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Working Toward a Definition of Futile Care in the United States Health Care System

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ABSTRACT

While end-of-life and palliative care measures are difficult subjects to address, decision-making for patients and family members becomes more complicated when there is a lack of understanding of when care is appropriate or when it is futile in nature. To date, there is no one definition of what constitutes futile care that is used by health care providers as they counsel patients and family members regarding what is appropriate care at the end-of-life. In fact, the recent debate and media coverage surrounding the Terri Schiavo case in Florida has brought this issue to a national concern. Thus the purpose of this independent study is to begin to develop and apply a definition of futile care and to discover if there are commonalities when a situation is thought to be futile.

The independent study used Imogene King's theoretical model, specifically the perception component of her model, to begin to define this concept. The study included an in-depth review of the current literature, both research-based and opinion articles to explore this issue. The goal of the study was to better define futile care in terms that health care practitioners and consumers of health care can understand and use in clinical settings. Implications for nursing would include better communications and improve care offered to patients in a variety of clinical settings, as patients at the end-of-life are seen in all clinical settings and among all age groups. By reviewing the literature on certain circumstances of the application of what is thought to be futile, a better working definition of futile care can be developed and patients and family members will hopefully become more informed decision makers. The study concludes with recommendations for nursing practice, research, education, and health policy.

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Working Toward a Definition of Futile Care in the United States Health Care System

Conflicting views on what is thought to be the application of futile care and actually defining futile care are becoming more complicated and increasingly important topics. Controversies arise due to lack of knowledge, whether by patients or their family members. Legal aspects regarding futile care also cause staff members to question the application of futile health care modalities. Defining “futile care” is something that may not be achievable, but with the advent of increasing numbers of “Shiavo” type cases, futile care needs to be explored and addressed as completely as possible.

The current health care climate offers unique opportunities to address the issue of futile care. Possible outcomes include the widespread use of advance directives, particularly the durable power of attorney for health care and cardiopulmonary resuscitation directives; the establishment of regional consortia for developing guidelines for the reasonable termination of care; and the use of patient registries and structured outcome studies to identify patients for whom treatment is likely to be futile. In addition to developing guidelines, regional consortia can serve as monitors for insurers or managed care plans that may attempt to limit care inappropriately (Parsons, Kobayashi & Gabow, 1994).

PROBLEM AND PURPOSE

The purpose of this paper is to begin to develop a definition for those patients who are seen as “non-benefiting” from treatment options. Different case scenarios where the situation was thought to be futile are presented, along with possible outcomes. In recent years, much attention has been given to conflicts that may occur when patients and their families insist on treatment that the medical staff feel is futile, sometimes defined as

care that potentates the patient's quantity of life, but not the quality of life. While end-of-life and palliative care measures are difficult subjects to address, decision-making for patients and families becomes more complicated when there is a lack of understanding in care, over-riding religion beliefs, and diverse health provider expectations that result in potential ethical dilemmas.

SIGNIFICANCE OF THE STUDY

The significance of the study was to review the literature to see if there exists a common ground among different cases, which will begin to form a definition of futile care. By doing so, this begins to better prepare healthcare providers and families members when the question of applying futile care is addressed and its potential psychological effects. Healthcare providers would then have a better understanding of a futile situation and can therefore educate all those involved in patient care with the difficult decision making related to end-of -life care.

THEORETICAL FRAMEWORK

Imogene King's theory of conceptual systems guided this descriptive, clinical study, dealing with the personal, the interpersonal, and the social aspects of futile care. Specifically, the perception component of her model guided the study.

First, a definition of perception:

- The process, act, or faculty of perceiving.
- The effect or product of perceiving.
- Recognition and interpretation of sensory stimuli based chiefly on memory.

- The neurological processes by which such recognition and interpretation are effected.
- Insight, intuition, or knowledge gained by perceiving (Ask.com, (2007 para.3).

Perceptions vary from person to person. Different people perceive different things about the same situation. But more than that, we assign different meanings to what we perceive. And the meanings might change for a certain person. One might change one's perspective or simply make things mean something else.

