpinnings of our system. We welcome this opportunity and offer this document as part of the larger discourse on the goals and limits of medicine, the benefits of palliative care, and the ways we can communicate effectively and respectfully with one another.

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Appendix A

Focus Group Summaries

The following pages are summaries of our twelve focus group meetings. The earlier format describes four key questions with respect to a specific case study (outlined in Fig. 3). These questions are the organizing element in the following summaries and address the most critical aspects of our document.

- **Concerns:** What are the main concerns regarding the case?
- **Futility:** Is this a case of medical futility? How is futility defined and determined?
- **Communication:** How should determinations of futility be communicated?

- **Conflict Resolution:** How should conflict be resolved?

In reality, our discussions were more dynamic, engaging, and comprehensive. To simplify their complexity, we have bulleted the principal thematic points raised by each question. The ordering of the bulleted points does not, however, reflect any priority among the opinions and insights shared by the group.

To avoid misunderstanding and misuse of these summaries, we note the following caveats:

- The discussions were descriptive, not normative. We have made no deliberate effort to evaluate the discussion or the participants' responses to our questions.
- The method is phenomenological. The facilitators' and reviewers' own biases were bracketed and are not included.
- Groups are not intended to be the "official voice" or perspective of their respective populations. As each population has its own internal differences, it is important to avoid generalizations based on group responses.
- The groups were intentionally small so that each participant's response would be heard.
- Despite a phenomenological methodology, the summaries do have an interpretative element. Reviewers' subjectivity in perceiving the session and interpreting the audiotapes is unavoidable.

African-American Focus Groups

1. *Cosponsored with Cristo Rey Center, Kansas City, Missouri, November 1, 2005. This African-American focus group included representatives of indigent populations and immigrants.*

A. Concerns

- Who knows the patient well enough to speak for him? "Who is in his corner?"
- Age should not be a defining factor in treatment decisions.

B. Futility

- Synonyms for “futility” include “hopeless” and “irreversible.”
- Treatment is futile if it causes more harm than benefit.
- Futility means that nothing more can be done to benefit the patient and that there is “no hope of meaningful recovery.”

C. Communication

- The attending physician should be directly responsible for seeing that communication is maintained. In this respect, it is invaluable for attending physicians to be adept in matters of communication and especially sensitive to the spiritual needs of the patient.

“When my nephew was murdered, the caregivers were most sensitive and respectful in their approach to the family, especially in requesting the retrieval of his organs for transplantation.”

- If possible, physicians must involve the patient in decision making.
- Providers need to inform the patient’s family clearly, regularly, and honestly, as to the patient’s condition and prognosis.
- Physicians need to avoid sending mixed messages by presenting treatment options as if they were feasible and effective.
- A provider's style of communication needs to be respectful and without any hidden agenda.

D. Conflict Resolution

- A clear set of guidelines can help to resolve conflict.
- These guidelines should include (1) a statement that medically futile treatment will not be offered; (2) a statement as to who makes the determination of futility; and (3), a clear description regarding redirecting treatment to palliative care and hospice.

“Guidelines must be applied equitably across the institution.”

- Educating the public about these guidelines may help to counter unrealistic public expectations.
- Rather than being strictly “from the medical perspective,” guidelines need to ensure respectful dialogue and collaboration with the family.

2. *Cosponsored with the Samuel U. Rodgers Community Health Center, Kansas City, Missouri, November 11, 2005.*

A. Concerns

- Faith traditions and beliefs play a major role for patients.
- Faith traditions underscore the importance of discerning “God’s will.”
- Faith traditions support the belief that comfort measures are all-important to manage pain and relieve suffering.
- If treatment is medically ineffective and without benefit, then there is no need for aggressive treatment.
- Age can be a relevant factor in assessing benefit/risk considerations.

Latino Focus Groups

3. Cosponsored with the Mattie Rhodes Center, October 24, 2005. This Latino group included immigrants from Mexico.

A. Concerns

- To help relieve further suffering, the clinical team needs to learn from the patient or spokesperson when "enough is enough."
- Alleviating suffering can be especially relevant for a person who is much older. Age is therefore a factor, although not the deciding factor.

B. Futility

- Providers need to consider the patient's will to live.
- Treatment is futile if there is little hope for improvement and no desire on the part of the patient to live.

"My aunt had stomach cancer. . . . When the providers told us there were no medical benefits to further intervention, we didn't know what to do. For us, it was important to know what she wanted. If she no longer had any desire or will to live, then intervention was futile. Signs, such as no longer eating, can tell us about a person's will to live."

