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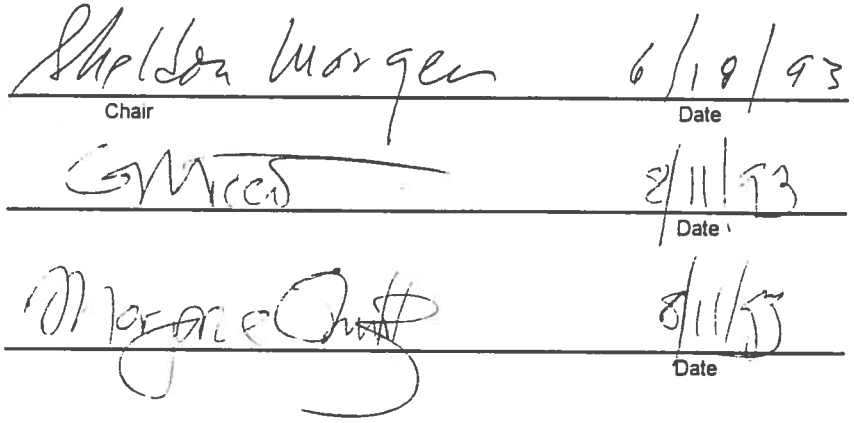

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Medical Futility: Legitimate Argument or Sophistic Reasoning?

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Carrie Adelia Sims

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"Whenever therefore a man suffers from an ill which is too strong for the means at the disposal of medicine, he surely must not even expect that it can be overcome by medicine".[1]

The justification for withholding or withdrawing care based on medical futility is not a new argument to medicine. Indeed, even in the days of Hippocrates, physicians attempted to distinguish when they could in good conscience apply their medicinal arts and when such application was misplaced. Being familiar with the intricacies of health and disease, physicians were in the best position to determine when the art of medicine would produce benefit and when such an attempt would be fruitless; attempting a hopeless cure was to display an ignorance "allied to madness".

Hippocratic medicine, however, was more than an healthcare occupation; it was a cultic devotion to "the art" in which "special cultic values like purity and holiness heavily influenced the interpretation of what would count as benefit."[2] The love of medicine and its ethos of healing held spiritual value to the practitioner. To administer "the art" was almost a religious experience. By taking the Hippocratic Oath, a person was committed to using one's knowledge to benefit the sick and to protect them from harm. With these goals in mind, to use the skill otherwise was akin to heresy.

While the practice of medicine has continued to have "quasi-religious overtones"[3], technical developments in the 19th century helped transform medicine from a healing trade into a scientific profession. With new diagnostic instruments like the stethoscope, microscope, and bacteriologic tests,

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[1]Hippocrates, "The Art," in Ethics in Medicine: Historical Perspectives and Contemporary Concerns, ed. by S.J. Reiser, A.J. Dyck, and William J. Curran (Cambridge, Mass.: MIT Press, 1977), p. 6.
[2]R.M. Veatch, A Theory of Medical Ethics (New York: Basic Books, Inc., 1982), p. 21.
[3]ibid., p. 22

physicians were able to observe objectively the disease process, confer on findings with their colleagues, and prognosticate with new accuracy.

As the guilds of physicians gave way to medical societies, the objectivity of science lent new legitimacy to the medical profession and a new sense of professionalism emerged.[4] As a profession, medicine gained a sense of autonomy in that it had "the exclusive right to determine who (could) legitimately do its work and the work that should be done."[5]

This notion of professionalism has become even more prominent in modern American medicine, setting the stage for the current futility debate. As medical technology has become more sophisticated, so too has the physician's role. Serving as both caregiver and skilled technician, the modern physician controls the administration of new technical developments. Yet, medical advancements have challenged society to reconsider definitions and moral beliefs about life and death, calling into question the physician's authority to control life-sustaining technology. In response, physicians argue that medical decisions, especially those concerning life and death, ought to be based on the expertise and knowledge gained by years of study, experience and insight. Moreover, because the goals of medicine are consonant with technologic advances, those with inherent insight into the worthy ends of the art, namely physicians, ought to be the ones making decisions concerning the application of medical advances.

This view, however, is at odds with another strong, although newer, concept of patient autonomy. Under this premise, the patient has ultimate control over his or her body, and decisions regarding health care are to be made

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[4]Paul Starr, The Social Transformation of American Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry, (New York: Basic Books, Inc., 1982), p. 136-138.
[5]E. Friedson, "The Profession of Medicine," in: Law, Science and Medicine, ed. by J. Areen, P. King, S. Goldberg, and A. Capron. (New York: The Foundation Press, Inc., 1984) p. 260.

in terms of their own particular goals and beliefs. While the physician may present various therapeutic options, respect for autonomy requires that the physician treat the patient in such a manner that allows or enables the person to make meaningful choices. Ideally, these choices should be free from controlling interferences or personal limitations.[6]

Generally, the notion of professional integrity and patient autonomy peacefully co-exist, primarily because the physician and the patient or the patient's family usually agree on therapeutic options and treatment plans.[7] Thus, loud and public disagreements about the futility of continuing life-sustaining therapy are rare. One cannot assume, however, that the paucity of disagreements represents a display of harmonious and equal decision-making.[8] While the expressed or implicit desires of the patient and physician may be in alignment, the motivations may be based on entirely different values and beliefs. Furthermore, some would argue that the power differences within the patient-physician relationship make the concept of "patient autonomy" virtually non-operational. Patient "choices" concerning therapy, therefore, may merely reflect the values, beliefs, and motivations of the physician.[9]

The notion of professional integrity and patient autonomy, however, collided in 1991 when a family in Minnesota challenged their physician's decision to terminate life-sustaining therapy. This complex story that sparked a

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[6]T.L. Beauchamp and J.F. Childress, Principles of Biomedical Ethics, (New York: Oxford University Press, 1989), p.68.

[7]According to Webster, integrity is defined as "an uncompromising adherence to a code of moral ...values" and professional integrity can be understood as a synthesis of Hippocratic devotion to "the art" with the claim to certain professional privelages. See Webster's New World Dictionary, Second College Edition, ed. by David Guralnik, (New York: The World Publishing Co., 1972), p. 732.

[8]M. Danis, L.I. Sutherland, and J.M. Garret. A prospective study of advance directives for life-sustaining care. *N Eng J Med.* 1991;324:882-888. This study demonstrated that patient preferences were respected as long as the doctor felt that the patient's choices resulted in the best decision.

[9]D. Orentlicher. The illusion of patient choice in end-of-life decisions. *JAMA.* 1992;267:2101-2104.

national debate concerning "futile" care began when Helga Wanglie, a spry 86 year old, fell and broke her hip. During her convalescence, she developed a respiratory infection which was complicated by underlying lung disease and was placed on a respirator. Following a turbulent hospital course in which she suffered two cardiac arrests, Mrs. Wanglie fell into a persistent vegetative state that her physicians believed to be permanent. Given the irreversibility of the situation, Mrs. Wanglie's physicians believed that life-support should be terminated and that to continue care would violate their sense of professional integrity. The Wanglie family disagreed.[10] When it became obvious that the medical provider and family were not going reach a consensus, the physicians turned to the courts for resolution.

It is interesting to note that the issue of whether or not a physician has the authority to deny life-sustaining care to those for whom he or she feels such care would be inappropriate was not presented to the courts. Rather, the hospital challenged that Mr. Wanglie was not fit to be his wife's conservator. The judge, finding no evidence that Mr. Wanglie was unable to perform the duties of a conservator, denied the petition. Furthermore, she reaffirmed the authority of the spouse as legal surrogate stating that such decisions are best left to the family when they are competent. Because Mr. Wanglie was "in the best position to investigate and act upon Helga Wanglie's conscientious, religious, and moral beliefs"[11], his substituted judgment was the best means available to protect Mrs. Wanglie's right to autonomy.[12] Mrs. Wanglie died three days later.

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[10]Although there is some confusion as to whether or not Mrs. Wanglie made her wishes known prior to becoming incapacitated, it is clear that she was a devout Lutheran, a minister's daughter and married to the same man for 56 years - facts that are not incongruent with Mr. Wanglie's substituted judgment that life support should be continued. For more information, see T. Kennedy, "Ruling will keep woman, 86, on respirator, *Boston Globe*, July 2, 1991, p. 3.

[11]M. Hansen, "Doctor's assert patient's right to die," *ABA Journal* , Oct. 1991, p. 26-27.

[12]When making decisions for incompetatnt patients, the standard of substituted judgement requires that the decision-maker attempt to reach the decision the incompetant person would

While those intimately involved in Mrs. Wanglie's care did not use the term "futility" *per se*, the case certainly fit within the larger scheme of withdrawing or withholding treatment the physician considers inappropriate.[13] Others, however, characterized the conflict in terms of the physician's prerogative to withhold or withdraw treatment deemed futile and supported the right to refuse treatment that violated professional integrity.[14] That is, physicians should not be required to provide medical care that does not benefit, or indeed harms, their patients. To do so would devalue the practice of medicine.

At first glance, the "futility" argument appears straight-forward and obvious: if the treatment is not going to work or benefit the patient, why bother? In fact, one might argue that initiating such treatment would constitute an ethical violation of *primum non nocere* - first do no harm.[15] Contributing to a therapeutic process that cannot possibly come to any benefit subjects a patient to unnecessary and sometimes painful procedures. Moreover, it would be cruel to allow a family to entertain hopes for an impossible outcome.