The central focus of King's framework is man as a dynamic human being whose perceptions of objects, persons, and events influence his behavior, social interaction, and health. King's basic assumption maintained that nursing is a process that involves caring for human beings with health being the ultimate goal. The concepts within the personal system and fundamental in understanding human beings are perception, self, body image, growth and development, time, and space. King viewed perception as the most important variable because perception influences behavior. King summarized the connections among the concepts in the following statement: "An individual's perceptions of self, of body image, of time and space influence the way he or she responds to persons, objects, and events in his or her life. As individuals grow and develop through the life span, experiences with changes in structure and function of their bodies over time influence their perceptions of self" (Williams, 2001, para. 2). It is important to understand that perception of what futile care is, as it can differ from individual to individual, thus creating the controversy of defining futile care. Since we are a society of multiple cultures and multiple faiths, herein lies the difficulty of coming to a group consensus of defining futile care.

RESEARCH QUESTIONS

The study explained the following research questions:

1. Can quality of life be measured?
2. Can futile care be defined?
3. If futile care can be defined, would the implementation of a futile care policy be beneficial for health care facilities?

DEFINITIONS

Futile- serving no useful purpose: completely ineffective (Merriam-Websters, 2006)

Quality of Life: An important consideration in medical care, quality of life refers to the patient's ability to enjoy normal life activities. Some medical treatments can seriously impair quality of life without providing appreciable benefit, while others greatly enhance quality of life (MedicineNet.com, 2007).

Medically Futile- (a) Futility means any treatment that, within a reasonable degree of medical certainty, is seen to be without benefit to the patient, as when the treatment at issue is seen as ineffective with regard to a clinical problem that it would ordinarily be used to treat. An example of this would be CPR for a patient with cardiac rupture or end-stage cardiogenic shock. (b) Futility judgments may also be made in such cases wherein treatment provides neither palliation, restoration or cure. An example of this would be hemodialysis or CPR for a permanently unconscious patient (Wear, Phillips, Shimmel & Banas, nd).

REVIEW OF THE LITERATURE

Case Study I: Mr. R is a 63-year-old male with a history of cardiac problems and cardiac angioplasty six years ago. On the day of admission, the patient suffered a cardiac arrest at home and was resuscitated by Emergency Medical System after about 20 minutes. The admitting diagnosis was anoxic encephalopathy. Two years later, the patient is in a critical care/step down unit in a persistent vegetative state on full life support. His wife and son visit and/or phone daily inquiring about his condition.

Case Study II: Katherine Lewis is an intelligent, unmarried, 40-year-old woman suffering from Guillain–Barré’s syndrome, a painful neurological illness that leaves its sufferers paralyzed for unpredictable lengths of time. Many people recover from the syndrome more or less completely and live long, relatively healthy lives. However, Katherine has been paralyzed for 3 years and, 10 months ago, it was recognized that she was unlikely to be able to move or breathe on her own again because of the extent of damage to her nerves and muscles; she now needs a ventilator to help her breathe.

Case study II, illustrates the relevance of questioning the value of a life, if for no other reason than that some people come face-to-face with the reality of asking this question about their own lives. The key consideration in end of life challenges is how that life is valued.

There are several reasons why one would request “futile-care. Some of those reasons include:

- Faulty reasoning, belief that doing the loving or right thing for the patient means

doing everything that is medically possible.

- Denial and guilt
- Unrealistic expectations
- Inability to trust professionals to act in the patient's best interest
- Religious conviction that life is to be preserved at all costs
- Economic considerations
- Entitlement mentality (Jacobs & Tylor, 2005 p.302)

An issue further complicating futile care delivery in the eyes of consumers is that some hospitals are promulgating "futile care" protocols that grant doctors the right to say no to wanted life-extending medical treatment for patients whose lives the physicians consider lacking in sufficient quality to justify the cost of care (Smith, 2000, para.1). Such policies, preserving palliative care delivery may be seen as removing decision-making from patient and family members.

A second issue at hand, is to view what quality of life is. The quality of life ethic puts the emphasis on the type of life being lived, not upon the fact of life. Lives are not all of one kind; some lives are of great value to the person himself and to others while others are not. What the life means to someone is what is important (Medical Ethics, n.d., p.109).

There is no current consensus on terms or concepts of what medical futility is. The American Medical Association's (AMA) Council on Ethical and Judicial Affairs has stated that denial of treatment "should be justified by reliance on openly stated ethical principles and acceptable standards of care" (Mareiniss, 2005, para.3). The AMA Code of Ethics further provides that this decision should not be based on "the concept of 'futility,'

which cannot be meaningfully defined.” In spite of this, several standards of futility appear in the medical literature (Mareiniss, 2005, para.3).