- Family members feel a duty to keep on fighting. "It is hard and we suffer, but being a part of family, we have the duty to fight 'til the very end."
- In Mexico, the family often provides a stable support system. Such a system is difficult to maintain in the United States. In Mexico, it

seems that everybody has more time to take care of the family.

- Determining futility considers age, diagnosis, prognosis, the person's will to live, family support, and economic resources.

"Here, you have to work so hard to pay all the bills that suddenly you are between the wall and the sword."

C. Communication

- Providers need to communicate in language free of jargon, preferably in Spanish.
- Communication must be honest, "clear and complete" regarding the facts — prognosis, risks, anticipated suffering, and benefits.
- Facts should not be simply stated. They need to be explained. For example, the phrase "very risky" is insufficient and must be clarified.
- Providers must offer resources (e.g., an interpreter and reliable websites) so that the family can obtain further information.
- Providers should sufficiently inform the patient, surrogate, and family about medications and their side effects.
- Family and patients have a duty to ask questions of the providers.
- Family members should write down any information.

"Our daughter had kidney cancer. After we requested an interpreter, we felt much better informed and supported by the medical team."

D. Conflict Resolution

- The key lies in the patient's own determination of his or her life and priorities.
- Even children who are patients have the right to decide for themselves at some point, even if opposed to the parents. However, parents still have a responsibility to act in that child's best interests and to fight for that child.
- Physicians must provide the relevant medical information, and decisions should generally be left to family.
- If the family cannot agree, then the ethics committee should provide guidance.
- If the family cannot decide, then in some cases the physician should.
- Financial burdens cannot be dismissed as irrelevant since someone, in many cases the family, bears the costs. Family should therefore discuss issues of financial accountability.

4. *Cosponsored with Mattie Rhodes Center, October 26, 2005. This focus group also included immigrants.*

A. Concerns

- Patients are persons and should never be objectified.
- Physicians should not be the primary decision makers.
- Relieving the patient's pain and suffering, physically and emotionally, remains most important.
- Providers need to avoid discriminating against patients based on their age, poverty, color of skin, or social usefulness.
- A patient should not be kept alive against his or her will.
- Sometimes there is a tension between respecting the patient's choice, the family's choice, and following God's will.
- The belief in God and in God's will is important to consider. We should not act as God.

- Suffering can have a redemptive value in that God tests not only the patient but the family through suffering. Patience is crucial.
- When death is certain and imminent, we ought to allow a person to die with dignity if this is what that person prefers.

B. Futility

- Futility depends upon what the patient prefers.
- Treatment is futile when all measures have been taken, nothing can be done to improve the situation, and there is no longer any hope for improvement.
- Treatment is futile when a treatment brings about more suffering and no benefits.
- For a few participants, as long as there is a possibility, even a slim one, of continued life, no intervention is futile, particularly since we need to accept God's will.

"My brother had leukemia, with a prognosis of one year. He lived for four years, and could have lived longer, but he no longer wanted treatment."

C. Communication

- Providers must communicate all relevant facts, especially probabilities, risks, and prognosis, with compassion, honesty, clarity, and sensitivity to patient and family.
- Latinos stress the importance of feelings, while also respecting the role of intellect. Feelings should not be downplayed.
- Latinos view the family as a natural support system.

"My neighbor has diabetes and amputated limbs, but he is regularly cared for by his children who live next door."

D. Conflict Resolution

- The key lies in ongoing, persistent communication.
- The patient's wishes remain the final word. Providers and family need to bear in mind the Golden Rule: how we would want to be treated if we were in a similar situation.
- In the case of deadlock, the ethics committee should act as guide.
- In case of continued deadlock, transfer to another institution may be necessary.

5. Cosponsored with El Centro, Kansas City, Kansas, October 26, 2005. This Latino group included representatives of indigent populations and immigrants.

A. Concerns

- Who knows the patient well enough to speak for the patient?
- The clinical team must ensure that capable patients are empowered to make their own choices.
- The clinical team needs to know and respect that religious beliefs are a major factor in patient care.
- Without a solid support system from family, primary care physicians, and social workers, patients will "fall through the cracks."
- The quality of communication with the patient and family is crucial.
- Communication should clearly be in the patient's language.

- The patient's quality of life is a vital consideration, and it is the patient who determines this.

B. Futility

- Treatment is futile if it has no positive impact.
- The determination of futility should result from a shared process. The physician presents the relevant medical information, particularly risks. The patient or surrogate weighs these risks along with the physician, and together, they reach a decision.
- Treatment is futile if it "does not improve the patient's quality of life." "Quality of life" is the patient's decision.