Closer examination, however, reveals that the argument for terminating life-sustaining care based on medical futility is far from obvious. While it is easy to accept that physicians should not be required to do what is physiologically

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have made if cognizant. That is, the decision should be based on the person's previously expressed values and beliefs.

If the incompetant person has never been competant (e.g. infants) the best interests standard is generally used. Under this principle, the decision-maker tries to make an objective assessment of what would be best for the patient taking into consideration issues of pain and suffering, prognosis, quality of life, etc. See Law, Science and Medicine, edited by J. Areen, P. King, S. Goldberg, and A. Capron. (New York: The Foundation Press, Inc., 1984), p.1163, 1165.

[13]Respiratory support was considered "non-beneficial" in that it could not cure Mrs. Wanglie's pulmonary disease, relieve her suffering, or return her to a conscious state. The respirator could prolong her life and, therefore, could not be considered "futile". S.H. Miles. Informed demand for "non-beneficial" medical treatment. *N Eng J Med.* 1991;325:512-515.

[14]T. Tomlinson, H. Brody. Futility and the ethics of resuscitation. *JAMA*. 1990; 264:1276-1280.

[15] Although this is often attributed to Hippocrates, Veatch argues that the principle of not harming superseding the principle of beneficence has its roots in Western thought. The emphasis in "The Epidemics" is not on avoiding harm and states "As to diseases, make a habit of two things --to help, or at least do no harm." see Veatch, A Theory of Medical Ethics, p. 159-162.

impossible, the term "futility" can be used in a variety of contexts. To some the term implies statistical improbability, to others it connotes an assessment of benefit. Without a universally accepted definition of the term, the notion of futility "hides many deep and serious ambiguities that threaten its legitimacy as a rationale for limiting treatment."[16] Furthermore, by characterizing the argument in terms of medical judgment, the value choices and beliefs inherent in decisions to terminate care are ignored. Indeed, the very way in which the argument is framed implies a relationship in which there is a winner and a loser; a situation in which a demanding patient or family must concede to the authority of the physician. In essence, the use of the term sets the stage for a relationship that has already failed. The question then becomes: if futility is not an objective assessment of what can or cannot be expected physiologically, what ethical problems does using "futility" as a justification for terminating or denying life-sustaining care raise?

This thesis will explore the issue of medical futility as a justification for denying care from an historical, legal, and ethical perspective in an attempt to answer two fundamental questions: why do patients "demand" futile care and why do physicians claim the right to deny this care. In order to address these questions, I will investigate the events and circumstances that have contributed to the increasing use of "futility" as a justification for denying life-sustaining care. In particular, how has the patient-physician relationship changed in response to an increasing dependence on technology, the changing economic structure of medicine, and the emergence of rights theory? How have these changes influenced the futility debate? I will also explore patient autonomy and the physician's responsibility to incompetent patients from a legal perspective,

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[16]R.D. Troug, A.S. Brett, and J. Frader. The problem with futility. *N Eng J Med.* 1992;326:1560.

demonstrating that the legal right to deny futile care without patient consent is, at the very least, a tenuous assertion. Lastly, I will investigate the ambiguities, assumptions, and problems that make this a less than ideal way of addressing patient-physician conflict. In the final analysis, I believe that the medical profession cannot ethically use "futility" as a justification for unilaterally withholding or withdrawing life-sustaining care.

Chapter 1:
Historical Perspective

If the impetus behind the use of "futility" as a rationale for limiting life sustaining therapy is to be understood, it can only be understood by investigating the historical development of the patient-physician relationship. Over the course of the last century several factors have converged to reshape the medical experience such that patients are less likely to trust their physicians' judgment of medical futility. With an increasing dependence on technology and the consequent subspecialization of the medical field, the patient-physician relationship has become a more "depersonalized" and less intimate experience. Changes in the economic practices of medicine have also served to distance the physician from the patient by creating an overall aura of business rather than one of beneficence. Finally, the emergence of rights theory as a method for delineating the responsibilities inherent within the patient-physician relationship has served to dispel any romantic notion of the therapeutic bond. Essentially, these factors have lead to the breakdown of the traditional patient-physician relationship and with this breakdown a sense of distrust and disempowerment of the medical profession has emerged. Patients are less likely than they were in the past to trust their physicians implicitly. They question medical authority, take a more active role in their healthcare decisions, and make demands on their clinicians. The increasing use of the term "futile" and the vehemence with which physicians assert their professional prerogative may reflect a backlash to this loss of prestige and authority. This section will investigate how advancing technology, the changing economy and the development of rights theory have contributed to the emergence of the futility debate.

A. Science/Technology:

The art of medicine has a precarious relationship with science and technology. On the one hand, advances in science have helped promote the ends of medicine by curing disease, improving health, and delaying death. On the other hand, the impassioned pursuit of medical knowledge with its associated technology has sacrificed the patient as person. That is, in the name of science the patient as a human being worthy of dignity and respect has been forsaken. In both research and teaching situations, patients are often used as means rather than being treated as valuable ends unto themselves.[17] An over reliance on technology has also served to create an impression of the medical encounter as alienating, uncaring, and sterile. The de-personalization of medicine coupled with a perceived lack of compassion has generated patient distrust; and without trust, the therapeutic relationship is less than functional. As scientific advances presented new ethical dilemmas, patients were less likely to trust their physician to make these life and death decisions alone and the professional authority that physicians previously enjoyed began to lose its influence. In the final analysis, the zealous pursuit and over-dependence on science and technology have contributed to the futility debate by creating an environment where trust has been eroded.

Traditionally, medicine has been practiced in order to benefit the sick; to either return them to a state of health or to ease their suffering. Even when new therapies or procedures were attempted, the effort was under the premise of

[17]According to Immanuel Kant, a person's autonomy is violated if they are treated merely as means and not as ends. Because all persons have unconditional worth and the capacity to design and direct their own destiny, respect for autonomy requires that a person be treated in accordance with that person's goals. See T. Beauchamp and J. Childress, Principles of Biomedical Ethics, p. 71-72.

benefiting a particular patient.[18] Within the context of the therapeutic relationship, a patient presumably could trust that the physician was working with his or her best interests in mind.

In 1966, Dr. Henry Beecher shattered this illusion by publishing a report that exposed several instances of ethically dubious research involving human subjects. Citing 22 cases, ranging from withholding known effective therapy from patients with streptococcal infections to inoculating hospitalized patients with live cancer cells, Beecher's investigation revealed that participating patients were often not aware of the risks involved in the research. In fact, many were not even aware that they were research subjects in the first place. Moreover, unlike previous medical research in which the patient stood to potentially benefit, many experiments were not only nonbeneficial to the subjects, some were actually quite harmful.[19]

Beecher's expose revealed that patients' interests were often sacrificed unconsensually in the name of science. More importantly, however, it informed the public that the one person they trusted to care for their needs when sick and vulnerable, namely the physician, was potentially the perpetrator of uninvited experimentation and, therefore, not trustworthy.[20]

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[18]David Rothman, Strangers at the Bedside: A History of how Law and Bioethics Transformed Medical Decision Making, (New York: Basic Books, Inc., 1991), p. 18-23.

[19]For example, even though aplastic anemia was a well-established, dose-dependent side effect of chloramphenicol, 41 patients were randomly selected to test its toxity profile. Twenty patients received 2 grams of chloramphenicol per day and twenty-one received 6 grams per day. After 18 patients in the 6 gram/day group developed toxic bone marrow suppression, as compared to only 2 subjects under the 2 gram protocol, it was concluded that the lower dose regimen was safer. Although, the incidence of associated morbidity and mortality was not mentioned in Beecher's article, the twenty individuals who developed aplastic anemia were obviously placed in a position of unacceptable risk. H. Beecher. Ethics and clinical research. *N Eng J Med.* 1966;274:1354-1360.

[20] Before publishing his findings in the New England Journal of Medicine, Dr. Beecher informed the public of his research by presenting his findings at a conference on drug research. The *New York Times* and *Wall Street Journal* both published extensive articles covering this talk. See Rothman, Strangers at the Bedside, p. 72

Violations of trust, however, were not limited to the realm of private research and in 1973 the public was shocked to learn that government agencies designed to protect and promote public health were also capable of conducting research that *intentionally* harmed the public. From 1932 to 1973, the U.S. Public Health Service (USPHS) had been studying the course of untreated syphilis even though "every textbook of syphilis at the time (of the study's inception) strongly advocated treating syphilis even in its late stages".[21] In order to get the 400 infected African American men in Macon County, Alabama to volunteer, the Tuskegee study relied on deception and false advertising. After being tested, those with "bad blood", a colloquialism for syphilis, were offered ineffective "treatment" in the form of aspirin and noneffective topical ointments and free meals on check-up days. The volunteers were later offered a "special treatment" in the form of a spinal tap to check for neurosyphilis. The Tuskegee subjects truly believed that they were receiving treatment for their "bad blood"; and the investigators relied on this facade to keep the experiment going for almost forty years.[22]

What makes this study even more of a tragedy is that penicillin had been available and known to be the drug of choice for treating syphilis since 1945.[23] Moreover, the USPHS went out of their way to insure that subjects did not receive curative therapy by writing local physicians in the area and directed them to send any of the subject patients back to the USPHS for care. They also directed the draft board not to treat or draft subjects and instructed the Alabama Health Department not to send a venereal disease outreach van to the area

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[21]A.M. Brandt. Racism and research: the case of the Tuskegee syphilis study. *Hastings Center. Report*. December,1978 :21-29.

[22]ibid., 21-29.