Who should have the right to decide whether one receives life-sustaining medical treatment during a critical or terminal illness? Most would say with great confidence, that the person directly affected by the situation should have the final decision, Or, if the patient is unable to decide, then family members should be consulted.

The incidence where situations of withholding and withdrawal of life support from critically ill patients’ has increased to the extent that these interventions now occur in well over half of all deaths in many intensive care units (Luce, 1997, para.2). Although the forgoing of life-sustaining therapy is ethically acceptable and clinically desirable in certain instances, and although physicians do not have a responsibility to provide what is thought to be considered futile care, even if a patient or surrogate insists on it, the physicians and primary care providers must be cautious in exercising their influence, if not authority, over patients and surrogates in prompting the withholding and withdrawal of life support. Such caution is particularly indicated because managed care has made patients suspicious of health-care institutions and physicians who are rewarded for restricting access to care. Most patients and surrogates agree with reasonable physician recommendations to forgo life-sustaining therapy. When they do not agree, physicians should not limit care on the basis of their own personal notions of what they think is futile, but should instead rely on institutional or multi-institutional futility policies. Such policies should be developed by health professionals, patients, community leaders, and, when appropriate, participants in managed-care organizations. They should

specify which treatments and interventions are beneficial, address potential conflicts of interest, and be available to persons who could use such information in selecting the source of their care (Luce, 1997).

Futile Care Theory is not a "theory," but a purposeful mislabeling of a body of ethical problems that generally pertains to the difficulty of defining "futility" in terms that could be applied to treatment guidelines and to the ethical difficulty (though it is inescapable) of introducing "prognosis" and "quality of life" into policy decisions about allocating resources. Merely because a viewpoint is raised by an advocate is not a reason to dismiss it. On the contrary, compelling problems (both personal and public) about the benefits of care lie at the core of medicine and are openly confronted in managed care. There is little difference logically when asking if a treatment is "futile" compared to asking when it is "beneficial." This question is inherent in every recommendation from a clinician; every informed consent faced by a patient; every coverage policy from an insurer; every malpractice judgment; every research trial; and every decision to stop cardiopulmonary resuscitation.

"Futility" versus "benefit" is the fundamental problem of medical therapeutics (Victoroff, 2004). At some point, is it wrong to say that a patient may benefit from the application of futile care? They are not necessarily opposite. When a patient is at a point where he/she no longer will benefit from any type of medical treatment, it may be beneficial that a futile care policy would be in place so as to further reduce any type of suffering. In a study by Meltzer and Huckabay (2004), reasons for nurses' engagements in these practices of futile care included an overwhelming sense of responsibility for patients' welfare, a desire to relieve patients' suffering, a sense of frustration due to lack

of physicians' responsiveness to that suffering, and concern about the excessive use of life-sustaining measures near the end of life.

Futility is a complex concept associated with the accomplishment of goals. An act is considered futile if its goals are not achievable or its degree of success is empirically implausible. Among the challenges presented by futile care is its effect on professional caregivers. Medical investigators have articulated concern about over treatment of dying patients and the negative effect of such treatment on staff members. In a survey of 759 nurses and 687 physicians by Meltzer & Huckabay (2004), 50% of nurses, 30% of attending physicians, and 70% of house staff reported treating patients against the caregivers' standards and conscience. Treatments particularly stressful include cardiopulmonary resuscitation, intubations and the insertion of central lines and insertion of feeding tubes and nasogastric tubes.

According to a 1991 survey by the American Association of Critical-Care Nurses, (Ferrell, 2006), of 1100 critical care nurses across the United States, ethical dilemmas were among the most difficult issues encountered. One half of the participants rated the decision to withdraw or withhold life support as the second most significant issue in their profession; the most significant issue was authority to make decisions about patients, which was 69%. It was reported that critical care nurses were concerned that patients received meaningless and excessive care. Much less attention has been focused on the human impact on nurses caring for patients for whom they believe treatment is futile. Discourse in the field of ethics has begun to recognize that participation in medically futile efforts undermines the core of nursing practice and creates moral distress that is destructive to individual nurses and to the profession (Ferrell, 2006).