"When money is mentioned, some families may feel that they are being discriminated against on the basis of their ethnicity. Providers need to be aware of that possibility."

C. Communication

- There must be clear and honest communication with the patient, or surrogate, and family.
- Providers need to avoid unclear and mixed messages that can be interpreted differently by family members.
- The family's financial risks should be discussed, even though such considerations may be taken out of context.
- Providers need to explain the risks of treatment intervention in a sensitive manner. A conversation about risks can make Hispanic patients "fearful," particularly in the case of immigrants, who already find the hospital setting intimidating.

- Physicians, particularly the attending, should clearly present the medical facts.
- Medical facts provide a knowledge base for decision making, which “rests with the patient and family.”

“I don’t have the last word; I’m not God ... Nature is different in everybody, so the decision is up to the patient first, and second, the relatives, the closest.”

D. Conflict Resolution

- The physician should hold a group meeting involving a social worker and interpreter to explain the situation clearly to the family.
- In Hispanic culture, hospice support is an option in all cases of terminal illness.
- Cultural sensitivity is crucial so that the “presentation can be non-insulting.”
- In Hispanic culture, if there is no family agreement, “we respect what the mother-in-law would say,” and the family shares in caring for the patient.

“Hospice support is an option in all cases of terminal illness.”

Vietnamese Focus Group

6. Cosponsored by the Vietnamese-American Community, Inc., Kansas City, Missouri, January 14, 2006.

A. Concerns

- Alleviating the patient’s suffering is of the utmost importance.

- The clinical team and family ought to allow the patient to die naturally. “In my country, this is about more than love . . .” It is best to “let him go,” even if he can eat for some days, as long as “he dies naturally.”
- Given the importance of letting go, age matters in that after a full life the patient should be “ready to go,” especially if a support system and relatives are lacking.

B. Futility

- Definitions of futility were not discussed in this focus group as a separate topic. For these participants, “allowing the patient to die naturally” seemed to be a primary consideration.

C. Communication

- What matters most is showing that one truly cares.
- Physicians need to be clear, honest, respectful, and sensitive to the patient’s cultural background and beliefs.

D. Conflict Resolution

- If the family cannot decide among themselves, the best course is to let the patient “go,” especially if further treatment is no longer effective.
- For many participants, especially first-generation immigrants, it is important to take the deceased’s body home to Vietnam.

“But our father had no advance directive, and even though he had told us that he wanted to be let go, we couldn’t do it.”

Persons with Disabilities

7. *Cosponsored by The Whole Person, Kansas City, Missouri, October 19, 2005.*

A. Concerns

- Who speaks for the patient?
- How health providers view persons with disabilities is a crucial concern. The situation of each individual patient is unique, with variables that are often either unknown or disregarded by the medical team.
- Many examples were offered by the participants, themselves “disabled,” in which the provider's perspective had overlooked situational variables with respect to their care.
- The clinical team needs to deliver care holistically.

“What does it mean for a patient to be ‘disabled’? Do you know?”

- A holistic approach would include ideas and approaches to both curative treatment and comfort care.
- Providers must avoid mentioning treatment options that are really medically futile. This sends mixed messages to patients and families.

B. Futility

- Determining futility is a highly personal assessment, so that personal futility is distinct from medical futility.
- If treatment merely sustains an existence without any quality of life, that treatment is futile.
- If treatment offers no hope for recovery, that treatment is futile.

- If treatment offers no benefit, such treatment is futile.
- Persons with disabilities are often highly suspicious of judgments of futility, fearing that such judgment may be premature.

C. Communication

- The primary care physician should be the person responsible for ensuring proper communication.
- The responsible physician must see to it that all affected parties meet together to discuss relevant facts such as risk, diagnosis, and prognosis.
- Finances and resources need to be honestly and sensitively discussed.
- The hospital is responsible for ensuring that all necessary paperwork is in order.
- There should be ongoing exploration of various options/styles of communication.

D. Conflict Resolution

- Providers need to be sensitive to and aware of hidden biases and how they affect perception. For example, in addition to disability, age may be a factor in perception.
- Providers need to understand that quality of life views are unique for each individual.
- Sustained education about differing perspectives is needed, particularly regarding persons with disabilities.

“Sometimes it feels like the patient has been objectified and is being treated experimentally, like a guinea pig.”

Elderly Focus Groups

8. *Cosponsored with Senior Services Center, Heartland Regional Medical Center, November 22, 2005. This group consisted of senior citizens and people working with senior groups.*

A. Concerns

- Family members need to avoid self-interest and focus instead on what the individual patient, their loved one, would choose.
- Who speaks for the patient? Who can step away from self-interest to act as patient advocate?
- The responsible physician needs to communicate the medical facts clearly.
- The responsible physician should also weigh these facts in view of the patient's values.
- The responsible physician needs to discuss these values with the patient or surrogate.