[23]Untreated syphilis is a deadly disease with high morbidity. Patients with tertiary syphilis can develop cardiovascular disease, aortic aneurysms, dementia, paresis, liver disease, joint disease, etc. Robins Pathologic Basis of Disease, 4th Edition, ed. by R. Cotran, V. Kumar, and S. Robbins, (Philadelphia:W.B. Suanders Company, 1989), p.370.

being studied. Lastly, when the question of whether or not to continue the study was raised in 1969, the consensus among the physicians involved was to allow the experiment to proceed with one physician remarking "(y)ou will never have another study like this; take advantage of it".[24]

If science could not be trusted to respect and protect patients in general, its application has also served to change the quality of the medical encounter and promote distrust at the level of the individual patient. On the most elementary level, technology can separate the patient from the medical experience. That is, the medical professional often focuses on the technology, forgetting the patient, or perceives the patient as an extension of the medical apparatus. The science rather than the person becomes the center of attention. In The Woman in the Body: A Cultural Analysis of Reproduction, Emily Martin explores this issue and provides a vivid example of this detachment phenomenon as experienced by one woman during the birth of her first child:

"And even standard monitors that have to be strapped to the woman's body or wired to the baby's head have the effect of removing the mother. The doctor or technician literally turns his back to see the screen or printout describing what is happening inside her. As one woman put it (her baby was registering fetal distress) 'I can remember all these official-looking people coming in and hugging the monitor, when I needed the hug. All these smart people were hugging the monitor'"[25]

This sense of being "forgotten" is a common occurrence. In the cold and sterile world of modern medicine, patients often feel they are cogs in the medical machinery. Engulfed in CAT scans, attached to machines that breathe for them, and sectioned into MRI images, it is no wonder patients feel that the entire experience is surreal; that they are detached. The medical community contributes to this "unrealness" by relating to the technology rather than to the

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[24]Brandt, p. 21-29.
[25]E. Martin, The Woman in the Body: A Cultural Analysis of Reproduction, (Boston: Beacon Press, 1989), p.145-146.

patient. To the public it appears "(m)odern scientific medicine, as exemplified in complex teaching hospitals, has advanced technical skill at the cost of personal warmth."[26] The public is now asking in no uncertain terms: "What is happening to American medicine? Are we turning our physical and mental health over to machines rather than people? What ever happened to just plain caring?"[27] Somewhere in the pursuit of science and its increasing reliance on technology, the value of human compassion and the art of caring are being lost.

But it can be argued that while technology has changed the way medicine is delivered, perhaps making it less personal and more mechanistic, it is the very construct of Western medicine that serves to depersonalize the medical experience. By classifying illness into disease categories, the validity and value of the individual's experience of his or her illness is diminished. While the search for patterns of signs and symptoms may help develop a differential diagnosis, it stifles the idiosyncratic experience, in favor of the pathognominic. With ready access to diagnostic technology, the "unreliable", subjective nature of patient reports is replaced with objective data that can be used to reliably monitor the disease process. The patient no longer owns his illness with its subtleties and significance; it has become a traceable, classifiable entity.[28]

Medical education serves to promote this "de-personalization" phenomenon by abstracting and objectifying the patient. During the first two years of medical training, students in most traditional schools learn medicine in the abstract. While human disease is examined in intimate detail, the living person *who has the disease* is rarely introduced -- or, if one is, the presentation is usually in the form of a statistic (e.g. disease X is commonly found in women

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[26]Willard Gaylin. The Patients' bill of rights. *Saturday Review of the Sciences*. February 24, 1973, p.22.
[27]D. Switzer. "Whatever happened to caring?" *This World*, September 29, 1985, p. 20.
[28]S.R. Reiser. The era of the patient: Using the experience of illness in shaping the missions of health care. *JAMA*. 1993;269:1012-1017.

between the ages of 20-45). Physical diagnosis often represents the first real contact with patients. In the quest for physical findings, patients are percussed, auscultated, and touched in the most intimate ways. The student can "examine a patient in detail, listen with care to heart and lungs and stomach, feel all pulses, look deep into the eyes, study a lesion with great attention -- and never see the person."[29] Because the task is to find physical findings, to discern the normal from the abnormal, the "unusual" finding on physical exam is regarded as fortuitous. In a teaching hospital the word quickly spreads that there is an interesting holosystolic murmur in room 42 or a grossly enlarged spleen in room 38. The patient becomes synonymous with his or her abnormal finding. As a student goes through medical training, the ability to abstract becomes more sophisticated, but the basic thinking remains the same. Instead of seeing the patient as a person who is ill, the patient and the disease become interchangeable.[30]

In addition, most medical training is conducted at teaching hospitals where students rotate from one service to the next every six to eight weeks. While this might be good for learning, it is not good for fostering intimate relationships with people who have long-term and challenging problems. By the time the patient and family has developed a relationship and explained the intricacies of their particular situation, it is time to move on to the next rotation. Worse yet, students may not be encouraged to see patients as sick people with anxieties, hopes and fears. "Patients are not looked on as ill people, but as almost impersonal beings that exist for the student's own development."[31]

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[29]P. Klass. A patient is more than the sum of physical findings. *Discover*. October, 1986, p. 21-22.

[30]ibid., p.21-22.

[31]This comment was made by Dr. Ludwig Eichna, a retired department of medicine chairperson who went back to medical school for four years in order to examine medical education first hand. D. Switzer. "Whatever happened to caring?" *This World*, September 29, 1985, p. 20

Patient care becomes another academic exercise in which patients are considered as much a part of the educational equipment as one's stethoscope.

Advancing technology has also changed the quality of the patient-physician relationship from the perspective of the physician. Medicine in the post World War II era witnessed a tremendous explosion in technology: technology, that for better or for worse, raised difficult ethical questions that would eventually challenge the physician's authority to make life and death decisions. Through the "miracle of science" it was now possible to maintain a person with damaged kidneys on hemodialysis indefinitely or replace a weak and failing heart with a healthy, albeit donated, one. Unlike any other previous time in history, it seemed as if physicians could literally decide who would live and who would die. Given the reality of scarce resources, was it appropriate for doctors, and doctors alone, to determine who should receive this life saving treatment, to play God as it were?

Physicians were divided on this issue. Those who pioneered long-term hemodialysis in the early 1960's turned to the community for help in addressing the issue of allocation. By asking the county medical society to appoint a small committee comprised of "quite ordinary people", the physicians recognized the value of having a variety of perspectives when making these life and death decisions. Essentially, the formation of this committee heralded the beginning of a more collective approach to medical decision-making.[32]

Those involved in the burgeoning field of organ transplantation, on the other hand, were firmly against outside involvement. After all, it was argued, these issues of resource allocation and triage were not new to medicine. Although the new advances appeared more glamorous and daunting, physicians

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[32] Rothman, Strangers at the Bedside, p.150.

had always confronted ethical questions; and they had done so without outside guidance. Only those with intimate knowledge and experience of medicine could possibly know what should be done with that knowledge and experience. Outside interference, although it might be well-meaning, could bring only disastrous results and would serve to hamper scientific advancement.[33]

When Walter Mondale, then a senator from Minnesota, introduced a bill in 1968 that would have established a commission on health, science, and society, it was met with strong opposition from physicians and researchers. Although Dr. Beecher and a few others supported a commission that would investigate the ethical, legal, social, and political implications of biomedical advances, the medical profession, in general, was unwilling to relinquish some of its authority to "outsiders" and the bill was defeated.[34]

By 1973, however, several serious scandals, including the infamous Tuskegee Study, had come to the public's attention, serving to diminish trust of the medical profession and to reinforce the apparent need for outside guidance. Under the direction of Senator Edward Kennedy, the question of whether or not medical research desperately needed more supervision was once again raised before the Senate. Witness after witness demonstrated that ethically questionable research, usually involving the poor and disenfranchised, was a common occurrence. According to David Rothman, a noted historian and professor of social medicine, "outsiders came to believe that the medical profession was incapable of self-regulation"[35] and that " medicine required a new kind of collective oversight".[36]

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[33]ibid, p.182.
[34]ibid, p.170-171.
[35]ibid, p.168
[36]ibid, p.184

Following Kennedy's hearings on human experimentation, the Senate established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. This commission would later widen its scope of investigation to include not only research, but all of medicine by becoming the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. It is ironic that the technology born out of the quest for medical advancement would raise questions that ultimately challenged the authority of the physician as expert in medical decision-making. Through a variety of abuses, the medical profession had proven itself untrustworthy and ethically culpable. Medical ethics could no longer be considered the exclusive purview of the physician.

From this history of patient distrust and physician disempowerment, the question of whether or not physicians have the right to withhold or withdraw care they consider futile has become the topic of great debate. While the concept of futility may have existed in the past as evidenced by "slow codes"[37], its invocation as a rationale for limiting life-sustaining care is a relatively new occurrence. That is, while some physicians may have considered life-sustaining treatment futile in certain patients, this sentiment was not openly acknowledged and was not reflected in the first formal policy discussions published in the late 1970's.[38,39,40] While the issue of limiting end-of-life treatment was discussed, the

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[37]If a patient has a cardiac arrest, a code is called to initiate cardiopulmonary resuscitation. "Slow codes" are codes in which the attending physician believed CPR would not be beneficial for a particular patient, but for one reason or another had not obtained consent to withhold CPR. The physician would informally inform the team of the "slow code" status. If the patient arrested, a code would be called, but the team would be slower to respond. Although the team would go throught the motions of a code, it was highly unlikely that the patient would survive.