It is the healthcare professional's duty to advise and guide patients and families through this difficult time based on the provider's clinical expertise. Consideration has to be made with regard to saving lives but also to the prevention of suffering. Issues of futility have varying meanings in a personal context for patients and families and raise significant emotional responses and frustration by staff. Nurses and other healthcare professionals should recognize that their perspectives on the best treatment decisions are based on years of experience and education, whereas most patients and families are facing life and death decisions with little or no previous information or experience (Ferrell, 2006).

The determination of medical futility can be made only within the context of the individual clinical situation. For example, performing cardiopulmonary resuscitation on a patient with multiple organ dysfunction would be a "physiologically" futile act, and cardiopulmonary resuscitation may be withheld on these grounds because the probability of success is truly zero; moreover, resuscitating a patient whose chances for survival are small, but existent, would not be considered futile care. Controversy exists, of course, on whether heroic treatments in cases such as the first example are to be viewed as prolongation of life or prolongation of dying. This issue has no easy or correct answer (Meltzer & Huckabay, 2004).

What situations are considered futile? In Katherine Lewis' case, she was an intelligent 40-year-old woman, who unfortunately suffered from Guillain-Barré's syndrome. With little or no chance of recovering at this point, being able to breathe on her own or move her extremities, she recognized that she was never going to be satisfied with this type of life. This she viewed as a poor quality of life.

The clinical course and outcome of a persistent vegetative state depend on its cause. Three categories of disorder can cause such a state, including acute traumatic and non-traumatic brain injuries, degenerative and metabolic brain disorders, and severe congenital malformations of the nervous system (“Medical Aspects of the Persistent Vegetative State,” 1994).

Recovery of consciousness from a posttraumatic persistent vegetative state is unlikely after 12 months in adults and children. Recovery from a non-traumatic persistent vegetative state after three months is exceedingly rare in both adults and children. Patients with degenerative or metabolic disorders or congenital malformations who remain in a persistent vegetative state for several months are unlikely to recover consciousness. The life span of adults and children in such a state is substantially reduced. For most such patients, life expectancy ranges from 2 to 5 years; survival beyond 10 years is unusual (“Medical Aspects of the Persistent Vegetative State”1994).

The complicated legal battle surrounding Terri Schiavo received great attention in the national press. Issues of patient autonomy and bioethical concerns sparked debate over legal and ethical standards of review. Terri Schiavo suffered a myocardial infarction in 1990. The event resulted in prolonged anoxic brain injury and left her in a persistent vegetative state (Mareiniss, 2005). According to Perry, Churchill and Kirshner (2005), persistent vegetative state is distinguished from several other states of reduced consciousness. Brain death implies the loss of not only all higher brain functions but also all brainstem functions, including papillary light reflexes, reflex eye movements, respirations, and gag and corneal reflexes. Determination of brain death is straightforward and is generally accepted as a criterion for death. Coma is a complete

state of unresponsiveness to stimuli, although the patient may have brainstem reflexes.

Requirement for the Examination and determination of one in a persistent vegetative state include:

- No evidence of awareness of self or environment, no interaction with others, no meaningful response to stimuli
- No receptive or expressive language
- Return of sleep-wake cycles, arousal, even smiling, frowning yawning
- Preserved brainstem/hypothalamic autonomic functions to permit survival
- Bowel and Bladder incontinence
- Variably preserved cranial nerve and spinal reflexes. (Perry, Churchill & Kirschner, 2005 p. 747).

Vegetative state can be diagnosed at one month after an acute brain injury or hypoxia, and the permanent vegetative state can be diagnosed after three months in patients with non-traumatic brain injuries and after twelve months in patients with traumatic brain injuries (Perry, Churchill & Kirshner, p.744, 2005).

Another bioethical concept that appears to directly conflict with the principle of autonomy in the Schiavo case is medical futility. Ironically, in her case, futility seems to favor the proxy's directive to discontinue care. This is unusual, because discontinuing treatment on the rationale of futility usually is in opposition to autonomy and is seen as the ultimate paternalistic act. Futility is a concept rooted in ancient Hippocratic text, which establishes the point at which further medical care should be deemed futile. This concept was one of the three fundamental principles that Hippocrates declared for the practice of medicine: to cure; relieve suffering; and refuse to treat "those who