B. Futility

- "To me, it is whatever is useless."
- Treatment is futile when it entails suffering that far outweighs any benefits.
- In determining futility, the patient's own quality of life is critical, and medical facts need to be weighed in this context.
- Although there is always room for hope, hope should not be unreasonable.

C. Communication

- Spirituality is a critical dimension throughout communication.
- Spiritual guides or clergy can help to mediate and support, but [should] not offer answers.
- The responsible physician should shoulder the burden of making and conveying the medical determination.
- By sharing this medical determination with the patient, surrogate, and family, physicians can provide some measure of comfort by

making it clear that "the medical decision has been made—that they are not putting that burden" on others.

- The ethics committee can be an invaluable resource in communication and support.
- Institutional guidelines would be most useful.
- Communication should involve all parties.

D. Conflict Resolution

- "Explanation is everything."
- Timing is crucial. The family ought to be allowed sufficient time to work things out and garner support.
- There needs to be discussion among family members and with physicians before the matter becomes suboptimal.
- Pre-planning includes the need to discuss advance directives.
- Early and sustained education is essential and will affect awareness, attitudes, and decision making.
- For some participants, if there is no agreement, decision makers should err on the side of life.

"When my grandmother died, she was very religious and wanted everything done, but education changes things. A generation later, my parents didn't want all that. They had advance directives."

- Although cost factors should not determine the outcome, they remain relevant and need to be considered.

Faith-based Focus Groups

9. Cosponsored with the Greater Kansas City Interfaith Council, Shawnee Mission Medical Center, Shawnee Mission, Kansas, November 29, 2005. This group was comprised of faith leaders, ministers, and devotees in major faith traditions.

A. Concerns

- The alleviation of suffering is crucial.
- What the patient prefers is the primary concern.
- Prolonging bodily life is not an ultimate value.
- Even though there is a clear need for advance planning and advance directives, open, honest, and ongoing discussion among all affected persons is essential.
- There is a clear need for involving, if relevant, a spiritual caregiver.

Jewish perspectives

- Here is a test to apply in these situations: Is the illness permanent/terminal? Is the patient suffering? What does the patient want done?
- The key value is to act in ways that will relieve the patient's suffering.
- Act cautiously: withholding some treatments, including surgery for tube feedings, might lead to further suffering ("starvation").
- If surgery will alleviate or prevent suffering, it seems justified even if it does not prolong life.
- There is only a slight difference between "futility" and "terminal."
- There is a dignity in dying with as little suffering as possible, and this is something to strive for.
- One ought to avoid both doing something invasive to prolong life (and suffering) and acting in ways to end life prematurely.

Hindu perspectives

- Alleviating suffering is a primary value.
- We ought not to sustain bodily life if doing so comes at the cost of increased suffering.
- The body is a vehicle for the soul.
- This life is a transition from one body to the next, one life to the next.
- We should not do "everything" just to preserve this body, this life. Rather, we should do what [we can] to alleviate suffering, short of killing.

Baha'i perspectives

- One's purpose in life is to know and love God.
- We have two natures: one spiritual and one physical. The physical life is preparation for the spiritual, for transition to the next world.

"Making the transition from the physical world to the spiritual world is not expected to be an easy process."

Sikh perspectives

- A Sikh lives "as one who is going to die. We have to remember that we're here on this earth just to go on, and life is just another stage of going from one room to the next."

Christian Science perspectives

- We must not assume to know what suffering is like for any patient.
- Suffering is experienced differently by different people, and in some cases, it may lead a person to a higher state of consciousness in relationship with the Divine.

Rural Focus Group

10. *Cosponsored with Lafayette Regional Hospital, Lexington, Missouri, December 14, 2005. Healthcare professionals and residents in rural areas participated in this group*

A. Concerns

- Can the patient speak for himself?
- If not, who knows the patient well enough to speak for him?

B. Futility

- Treatment is futile if it does not improve the patient's quality of life, such quality to be determined by the patient.
- Prolonging life for its own sake without regard to quality is not an option.

C. Communication

- All those involved with the patient's care (patient, family, healthcare team, spiritual advisor) should meet and review the relevant facts.
- Clinicians need to recognize the importance of the patient's religious and or spiritual advisor, especially since decisions are not purely medical.

D. Conflict Resolution

- Clinical providers need to provide realistic options to the family in clear, honest, and sensitive terms.
- These options include an ethics committee consult, the transfer of the patient to another provider/institution, and a legal remedy as a last resort.