[38]S.J. Youngner. Do-not-resuscitate ofrders: no longer secret, but still a problem. *Hastings Center Report*. February, 1987, p. 24-33.

[39]Clinical Care Committee of the Massachusetts General Hospital. Optimum care for hopelessly ill patients. *N Eng J Med.* 1976;295:362-364.

[40]M.T. Rabkin, G. Gillerman, and N.R. Rice. Orders not to resuscitate. *N Eng J Med.* 1976; 295:364-366.

term "futile" was never mentioned. Although terms like "irreversibly" and "irreparably" were defined in ways that could easily be construed as "physiologically futile" by today's definitions, the right to withhold "futile" treatment was not considered. In fact, even if a person was irreversibly and irreparably ill, facing imminent death, and "resuscitation (was determined) medically inappropriate," resuscitation was still considered the patient's choice. The do-not-resuscitate order would become effective "only upon the informed choice of a competent patient." Decisions could be made for incompetent patients provided strict guidelines designed to protect patient autonomy were followed.[41]

Today, however, the locus of control appears to be shifting away from patients as physicians claim a comparable right to autonomy. Physicians may be claiming the right to withhold or withdraw treatment they consider futile in response to the disempowering impact patient autonomy has had on the medical profession.

While the zealous pursuit of scientific advancement may have promoted the ends of medicine, it has also contributed to the erosion of patient trust. Scientific misconduct and the depersonalization of medicine have left patients wary of the medical profession. The current futility debate may reflect this sense of distrust, as well as the medical profession's response to the impact this distrust has had on the traditional patient-physician relationship.

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[41] ibid., 364-366.

B. Economics:

Changing economic practices in American medicine have also contributed to the distrust and disempowerment of the medical profession. Now more than ever, society must address the reality of scarce resources and both patients and physicians are frustrated with the current state of healthcare crisis. Patients feel they are spending too much for medical services, while many go without the most basic. Physicians are disillusioned and disgruntled that outside forces are dictating how they should practice medicine. In these tumultuous economic times, how has the patient-physician relationship changed and how has this changing image contributed to the "futility" debate?

The first official inkling of a healthcare crisis emerged in the late 60's. By 1970, business forecast magazines were declaring American medicine on the verge of collapse.

> Much of U.S. medical care ... is inferior in quality, wastefully dispensed, and inequitably financed. Medical manpower and facilities are so maldistributed that large segments of the population, especially the urban poor and those in rural areas, get virtually no care at all... Whether poor or not, most Americans are badly served by the obsolete, overstrained medical system that has grown around them helter-skelter.... the time has come for radical change.[42]

But radical change did not occur and the health care budget grew from 7.2% of the GNP in 1970 to 12.2% in 1990.[43] Despite the enormous amount of money this nation spends on healthcare over 33.6 million Americans are unable to get the medical care they may need or want.[44]

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[42]"It's time to operate" *Fortune.* January 17, 1970, p. 79 cited in The Social Ttransformation of Medicine, p. 381.

[43]U.S. Bureau of the Census, *Statistical Abstract of the United States*: *1992* (112th edition) Washington, D.C., 1992, p. 97.

[44]These figures represent statistics from 1990. The figure of 33.6 million represents the total number of uninsured Americans, it does not include persons who may be inadequately insured or

Because the physician is the only one who can provide these necessary services, the professional as gatekeeper is under siege. Although physicians lament that they too are suffering under the current system, it is hard for the American public to sympathize with a group whose average income is six times that of an average worker and rising at a higher rate. This position is especially true considering that 60% of those polled today believe that physicians should bear at least part, if not most, of the blame for today's health care crisis.[45]

Changing economic practices in medicine have, in part, contributed to this apparent loss of public faith. Medicine and money have an interesting relationship in that, ideally, the physician is required to balance altruism against self-interest. The physician as healer is called upon to tend to the suffering of humanity. Yet, this noble pursuit is also the method by which she makes her livelihood. To offset the inherent conflict, the physician must uphold the highest ethical standards and not take advantage of the vulnerable in order to further self-interests. The "good" physician would not become wealthy off of the misfortune of her patients.

To the American public, however, the ideal of the "good" physician has been compromised for the benefit of financial gain. Because physicians have "cornered the market" on medical expertise, they not only set the fee schedule, they can also generate their own business. Cardiac surgery provides an interesting example. Despite the fact that cardiac surgery has become technically easier with simplified procedures and more technical assistance, fees for cardiac surgery have outpaced the rate of inflation with the average cardiac surgeon in 1980 grossing over $500,000.[46] When these figures are coupled

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those who are on Medicaid. *Statistical Abstract of the United States: 1992* (112th edition) Washington, D.C., 1992, p. 105.

[45]M. Beck, M. Hager, P. Rogers, S. Miller, D. Rosenberg, and K. Snow, "Doctors under the knife", *Newsweek*, April 5, 1993, p. 28-33.

[46]Starr, The Transformation of American Medicine, p.386.

with the fact that in one recent study approximately 14% of coronary artery bypass surgeries done during this time were not medically indicated, one gets the impression is that some doctors are more concerned with their pocketbooks than with patient care.[47]

This impression is further enhanced when endeavors to cut the rising cost of health care are examined. When fee controls are instituted, it appears that doctors attempt to minimize the financial impact by increasing the number of return visits and by conducting more diagnostic tests. When patient visits decline, physicians increase their fees.[48] This manipulation of fees and services leaves patients wondering *whose* interests are being served when they go to the doctor.

By the early 70's the image of medicine as an altruistic profession began to lose credence. In response to the emerging healthcare crisis and a growing distrust of the medical profession, people began to view medicine more and more as a profit-making enterprise in which naive patients were readily exploited. As such, patients were cautioned to be wary of their physicians:

> The image and myth of the doctor as humanitarian, which has been so assiduously sold to the American public, is out of date ... Most men in practice today most closely resemble the American businessman: repressed, compulsive, and more interested in money (and the disease process) than in people ... We want you to be more alert to your responsibility, just as you would in any other adult relationship *where you are purchasing services.*"[49] (emphasis mine)

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[47]In 1979, 1980, and 1982 the rate of inappropriate coronary artery bypass grafts (CABG's) in New York State was 14%. In 1990, the rate of inappropriate CABG's fell to 2.4%. Seven percent of the CABG's were of uncertain indication. The decrease in rate was attributed to an overall decline in the number grafts for one- and two-vessel disease (51% of surgeries to 24% of surgeries in 1990). L.L. Leape, L.H. Hilborne, R.E. Park, S.J. Bernstein, C.J. Kamberg, M. Sherwood, and R.H. Brook. The appropriateness of use of coronary artery bypass graft in New York State. *JAMA*. 1993;269:753-60.

[48]Starr, The Social Transformation of Medicine

[49]Boston Women's Health Book Collective, Our Bodies, Ourselves. (New York:1971), p.252-53.

Clearly, medicine had entered the marketplace; and the mystique of the patient-physician relationship was reduced to the exchange of currency for services. Under this capitalist model, patients as consumers were encouraged to be in complete control of their healthcare. They could choose their medical provider, determine their own treatment regimen, and "fire" their physicians whenever services were not satisfactory.

Consumerism in medicine, however, has fostered unreal expectations about the infallibility of medicine. As a consumer, good results are expected whenever services are purchased. If a specialist is consulted, especially good outcomes are anticipated. Unfortunately, medicine is not a perfect science. The best physician is just another human being and the best diagnostician will eventually make a mistake. Even when procedures are technically perfect, the human body is never 100% predictable and things will still go amiss. As a consumer, if a defective product is purchased, it is either replaced or the customer is reimbursed. If the defective product causes harm, the company can be held liable for damages. Analogously, the patient as consumer may be more likely to take the doctor-businessman to court if the expectation of a good outcome is higher; and in the last 15 years, malpractice litigation has increased dramatically with an overwhelming number of suits being filed against specialists.[50]

Aside from creating a more litigious environment, consumerism in medicine has had several other deleterious effects. First, while a contractual relationship is well-suited for business affairs, it does not adequately describe the intricacies of the patient-physician relationship. The doctor is not merely a purveyor of health or a "high-tech" auto mechanic who accepts fees for services

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[50]M.I. Taragin, A.P. Wilczek, M.E. Karns, R. Trout, and J.L. Carson. Physician demographics and the risk of medical malpractice. *Am J Med.* 1992;93:537-542.

rendered. The transformation of medicine into a business relationship implies a level of equality that in reality does not exist. Patients seek the aid of a physician when they are at their most vulnerable. Physically weakened and spiritually taxed, they are in a position of neediness and dependency; a dependency which is enhanced by a disparity of knowledge. Unlike when she purchases an automobile or refrigerator, the patient cannot consult a "consumer report" and design a truly informed treatment regimen.[51]

Moreover, in a truly egalitarian relationship both parties would be free to engage in or abstain from the relationship. While patients are free to fire their physician, physicians are not accorded the same degree of freedom. Unlike other businesses that reserve the right to refuse service, physicians are generally obligated to continue caring for their patients. Doctors cannot, for example, stop seeing a sick patient they find disagreeable or refuse to treat unpleasant diseases. A physician who cannot transfer his difficult patients to another practitioner is compelled to continue caring for them.