are overmastered by their disease”(Mareiniss, 2005, para 7). It is a common thought in some medical establishments and practices that "futile treatment " is to be dismissed as it is seen as illogical to continue treatment of a patient if the resultant effect of that treatment will seemingly fail to establish any possible effect (Manoj, 2002). A discussion found on an Internet based Bioethics Discussion board discussed a terminally ill AIDS patient who was dragged out of a pitiable state, and later denied full medical services which included Intensive Care, on grounds of "futile care." The resultant effect of the discussion ruled in favor of the physicians' decision to suspend treatment. The justification was sought out through a reference from the Hippocratic Oath itself. It was pointed out that the Hippocratic Oath justifies the physicians' right to suspend treatment if the outcome is to be of no purpose, i.e.... futile. Thus, the Hippocratic Oath strikes a critical review (Manoj, 2002, para 5).

The Schiavo case demonstrates the difficulty in making a decision of whether or not her situation is deemed futile because based on families perception of her state and quality of life, each person has their own opinion and beliefs of what should happen. Was she in a persistent vegetative state? According to the above guidelines, yes. Having a policy in place defining what futile treatment is prior to her having this unfortunate event may have eliminated the intense debate that followed.

In the late 1980s and early 1990s, the concept of medical futility as a basis for unilaterally withholding or withdrawing medical treatment provoked great controversy in American medicine. Proponents of medical futility stated that health care providers have the right to deny care that is deemed futile (Mareiniss, 2005, para 4).

SUMMARY

If the principle of medical futility is to be used in clinical practice, the concept must be defined clearly with adequate outcome data or experience to support it. Any determination of futility should be discussed with the patient and or family members (Curtis & Burt, 2003). "Futility" is not a straightforward or univocal topic. The question of when treatment should be discontinued from cases with little or no hope of benefit is a highly faceted issue, a moving target as biotechnology and delivery systems change. Although it overlaps the territory of "advance directives," the "futility" problem is grounded almost entirely in the difficulty of proxy decision making for vulnerable persons, where "autonomy" is not the driving concern. There is no "theory" that tells us how to do that (Victorof, 2004). The concept of medical futility is difficult to grasp let alone define, due to the fact that there are so many values and beliefs that differ amongst all people.

NURSING EDUCATION AND PRACTICE

Implications for nursing practice based upon this discussion are numerous. In addition to planning and delivering nursing care, nurses have a responsibility to keep patients and their families free of harm. Informed families are the exception rather than the rule in most cases, and clinicians' communication can be seen as inadequate, or non-fulfilling. Nurses and physicians underestimate the information needs of those whose care or treatments are seen as non-benefiting. Caregivers frequently lack the skills to communicate complex medical information or are unable to address a family's emotional needs. Attempts to communicate are often ineffective: half of family members fail to understand even basic information about the patient's diagnosis, prognosis, or treatment.

As a result, anxiety and confusion among family members may be widespread.

Communication with families has been "consistently identified as the most important and least accomplished factor in quality of care" by family members of critically ill patients.

In two studies of families of deceased patients, concern over communication with the medical staff was the family's number one complaint (Uptodate.com, 2007, para 3). By not having a working definition of what "futile care" means, it is difficult to give the best possible care to patients and their families. It creates confusion and becomes a very complex problem if one is seen as being non-benefiting from treatment by the caregiver, and the families' feelings differ. In effect, a policy could do what amounts to a detailed clinical protocol regarding proper response to and management of such troubling cases.

By developing and implementing a futile care policy for medical staff and all involved in primary care of patients whose situation is deemed futile, the hope would be that there would be less controversy between patients and their families and medical personnel when a situation is defined as futile. Educational in-services could be given along with educational materials to patients and family members upon admission.

FURTHER STUDIES AND INVESTIGATIONS

Further studies could be done post futile care policy implementation to see if there have indeed been fewer controversies when patients, families and caregivers are involved in medical situations that are difficult and seen as futile or non-benefiting. A study could be done with critical care nurses who now use a futile care policy to see if they have less burnout than prior to a policy being put into place. Further research could focus on older persons, who often have multiple chronic illnesses or geriatric syndromes that make the

management of care challenging. Furthermore, older adults are faced with increasingly complicated decisions about care giving, end-of-life preferences, and how to relieve the impact of inter-generational care on families and friends. We can seek to support research that improves our understanding of patient, family, and provider preferences with respect to futile treatment, advance directives, care at the end of life, genetic testing, and optimal systems of care and also seek to support research that addresses the appropriate and effective use of new medical technologies and interventions for those seen as non-benefiting, with an emphasis on the development and testing of new quality of life measures (“The AGS Foundation for Health in Aging”,1999).