"It is important to determine how the patient views his or her own quality of life. The decision rests with the patient or patient's surrogate."

Palliative Care Groups

11. *Cosponsored with the Lawrence Memorial Hospital Palliative Care Team, October 6, 2005.*

A. Concerns

- Who can speak for the patient if the patient cannot speak for himself?
- It is critical to know the patient's view of his or her quality of life.
- It is critical to know whether the patient has a support system.
- It is critical to know more about family customs and connections to spiritual resources.

B. Futility

- Comfort care is never futile.
- Physicians need to avoid presenting the issue as simply a matter of either/or.
- Physicians must consider the whole person and not view the patient mechanistically as just an organ or part.
- Quantitatively, a 10 percent likelihood of recovery weighs in favor of continued treatment.
- If treatment offers no hope of recovery or cannot restore the patient to what he or she considers to be an acceptable quality of life, such treatment is futile.

"Perhaps we have so many conflicts about futility because of a prevailing tendency to medicalize the whole of life."

- The key question lies in what the patient wants and what the patient may consider as futile.
- The family can be helpful in discerning what the patient truly wants.

- There is a distinction between medical futility and “life futility.”
- Value judgments always enter in, so that adapting to the family’s notion of quality of life takes time.

“Futility is imposing care on a person for whom the outcome will be unacceptable . . . the patient would face an unbearable future from having her life saved.”

C. Communication

- Physicians and the clinical team need to initiate and sustain an open and honest discussion with the patient and family to learn how they would “characterize a good death.”
- Clear and honest communication is critical so that patient and family members can understand the diagnosis and prognosis, and weigh them in view of the suffering experienced by the patient.
- A realistic assessment should be made of the patient’s condition trajectory and the probable effects of further intervention.
- In guiding the family, the clinical team should not impose any agenda, but should enable families to make the decision their way. Physicians must be honest in providing the medical facts and effects of continued treatment.
- Guidelines would be most valuable.

D. Conflict Resolution

- Listening is the key. The clinical team needs to listen to the family, clarify when necessary, and give the family time to validate its decision.
- Communication must continue, and every effort must be made to bring the family and physician together.

- The clinical team must avoid a situation in which the various parties dig in their heels.
- Decisions cannot be rushed, but require time and patience.
- Providers must not only enable the family to process the situation; they should also be able to live with any decision the family makes.
- Clinicians need to encourage family members to discuss matters of death beforehand.
- For some, the value of suffering will be brought up, but again, we cannot take ownership.
- Futility is best dealt with on a case-by-case basis. We have to know our limits.

“A person’s dying is as special and individual as their being born.”

- Guidelines could be invaluable; they can be shared with the family as an institutional vehicle and guide for the family’s decision.
- The clinical team must constantly reassure the family that comfort care is never futile and will always be given to the patient.

12. *Cosponsored with Boone Hospital Center, Columbia, Missouri, December 9, 2005. Participants were members of the palliative care team.*

A. Concerns

- There must be an earnest effort to determine whether the patient can decide for himself. If not, then someone who knows the patient needs to speak on his or her behalf.
- It is most important that the patient’s values and life goals be respectfully and seriously considered.
- The family’s access to social and spiritual support must be given serious weight.

B. Futility

- Treatment is futile if it does not improve the patient's quality of life, and it is the patient who determines his or her own "quality of life."
- Treatment is futile if it does not alter the course for a dying patient.

C. Communication

- There must be open, honest, and clear communication —a conference — with all affected persons, namely, the patient, surrogate, family, health providers, social worker, and chaplain.
- During this conference, options need to be sensitively conveyed to the family to help them decide what the patient would prefer.
- During this conference, discussion should occur in a way that encourages family members to act on behalf of the patient, so that they are not imposing their own set of values.

"Sometimes confusion and misinterpretation occur because the providers haven't clearly indicated that the patient is dying."

D. Conflict Resolution

- Advance planning and advance directives can help to avoid, lessen, and address conflicts.
- In the absence of advance directives, the clinical team must meet collectively to discuss what and how certain options can be presented to the family.
- During this discussion with the family, it is critically important to know the family's goals and expectations regarding further treatment.
- In the course of discussion with the family, all relevant facts need to be clearly conveyed and properly explained.
- One important option: a time-limited trial if it is consistent with the patient's values.

"Consultation with the ethics committee is always an option, and often helps the family and clinical team find common ground."

- Another option: seek guidance from the institution's ethics committee.
- Prolonging life indefinitely is not an option.
- If all else fails, consult with hospital counsel.

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