In fact, doctors are held to a moral standard that goes beyond individual contracts. Consider an example of an emergency medicine doctor who after finishing a shift at the local hospital stops at the grocery store to buy milk. While standing in line, the man in front of him shouts "my heart, my heart!", clutches his chest, and slumps to the ground. Amidst the bedlam, the physician carefully steps around the unconscious man, puts the cash for the milk on the counter, and walks away. The man dies of heart attack. While the doctor, having not entered into a contract, is not legally required to stop and assist, most people would find the physician morally culpable. This perceived moral obligation

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[51]Even the physician who becomes a patient is ill-advised to self-diagnose and self-medicate. J. La Puma and E.R. Priest. Is there a doctor in the house? *JAMA* 1992;267:1810-12.

stems from a belief that physicians are held to an oath of compassionate service that transcends contractual ties.

Demoting medicine to the status of a profit-making enterprise calls this assumption into question because it transforms the ends for which medicine is practiced. The doctor-patient relationship can be viewed as "an asymmetric human relationship explicitly defined relative to one person's illness and another's professed devotion to healing and comforting."[52] As a professional, the physician is ideally dedicated to a good that transcends self-interests and "professes" devotion to this higher calling by the way in which he lives his life. His actions are not inspired by monetary gain and "the activity of healing is, both in principle and in fact, distinct from the activity of gaining remuneration for healing."[53] To view medicine as an act of employment, that is making a profit from one's handiwork, is to shift one's devotion from healing and comforting to that of coveting money.[54]

Secondly, unlike most business transactions, the therapeutic relationship is fiduciary in nature.[55] Patients must be able to trust their physician is operating with their best interests at heart because they are in a vulnerable position and the stakes are high. In order to fully comply with treatment, they must be able to trust that the proposed treatment is for their benefit and not for the physicians

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[52]L. R. Kass, Professing ethically: on the place of ethics in defining medicine, *JAMA*, 1983;249:1306.

[53]ibid., p. 1306.

[54]That is not to say, however, that a physician who accepts fees for services is by definition unethical. Rather, doctors can ethically accept fees provided they remain true to their devotion of healing and comforting humanity. Physicians ought to practice medicine because they are dedicated to an idealistic vision of compassionately caring for others without concern for egoistic gain. Monetary reimbursement should be a secondary consideration; in essence, a side effect of the commitment rather than the focus.

[55]The term fiduciary is derived from Roman law and according to Black's Law Dictionary means "a person holding the character of a trustee, or a character analogous of a trustee, in respect to the trust and confidence involved in it and the scrupulous good faith and candor which it requires. A person having duty, created by his undertaking, to act primarily for another's benefit in matters connected with such undertaking." Black's Law Dictionary, Sixth Edition, (St. Paul :West Publish Co., 1990), p. 625.

gain. In the world of commerce, on the other hand, while one hopefully can presume that the service or product being purchased is trustworthy, one need not trust the salesperson is. That is, the benefit received from the product or service is not necessarily dependent on the moral character of the salesperson. Moreover,

> Business, under the profit motive, tries to create needs, to sell more and more goods and services. Medicine, as a true profession, tries to discern the real needs of the patient and satisfy them *in the interests of the patient* (without rationalization that *might* be quite justifiable)[56]

To perpetuate the concept of medicine as a business is to perpetuate the image of the patient-physician relationship as inherently distrustful.

Even in the era of health maintenance organizations in which cost-containment precludes the overzealous prescription of goods and services, the ethics of business are not necessarily the ethics of medicine. In order to maximize profits, HMO's try to minimize expenditures. One method of reducing costs is to invest in preventative care. By keeping the patient population healthy, less resources are utilized. When patients become ill, however, a potential tension between containing costs and compromising patient care exists.

Private insurance presents a similar situation in that insurance companies profit when patients do no use services; and patients who develop diseases that require expensive interventions and procedures may soon find themselves without a carrier.

If patients are worried that cost containment measures may compromise the quality of care they receive,[57] this fear can be amplified when patients and

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[56]L.S. King. Medicine: Trade or profession? *JAMA*. 1985;253:2710.
[57]Beck *et al.*, "Doctors Under the Knife," p. 28-33.

their families find themselves in the unexpected and often traumatic position of having to make end-of-life decisions. To the distraught family member, futile treatment might easily be equated with expensive treatment; and they may feel the physician wants to stop life-sustaining treatment prematurely in an effort to save money. They may demand futile treatment because they really do not trust their physician is acting in their best interests.

Families may also demand "futile" treatment because they have, in a sense, pre-purchased the care. Having paid their insurance or HMO premiums, they may expect good care. To some "good" care constitutes "everything that can be done." Because life-sustaining technology has been offered in the past, precedent has been set for its continued utilization. Patients and their families, therefore, may expect that it is an available option that can either be accepted or rejected. This sense of wanting "good" care may also be true for the uninsured. Having finally gained access into the system, those who have been refused care in the past may feel that they will once again be denied. They may demand "futile" treatment because they fear that if they do not, they will receive suboptimal care.

Unfortunately, the individual never sees the real cost of medical care and, therefore, may be more inclined to demand expensive, but "futile" care. It is estimated that the average cost of treating a patient in an intensive care unit ranges from $2,000 to $3,500 per day.[58] For patients with chronic problems that require long-term intensive management and monitoring, it is easy to appreciate how rapidly the cost of care could accrue.[59] Patients and their families, however, see only a fraction of the total figure because the burden of cost is distributed to

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[58]K. Sasse. Prognostic scoring systems: Facing difficult decisions with objective data. *Cambridge Quarterly of Healthcare Ethics*. 1993;2:185.

[59]It is estimated that Mrs. Wanglies care totaled over $800,000. See Ronald Cranford, Helga Wanglie's Ventilator, *Hastings Center Report*, July-August, 1991, p. 24.

other beneficiaries of the insurance policy or HMO. If the patient is uninsured, the expense is passed on to the taxpayers. It is conceivable that the patients and their families may be more likely to insist on "futile" care because they pay only a small fraction of the real cost.

Physicians are also feeling the crunch of the healthcare crisis. They are worried about seeing more patients, spending less time with each, and being forced to work in impersonal corporations where others make decisions.[60] Essentially, they are concerned that the very factors that make a physician a good doctor will be lost as medicine goes corporate.

As health care expenses continue to rise at an alarming rate, physicians are being asked more and more to directly contain costs and their practicing patterns are being scrutinized with the intention of cutting out the unnecessary. Essentially, they are being asked to cut corners without being able to choose which corners ought to be cut. Thus, the physician is often placed in the potentially compromising position of having to be an advocate for patient care on the one hand and having to be the agent of somebody else's cost containment strategy on the other. Instead of being perceived as uniquely qualified to make health policy and economic decisions, physicians feel they have become pawns in the game of medical cost management.[61]

The futility argument can be viewed as a response to this loss of power and control. By declaring the determination of futility a medical decision, the locus of control remains with the physician. Reasserting the authority of the physician accomplishes two things. First, it wrests the authority away from the consumer. By making the "futile" treatment an unavailable option, it becomes

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[60]Beck *et al.*, "Doctors Under the Knife," p. 28-33.

[61]In a recent poll, forty percent of American doctors would not go into medicine today and most cited outside interference as the primary reason. See M. Beck *et al.*, "Doctors Under the Knife," p.30.

non-negotiable. It is simply not for sale.[62] Second, it addresses the issue of cost containment. The type of treatment that is usually labeled "futile" is expensive. Very little fuss is made over the "futile" use of antibiotics to treat colds and it would be naive to believe that money did not influence the cost-benefit calculus in some fashion. Because "futile" treatment is frequently expensive, physicians are often asked to justify its implementation. In fact, some hospitals keep a running tab in the patient's chart. When the bill exceeds the anticipated reimbursement, doctors are often asked to explain their expenditures.[63] As the cost of care rises and the need to justify practicing behavior increases, physicians may be more inclined to call treatment of questionable benefit futile.

Physicians may also feel a responsibility that goes beyond a particular patient and extends to society in general. Physicians are in the unique position of having first hand knowledge of the effects of resource allocation (or misallocation) and they are not immune to the suffering created by the disparity in access. Everyday, they see expensive resources administered to those for whom benefit is not anticipated. Given that many cannot even afford the most basic care, that many die from the complications of very curable, if not preventable diseases, that many cannot obtain prenatal care, it is no wonder the situation appears impossible, if not futile. From this vantage point, the argument can be made on grounds of justice, that to provide "futile" care when others are denied even the most fundamental care is immoral.

Yet, "in an age of consumer rights and in a more litigious environment, many physicians may believe that moral evaluations must be couched in

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[62]That is not to say, however, that the physician is consciously aware of this loss of power or that the "futility" of the proposed treatment cannot be justified. By making it a medical decision, the futile treatment moves out of the realm of available medical options.

[63]This example was raised during one of Dr. Tommi Kushner's ethics classes, UC Berkeley, Spring Semester 1992.

technical, medical terms."[64] Because "futility" has the ring of objectivity, physicians may feel more comfortable expressing their moral predisposition in the form of a medical decision. Doing so obviates any necessity to explain why their morality should supersede that of the patient's or to justify their treatment decisions.

Overall, the emerging healthcare crisis and the changing economic structure have helped to move the image of medicine from a profession of benevolent compassion toward one of rapacious commerce. Patients may demand "futile" care because they do not trust their physician is operating from a motive fiduciary responsibility or they may feel, as consumers, they have a "right" to any care they deem necessary or appropriate. Physicians, on the other hand, may resent consumer-directed medicine or perceive a moral obligation that transcends individual patients to embrace society at large; and, thus, reassert their authority *qua* physicians to distinguish and deny treatment that is futile.