POLICY

By having a policy in place, this should greatly lessen the burden of healthcare providers by having something that is set up and in place to explain to patients and family members. An example of a futile care policy is:

The judgment that a given treatment, or aggressive treatment in general, is medically futile may be made by the patient's attending physician and treatment unilaterally withheld or withdrawn without patient or surrogate consent when the following steps have been accomplished:

1. Another attending physician, other than a physician member of the VAMC Ethics Advisory Committee (EAC), has concurred with the futility judgment.

2. Two members of the Ethics Consultation team or the EAC have consulted on the case.
3. The Chief of Staff concurs with the judgment of futility.
4. The patient or, if incapacitated, the patient's surrogate, has been notified of this judgment and has been appropriately counseled as to its implications.

After completion of the process described above, but before the proposed action is taken, the attending physician will inform the patient, the patient's legal representative or surrogate, of the options open to them:

- a. that the patient may be transferred to another facility;
- b. that the cost of arrangements for such transfer will be borne by the patient, the patient's legal representative or surrogate; and
- c. that the patient, the patient's legal representative or surrogate has the right to challenge the decision by petitioning the appropriate court to enjoin the Medical Center from abating the action(s) it has determined to be medically futile.

Given the serious and unilateral character of such judgments, a formal hearing by the Ethics Advisory Committee should generally also occur between steps 2 and 3, TIME PERMITTING. In any case, a full retrospective review of any such futility judgment must be conducted by the Ethics Advisory Committee at least by its next monthly meeting.

Aside from incorporating the input of relevant parties in the process, the aims of the policy include making sure that the futility claim is well based scientifically (step #1: concurrence by another attending physician), confirming that adequate counseling had already been attempted toward removing the disagreement (step #2: consultation by EAC members), and securing institutional support (step #3: approval by Chief of Staff). Conclusion of the process without formal EAC review was contemplated only in emergent and clear situations, e.g. cardiopulmonary arrest consequent to end stage cardiogenic shock (Wear, et al., n.d., para.18).

An example of a midwestern policy for futile treatment follows:

Number: 2120

Policy: Medically Futile Treatment

Effective: May 2, 2005

Purpose

To assist healthcare providers in decision-making regarding medically futile treatments; to affirm the moral and ethical appropriateness of forgoing medically futile treatments; to ensure that the decisions to forgo treatment focuses on respect of the patient and on the minimization of suffering and indignity; to provide institutional guidelines that ensures a fair process at resolving conflict over medically futile treatment.

Policy

- A. It is the policy of Altru Health System that patients have the right to accept or refuse interventions once the requirements of informed consent are met. Patients have the right of self-determination to control their own medical treatment, but they do not have an absolute right to demand any medical treatment they happen to choose. Physicians have a duty to practice medicine responsibly. They are called to use professional norms, standards, and values as guidelines in making judgments on the appropriateness of medical interventions involving their patients. Thus, physicians are not required to offer an intervention, and may refuse a request for same, if the intervention is medically ineffective or contrary to generally accepted healthcare standards. A once effective intervention may become medically futile due to a change in the patient's condition or goals of treatment.
- B. Should a conflict arise between the primary physician, other healthcare providers, and the patient or his/her agent, legal guardian, or surrogate (hereafter referred to as authorized decision-maker) on the decision to forgo medically futile treatments, the procedural steps set forth in this document may be implemented by any of the involved parties.
- C. If all procedural steps are followed, and it is determined that a treatment is medically futile, the physician should be encouraged and supported in the transition to palliative care.

Definitions

Medically futile treatment: Any course of treatment that confers no beneficial outcome or is medically ineffective and contrary to generally accepted healthcare standards may be considered medically futile. For example, performing CPR on a patient with widely metastatic, end-state cancer could be a medically futile course of treatment. Declaration of a treatment as medically futile should initially be left to the patient's attending physician in consultation with attending specialist physicians as appropriate. Physicians shall base their judgments on prevailing standards of medical care, recognizing the uniqueness of patients and diseases and weighing the relevant medical literature, opinions of consultants, clinical experience, patient's wishes, and patient's determinations of quality of life.