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[64]M. Solomon, "Futility" as a criterion in limiting treatment, *N Eng J Med*, 1992;327:1239.

C. Rights:

Finally, the emergence of rights theory as a method for delineating rights and responsibilities within the patient-physician relationship represents a dramatic departure from the traditional paternalistic provider - compliant patient interaction. With a new rights-based vocabulary, both patients and doctors have claimed the moral right to control the administration of futile care. I contend, however, that the language of rights fails to capture the essence of what it means to practice medicine and represents an adversarial method of coping with patient-physician conflict.

Historically, the development of patients' rights found its roots in a larger rights movement that swept the nation in the 1960's. The social unrest of the 60's was fertile ground for revolution in which disempowered groups challenged the status quo and demanded previously unrecognized rights. Whether fighting for civil rights, gay rights, or women's rights, the political climate "fostered an extraordinary identification with the underdog and minority."[65] Equality was perceived as the ideal and a general distrust of authority was pervasive. The scrutiny of the 60's did not spare the medical profession, and patients easily found themselves among the ranks of the disenfranchised needing protection.

The feminist movement, in particular, exemplified the distrust of medical authority and served as a major catalyst for the development of patients' rights. Women were in the interesting position of being in two disempowered groups: they were women fighting sexist ideology that pervaded every aspect of society and they were patients struggling against the reins of paternalism. The field of obstetrics and gynecology represented the worst of both worlds. For the most part, the physicians in this field were primarily men and were, therefore, naturally

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[65]Starr, The Social Transformation of Medicine, p.98

suspect to feminists. More importantly, however, medicine had a long and notorious history of oppressing women. According to the prevailing medical dogma, every aspect of a woman's reproductive physiology was pathologic.[66] When women were sick, their complaints were often minimized or they were diagnosed with psychosomatic ailments and treated with Valium. When women were socially "sick", that is they behaved in socially inappropriate ways, medicine provided a "cure" .[67] If medicine was paternalistic to patients in general, it was repressive to women in particular. As such, medicine was viewed as an organized "old boys network" that excluded, subjugated and patronized women. Because male chauvinism was synonymous with medical paternalism, women were warned:

> The medical system is not just a service industry. It is a powerful instrument of social control, replacing organized religion as a prime source of sexist ideology and an enforcer of sex roles.[68]

Women responded by asserting their rights as consumers. They formed health collectives, propagated a successful self-help movement, and demanded the right to be fully informed decision-makers in their own health care.

While the right to patient autonomy was a popular theme in the women's movement, its empowering appeal gained a wider audience among patients in general. Patients began to challenge the paternalistic tradition, demanding the right to consent and to refuse medical care. When physicians failed in their

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[66]Menstruation was the product of a failed pregnancy that left the uterine lining denuded, hemorrhagic, and wounded. Pregnancy was a state of confinement and illness that required medical intervention and technology. Menopause was the result of failing ovaries, a disease of decreased estrogen production that ultimately rendered a woman withered and atrophic. For further information regarding this topic: Martin, The Woman in the Body, B. Ehrenreich and D. English, Complaints and disorders: the sexual politics of sickness. (New York:The Feminist Press, 1973), as well as Witches, Midwives, and Healers

[67]Hysterectomies were considered curative for the "hysterical" woman and lobatomies were employed to treat the rebellious or lazy wife. B. Ehrenreich and English D. Complaints and disorders: the sexual politics of sickness. (New York: The Feminist Press, 1973).

[68]Ehrenreich, Complaints and disorders: the sexual politics of sickness, p. 83.

correlative duties, patients took their grievances to the legal system and there was an "increase(ing) tendency of the courts to view the physician-patient relationship as a partnership in decision making rather than a doctor's monopoly."[69]

This sentiment was acknowledged in 1972 when the American Hospital Association published the Patients' Bill of Rights.[70] Although this document has been criticized as a vague reiteration of a patient's legal rights, it served to remind both patient and institution of these rights and opened the door for greater patient participation. [71]

The development of rights theory as a method for re-structuring the patient-physician relationship, however, represents a major sign that the therapeutic bond was, and is, failing. If, ideally, the intimate patient-physician relationship is founded upon trust, compassion and an unfaltering dedication to healing and comforting, I find it particularly strange to invoke a rigid structure of rights to describe an alliance based on ethereal concepts of trust and beneficence. To assert a right is to claim that the other person is, in essence, failing in his or her duty; that the relationship is, in reality, less than the ideal.

> To stand on one's right is to distance oneself from those to whom the claim is made; it is to announce, so to speak, an opening of hostilities; and it is to acknowledge that other warmer bonds of kinship, affection, and intimacy can no longer hold.[72]

I am not arguing, however, that there is not a proper role for rights within the patient-physician relationship. Rights are necessary because they guarantee that a level of care will be provided despite personal preferences or prejudices.

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[69]Starr, The Social Transformation of Medicine, p.388.
[70]American Hospital Association. "A Patient's Bill of Rights", 1972.
[71]G.J. Annas. A model patients' bill of rights. *Civil Liberties Review*.1974; 1:20-22.
[72]J. Waldron. When justice replaces affection: the need for rights. *Harvard Journal of Law and Public Policy*. Summer 1988;11:628.

> ...it is important for there to be a structure of rights that people can count on for organizing their lives, a structure which stands somewhat apart form communal or affective attachments and which can be relied on to survive as a basis for action no matter what happens to those attachments.[73]

Without a duty to care for patients that goes beyond ties of affection or beneficence, the physician could, according to whim or fancy, refuse to provide care, withhold information, or conduct experimentation without consent. Naturally, in such a situation, the security of predictable and consistent care would be compromised.

My argument is that while rights should serve as a background guarantee, the act of claiming them as rights is a symptom of a deeper problem. One generally only needs to demand rights within a relationship if the right being claimed is likely to be infringed upon. Asserting a right signifies that a precedent for misconduct or perfidious behavior has been set. For a person to claim a right within an intimate relationship is to declare that the other person cannot be trusted to fulfill the implied duties or respect the understood boundaries.

The language of rights, however, fails to capture the essence of what it means to practice medicine. Somewhere in the translation of altruistic motives and lofty ideals into obligations and claim-holds, the spirit of genuinely caring for humanity and the ideal of unselfish devotion to compassionate service is lost. The claiming of patient rights implies that the physician has gone astray from the noble pursuits of medicine and is failing to uphold the moral bargain. As such, the act of claiming rights can be viewed as an affront to professional integrity and potentially places the medical profession on the defensive.[74]

Moreover, to what extent can a patient claim rights? Some patients considered the notion of control that flourished in the era of paternalistic

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[73]ibid., p. 634.

[74]Nonetheless, to those who would claim rights, the physician has failed his or her moral duty and it matters little if the accusation bruises the physician's claim to professional integrity.

medicine morally oppressive. But if patients could completely dictate a physician's actions, this control would simply take a 180 degree turn and manifest itself as the "moral" weight of patient autonomy. The physician would become nothing more than a well-paid technician or mechanic. While complete patient autonomy is the *sine qua non* of a good relationship under the consumer model, most physicians would consider such a proposal distasteful. As the glare of patient autonomy grows brighter and brighter, is there any recourse but for physicians to claim rights as well?

With patients claiming the right to "futile" care and physicians counter-claiming the right to deny "futile" care, a spiral effect is generated; and the therapeutic relationship moves farther and farther away from a compassionate, trusting, and intimate alliance.

In conclusion, the increasing dependence on technology, the emergence of consumer-oriented medicine, the escalating healthcare crisis, and the development of rights theory as a method for restructuring the therapeutic relationship have all served to create an environment in which futility as a rationale for limiting life-sustaining therapy appears to be a plausible argument.

The conflict inherent in the futility argument, however, represents a major schism in the traditional patient-physician relationship. Physicians characterize the debate in terms of "demanding" patient or families and view the conflict as an attack on professional integrity. In order to regain a sense of control in a relationship that has expanded beyond the bedside, the doctor turns to science with its pristine sense of objectivity to bolster the decisions that were once the purview of the medical profession. Patients, on the other hand, may "demand" treatment because they may not share a common goal or interest with their medical practitioner, they distrust the medical profession in general, and they experience an intense loss of control in the clinical arena. They may claim a

right to "futile" care because they may fear that failing to do so could result in suboptimal care.

Chapter 2:
Legal Perspective

Recently, several articles have asserted that withholding or withdrawing life-sustaining therapy on the basis of medical futility not only has moral validity, it also has legal legitimacy.[75,76] The question of whether or not a physician can withdraw life-sustaining care against a patient's desire, however, has never been presented to the courts *per se*. Instead, the courts have been presented with a variety of cases concerning the individual's right to refuse treatment. Although several cases have legitimized the withholding or withdrawing of care, they have done so in the context of patient autonomy. That is, they were argued with family or patient consent, rather than purely from the perspective of medical benefit, futility or professional integrity. Although this section will investigate several legal cases concerning patient autonomy, end-of-life treatment decisions, and the physician's responsibility toward incompetent patients, it is by

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[75]Those who invoke legal authorization most often refer to cases that support the right of healthcare providers to refuse to participate in acts that violate their moral and ethical standards. In particular, Paris et al assert that the ruling in Brophy v. New England Sinai Hosptital "provided the legal basis for the refusal to accede to the parental request that mechanical ventilation be provided to Baby L", a severely neurologically impaired infant. The medical staff and ethics committee believed further life-prolonging medical treatment "would be futile and inhumane". See J.J. Paris, R.K. Crone, and F. Reardon. Physicians' refusal of requested treatment: the case of Baby L. *N Eng J Med*. 1990; 322:1012-1015.

In *Brophy v. New England Sinai Hospital*, 497. N.E.2d. 626 (1986), however, the circumstances were reversed. The wife of a patient in a persistent vegetative state wished to have artificial hydration and nutrition stopped in accordance with her substituted judgement of the patient's treatment preferences. It was the physicians who did not wish to comply. Although the court concluded the State's interest in perserving life did not outweigh Brophy's right to refuse treatment, they could not force the hospital and physicians to violate the integrity of the medical profession by directly contributing to the patient's death. The court authorized the patient's removal to the care of other medical professionals who could ethically honor the request. It should be noted that in this case, the State's interests in preserving life and the physicians' claim to moral integrity were in consonance. This agreement was not present in the Baby L. case.

[76]In another article supporting the physician's right to deny futile care, Dr. Rie refers to *Superintendent of Belchertown v. Saikewicz* for legal support on the basis of maintaining professional integrity. See M.A. Rie. The limits of a wish. *Hastings Center Report*. July-August, 1991, p. 24-27.

In *Superintendent of Belchertown v. Saikewicz* 370 N.E.2d 417 (1977) the preservation of ethical integrity in the medical profession was considered one of the four State interests the courts have when considering the right of an individual to refuse medical intervention. Once again, however, the preservation of medical integrity was in the context of promoting life, not death.

no means a legal analysis of whether or not physicians can, under protection of the law, refuse "futile" treatment. Rather, this section will demonstrate that the legal right, by virtue of a medical degree, to withhold or withdraw life-sustaining therapy without consent is, at the very least, a questionable assertion.

The application of unwanted medical treatment can be viewed as "an assault" or "trespass" on bodily integrity and the right of a competent adult to refuse medical treatment has a strong history of legal support.[77,78] Although the right to refuse medical treatment is not absolute and must be tempered by other competing state interests, an increasing de-emphasis of state interests in favor of greater concern for individual autonomy has occurred over the last 30 years.[79] It is now recognized that competent patients have the right to refuse medical treatment even when such a refusal would result in death or is contrary to customary medical practice.[80]

A comparable right to autonomy for incompetent patients, however, presents a more difficult challenge in that it is often difficult to know and respect

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[77] *Schloendorf v. Society of New York Hospital* 105 N.E. 92 (1914). Judge Cordoza. The case involved the removal of a fibroid tumor without the consent of the plaintiff who post-operatively developed a gangrenous left arm requiring the amputation of several fingers. She charged the hospital with medical liability and sought damages.

[78] Most recently, the Supreme Court, although acknowledging that the informed consent doctrine supported the right of a competent person to refuse medical treatment, found that a competent person also had a liberty interest under the Due Process Clause in refusing medical treatment. See *In re Cruzan* 497 U.S. 261 (1990).

[79] These interests include: (1) an interest in preserving life, (2) a need to protect innocent third parties, (3) a duty to prevent suicide, and lastly, (4) a commitment to helping maintain the ethical integrity of the medical profession. *Superintendent of Belchertown v. Saikewicz* 370 N.E.2d 417 (1977).

[80] In particular, *Bouvia v. Superior Court*, represents a major victory in the struggle for patient self-determination. Elizabeth Bouvia, a 28 year old, quadriplegic woman with severe cerebral palsy and painful degenerative arthritis, petitioned for the removal of her nasogastric tube. Although removing the nasogastric tube would hasten, if not deliberately cause her death, the California Superior Court found Ms. Bouvia's right to refuse treatment outweighed the state's interest in preserving life and preventing suicide. Moreover, her right even superseded the state's "concern for protecting the medical profession." The court concluded that the realization of patient self-determination in any real sense mandated that the patient's treatment decisions be respected *contra* the interests of the physicians. Contrary to medical opinion, the physicians were ordered to remove the nasogastric tube. *Bouvia v. Superior Court (Glenchur)* 225 Cal.Rptr. 297 (1986).

a patient's treatment decisions without the benefit of explicit directives. Given this element of uncertainty, it was generally assumed that all incompetent patients would want life-support measures continued. More recently, however, the courts have recognized that incompetent patients have the right to refuse medical care; and the case of Karen Ann Quinlan represents one of the most important landmarks in this struggle for patient self-determination. At the age of 21, Karen Ann Quinlan fell into a persistent vegetative state following several episodes of extended anoxia. Although she could cry out, blink, grimace, etc., it was believed that her cognitive functions had been irreparably damaged and that she would be permanently dependent on ventilator support. Given that Karen's current treatment would never restore her to a sapient state, Joseph Quinlan petitioned for the guardianship of his daughter and requested that all "extraordinary medical procedures" discontinued in accordance with Karen's previously expressed thoughts regarding the "futile use of extraordinary means".[81]

Disconnecting Karen's respirator, however, raised serious ethical and legal concerns. Karen was technically "alive" in that she did not meet the criteria for brain death and discontinuing "extraordinary means" would most likely lead to her death -- an end result that was unquestionably contrary to the state's interest in preserving life. Furthermore, discontinuing respiratory support was thought to be contrary to "medical practices, standards, and traditions".[82] The New Jersey Supreme Court was forced to weigh the rights of the individual to determine his or her own destiny against the competing interests of the state and medical profession.[83]

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[81]In *re Quinlan* 355 A.2d 647 (1976), p. 651-656.
[82]In *re Quinlan*, p.655
[83]In *re Quinlan*, p. 662-669.

The case of Karen Quinlan is interesting in several respects. First, the decision represents a triumph for patient self-determination. Drawing on previous decisions upholding the constitutional basis of the right to privacy, the New Jersey Supreme Court considered this right "broad enough to encompass a patient's decision to decline medical treatment under certain circumstances."[84] While the court said that the State has an interest in preserving the sanctity of human life, the weight this interest carries is proportional to the degree of bodily invasion and the medical prognosis. As the physical burden of care increases and the expectation of a good outcome decreases, the individual's right to privacy becomes a more compelling factor and will eventually "overcome the State interest". Believing that Karen Quinlan, if competent, would choose to have care withdrawn, the Court supported terminating ventilatory support on the basis of her right to privacy.[85]

Second, the Court's decision emphasized the importance of the patient's assessment of benefit in medical decision-making. While the language of the ruling emphasizes the unappealing nature of being in a persistent vegetative state, it is within the context of what constituted benefit *according to* Karen. The main crux of the court's decision rests on the patient's determination of benefit. The court found Karen's quality of life assessment more compelling than her physicians' interests in continuing her life-support; her right to have treatment withdrawn was to be respected even if it went against sound medical opinion.

Lastly, the ruling supported the unwavering nature of the right to self-determination in so far as a person has a right to privacy even when incapable of perceiving or appreciating the freedom to exercise such a right. If the right to privacy permitted Karen to terminate her care, "... then (the right) should not be

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[84]In *re Quinlan*, p. 663.
[85]In *re Quinlan*, p. 664.

discarded solely on the basis that her condition prevents her conscious exercise of choice." Given Karen was unable to express her desires, "(t)he only practical way to prevent destruction of (her) right" was to allow her parents and/or family to act on her behalf. Because her family knew her intimately, they were in the best position to determine what decision Karen would have made if she were competent.

Other state courts have also promulgated the incompetent patient's right to refuse life-sustaining treatment by recognizing the standard of substituted judgment. For example, in *Brophy v. New England Sinai Hospital, Inc.*, the court allowed the guardian of a persistently vegetative patient to terminate nutrition and hydration based on her substituted judgment of the patient's desires.[86] In a similar case involving the termination of nutrition and hydration, the New Jersey Supreme Court deferred to the family's judgment, stating "the family is the best able to decide what the patient would want" when the incompetent patient's treatment desires are unknown.[87] In *Superintendent of Belchertown v. Saikewicz*, chemotherapy for acute myeloblastic monocytic anemia was withheld from a mentally retarded patient based on the substituted judgment, that if competent, the patient would not want treatment.[88]

Other courts, however, have rejected the substituted judgment standard when making decisions for incompetent patients who have never had the capacity to exercise autonomous choice in favor of a "best interest" standard. According to this standard, treatment decisions should be made in consideration of what would be objectively best for a particular patient given his or her prognosis and quality of life. Unlike the substituted judgment standard, the

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[86]*Brophy v. New Engalnd Sinai Hospital*, 497. N.E.2d. 626 (1986).
[87]*In the Matter of Jobes* 529 A.2d 434 (N.J. 1987), p. 447.
[88]*Superintendent of Belchertown v. Saikewicz* 370 N.E.2d 417 (1977).

surrogate and physician can present their interpretation of what would be best for the patient, but the court remains the ultimate decision-maker; and there is no guarantee that the court will agree with the surrogate's "objective" assessment.[89]

Most recently *In the Matter Cruzan*, the Supreme Court upheld the constitutionality of one Missouri law requiring "clear and convincing evidence" when making decisions to withhold or withdraw life sustaining treatment for incompetent persons. Although this decision has been interpreted as a defeat for the patient self-determination movement[90], the "clear and convincing evidence" standard can be viewed as a measure that seeks to protect self-determination by a strict adherence to autonomy. That is, because the "substituted judgment" and the "best interests" standard depend on an interpretation of the patient's desires or an assessment of what would be best for the patient, they are subjective by their nature. An autonomous choice in the purest sense would rely solely on the patient's explicit directives and not on another's interpretation or judgment. This distinction becomes particularly significant when the interests at question are of great import. Writing for the majority opinion, Justice Rehnquist states:

> The choice between life and death is a deeply personal decision of obvious and overwhelming finality. We believe (states) may

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[89] For example, *In the Matter of Storar*, the mother of a 52-year-old mentally retarded patient with terminal bladder cancer requested that blood transfusions be discontinued. While the blood transfusions were not curative, they were considered palliative in that they replaced blood lost in the urine, gave the patient more energy, and potentially prolonged his life. Members of the medical profession testified that the transfusions might also serve only to prolong Mr. Storar's suffering and that treatment could legitimately be limited to pain relief. Because Mr. Storar had always been incompetent, the court, in contrast to *Superintendent of Belchertown v. Saikewicz,* considered it "unrealistic to attempt to determine whether he would want to continue potentially life prolonging treatment if he were competent." The court chose to exercise its right as *parens patriae* and intervene on behalf of this incompetent patient, stating that "a court should not...allow an incompetent patient to bleed to death because someone, even someone as close as a parent or sibling, feels that this is best for one with an incurable disease." In essence, the court disagreed with the legal surrogate that it would be in the patient's best interest to withhold further treatment. *In re Storar,* 52 N.Y. 2d 363 (1981).