Resource consumption, inability to pay, or rationing are not legitimate criteria to be used in defining medical futility.

Palliative care: Palliative care is never futile. Palliative care relieves pain and suffering while providing comfort and dignity to the patient and family. Palliative care neither hastens death nor prolongs life but allows a sense of control for the patient and family. Palliative care is an approach that improves quality of life of patients and families facing life-threatening illness by:

- Prevention and relief of suffering
- Assessment and treatment of pain and other symptoms
- Addressing psychosocial and spiritual needs as well as physical needs
- Uses the interdisciplinary team approach.

Procedure

In keeping with professional standards, especially those found in the American Medical Association Policy E-2.037 *Medical Futility in End-of-Life Care*, the following procedure is offered to direct physician interactions.

- A. When a physician considers a current or requested course of treatment to be medically futile, the physician should inform the patient or authorized decision-maker of the following:
 1. The nature of the ailment, the prognosis, the reasons why the intervention is medically futile, the options including palliative care and hospice. This should include a discussion of the goals of care.
 2. The assistance of a third party, such as a second physician, nurse, social worker, chaplain, ethics consultant or informed relative, may be sought to facilitate the patient's or authorized decision-maker's understanding and acceptance of the physician's explanation.
 3. Forgoing medically futile treatment does not constitute abandonment; rather it reinforces the commitment to continue the provision of palliative care.
- B. The primary physician should document in the patient's chart that the intervention under consideration is inappropriate and a discussion with the patient or authorized decision-maker has occurred.
- C. Exceptional reasons may exist for providing futile treatment for short periods of time in order to provide special accommodations to the family.

- D. Other healthcare providers (e.g., nurses, consultant physicians, etc.), who in their clinical judgment believe a treatment to be medically futile, may directly refer the case to the hospital Ethics Committee. These healthcare providers should discuss their assessment directly with the primary physician prior to referral.
- E. Conflict resolution.
1. Communication: Every effort should be made to resolve conflicts about providing futile therapy through respectful discussion among the parties involved in the dispute.
 2. Second opinion: If, after reasonable effort, agreement is not reached between the primary physician and the patient or authorized decision-maker regarding medically futile treatment(s), the primary physician is encouraged to obtain an independent medical opinion. This second medical opinion should be from a physician who has personally examined the patient and signed a note documenting his/her findings in the chart.
 3. Hospital Ethics Committee: If disagreement about the provision of futile treatment continues, the case should be referred to the hospital Ethics Committee for review.
 - a. If the committee's decision coincides with the patient's desires but the physician remains unpersuaded, arrangement will be made for transfer to another physician within the institution.
 - b. If the committee's decision coincides with the physician's judgment but the patient remains unpersuaded, arrangements for transfer to another institution may be sought. The accepting

institution and physicians should be willing to honor the patient's or authorized decision-maker's wishes.

- c. If transfer is not possible because no physician and no institution can be found to follow the patient's or authorized decision-maker's wishes, the intervention in question need not be provided.
- d. Prior to discontinuation of treatment, the patient or authorized decision-maker should be informed of their right to seek legal assistance.

ESTABLISHED DATE: July 27, 2004

CONCLUSION

A difficult ethical dilemma in the medical setting is determining when to withdraw or withhold treatments deemed medically futile and the actual definition of the concept of medical futility. These decisions are particularly complex when health care providers lack guidance with these discussions involving futile care. When families and providers disagree about benefits from treatment, it is usually because there are cultural differences, different religions; and amongst other issues, can create misunderstandings.

It is well established that there is no ethical obligation for health care providers to apply treatment that is futile. The question, however, is what constitutes futile treatment and how do we define it? Unfortunately, medical futility can have several meanings to different people. Failure to clarify the term can lead to miscommunication and masking of differing value judgments and biases, thus creating controversy.

Medicine cannot always achieve its desired goals. I would hope that health care professionals would not banish the "language of futility" because it is difficult to define,

but to examine that language more deeply and to look at the roots of the practice embedded in that language. Words that are central to health care, such as "heal" (which means "to make whole") and "patient" (which comes from the Latin "to suffer"), suggest that the goal of medicine is not merely to achieve a means, such as restoring heartbeat, unless that means leads to the end of healing the patient (Schneiderman, Jecker, & Jonsen, 1996).

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