[90] G. J Annas. Nancy Cruzan and the right to die. *N Eng J Med.* 1990;323:670-672.

> legitimately seek to safe-guard the personal element of this choice through the imposition of heightened evidentiary requirements.[91]

The strict standard of "clear and convincing evidence" places the burden of proof on those who would seek to terminate care. In doing so, it can be argued, the likelihood of an erroneous and irreparable outcome is decreased. To err on the side of continuing treatment is to preserve the possibility of executing an autonomous choice should new evidence or opportunity come to light.[92]

Although the dissenting opinion disagreed with the constitutionality of requiring a "clear and convincing evidence" standard, it did so because such a standard would deny the fundamental right to refuse unwanted treatment to a person who did not have the foresight to detail explicit treatment directives. According to Justice Brennan in the dissenting opinion, the heightened evidentiary standard creates "improperly biased procedural obstacles" that "impermissibly burden" the "fundamental right to be free of unwanted (medical treatment)." While the state has an interest in safe-guarding the accuracy of medical determinations made for incompetent patients, the proposed procedural requirements would not increase the likelihood that patients' "real" choices would be executed. Because most people do not leave living wills or explicit directives, testimony from family and friends who knew the "person" inside the patient may provide the most accurate sense of what the incompetent patient would have wanted under the existing circumstances. Under the pain of "clear and convincing evidence", the patient's wishes would not be honored if they were not formalized in some fashion.[93]

Therefore, while the affirming and dissenting opinions disagreed as to the means to protect a patient's autonomy, they did not disagree to the ends.

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[91] *In re Cruzan* 497 U.S. 261 (1990), p.281.
[92] ibid., p. 283.
[93] ibid., p. 302.

In contrast to the plethora of legal rhetoric regarding the patient's right to refuse unwanted treatment, very little has been written regarding the physician's legal obligation to incompetent patients. Presumably, a physician could still be held liable for the tort of abandonment if he or she failed to provide necessary medical care.[94] A physician may also be held criminally liable for failing to provide medical treatment that could prolong life, "...even if death was caused by the underlying disease."[95] And while, "the law clearly mandates...that physicians may decide when and how to withdraw life-support from any patient determine to be brain dead",[96] it is less clear what responsibility physicians have toward people who hover in the blurred margins of life and death.

The question of whether or not physicians have a responsibility to provide futile care was first raised in Barber v. Superior Court. In particular, this case examined whether or not Dr. Neil Barber and Dr. Robert Njdel were directly responsible for the death of Clarence Herbert and, therefore, should be charged with murder and the conspiracy to commit murder. Mr. Herbert, while under the care of these two physicians, suffered cardiopulmonary arrest following surgery and was placed on a mechanical respirator. After several examinations by different doctors, he was determined to have severe brain damage. The family requested that life-support be disconnected. The physicians discontinued ventilatory support, but Mr. Herbert continued to breathe on his own. The family then requested that artificial nutrition and hydration be discontinued. The

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[94]Once a patient and physician have established a relationship, the doctor is required to provide necessary medical care or else he or she is liable for abandonment. See Law, Science and Medicine, edited by J. Areen, P. King, S. Goldberg, and A. Capron. (New York: The Foundation Press, Inc., 1984), p. 368

[95]*In re Cruzan*, p. 261. Justice Scalia commenting on and citing *Barrow v. State*, 17 Okla. Cr. 340, 188 P. 351 (1920) and *People v. Phillips*, 64 Cal. 2d 574, 414 P. 2d 353 (1966).

[96]Sanders LM, Raffin TA. The ethics of withholding and withdrawing critical care. *Cambridge Quarterly of Healthcare Ethics.* 1993;2:175-184.

doctors honored the family's request, but continued to provide comfort care until Mr. Herbert died.[97]

From the essential facts of the case, it would appear that Barber v. Superior Court represents another case of patient self-determination. Mr. Herbert's family knew his desire to never "become another Karen Ann Quinlan" and wanted to fulfill his wishes concerning life-sustaining therapy. Unlike the previous cases which were civil in nature, however, this case was presented in context of criminal prosecution and, therefore, required the state to demonstrate that the physicians were negligent in their medical duty, causing the death of Mr. Herbert. In attempting to determine whether the attending physicians should be charged with murder, however, the California Court of Appeal raised an even more intriguing question. Namely, "at what point does (medical technology) cease to perform its intended function and who should have the authority to decide that any further prolongation of the dying process is of no benefit to either the patient or his family?"[98] Unfortunately, this interesting query is never fully addressed. At one point, Associate Judge Compton states:

> A physician has no duty to continue treatment, once it has proved to be ineffective. Although there may be a duty to provide life-sustaining machinery in the *immediate* aftermath of a cardio-respiratory arrest, there is no duty to continue its use once it has become futile in the opinion of qualified medical personnel.[99]

He later goes on to say:

> Given the general standards for determining when there is a duty to provide medical treatment of debatable value, the question remains as to who should make these vital decisions. Clearly, the medical diagnoses and prognoses must be determined by the treating and consulting physicians under generally accepted standards of medical practice in the community and, whenever

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[97]*Barber v. Superior Court* 195 Cal.Rptr. 484 (1983).
[98]*Barber*, p. 490-491.
[99]*Barber*, p.491.

possible, the patient himself should then be the ultimate decision-maker.[100]

When the patient is unable to make treatment decisions, a surrogate should base the treatment decisions on the patient's previously expressed thoughts and desires. Finding the physicians had no duty to provide ineffective treatment and that treatment was discontinued by the request of an appropriate surrogate, the court exonerated the physicians.[101]

It is interesting that Associate Judge Compton did not perceive a potential conflict between what qualified as "futile" treatment and that which could be considered "medical treatment of debatable value." For example, the nutrition and hydration Mr. Herbert received was considered life-sustaining in that it provided enough calories and fluid to maintain his biologic existence. Some would classify such treatment as "futile" in so far as it was an ineffective method of restoring Mr. Herbert's cognitive functions. Others could argue that while the treatment was effective, its use to perpetuate a state of permanent unconsciousness is of debatable value. Had Mrs. Herbert requested that artificial nutrition be continued, would the physicians have had a duty to accede to this request and provide life-support?[102]

The physicians caring for Mrs. Wanglie were presented with precisely this ethical dilemma and this case is "believed to be the first attempt in the nation to wrest control of a patient's fate out of a family's hand."[103] As described earlier, Mrs. Wanglie's family wanted to continue life-sustaining measures even though the hospital staff considered continued respiratory support "non-beneficial" .

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[100]*Barber*, p.492.
[101]*Barber*, p.492.
[102]Associate Justice Compton also referred to a "consensus" regarding the standard by which to evaluate treatment decisions for the irreversibly vegetative patient. I contend, however, that this consensus is potentially biased in that the cases he looked to for substantiation (*In re Quinlan*, *In re Dinnerstein*) were argued in the context that the incompetant patient in question would not have valued a vegetative existence if they had been competent to say so.
[103]M. Hansen. "Doctor's assert patient's right to die," *ABA Journal* , October, 1991, p. 26-27.

Because the respirator was considered "non-beneficial", the healthcare providers believed they were not obligated to provide it. According to Dr. Steven Miles, the ethics consultant at the hospital caring for Mrs. Wanglie, the hospital chose to address the issue of whether it was obligated to provide "non-beneficial" treatment by first asking for the appointment of an independent conservator who would decide if the respirator was beneficial. If this person concurred that the respirator was not beneficial, the hospital would request a second hearing to address whether there was an obligation to continue providing this non-beneficial treatment.[104] Naturally, Mr. Wanglie cross-filed requesting conservatorship of his wife.

Several authors have critiqued the manner in which this case was litigated.[105,106] If the actual issue was whether or not physicians are required to provide treatment they consider "non-beneficial", requesting an independent conservator was perhaps misdirected, if not inappropriate. Mr. Wanglie was the most suitable person to act on behalf of Mrs. Wanglie's interests and previously expressed convictions concerning life-prolonging care. Although, there was some debate about whether she had explicitly expressed her desires, it could be easily deduced that she might have chosen to continue respiratory support given her religious background and moral convictions.

Robert Schwartz, in "Autonomy, Futility, and the Limits of Medicine" contends that Mrs. Wanglie's physicians should have argued the real issue, namely, that continuing life-sustaining care in persistently vegetative persons is beyond the limits of medicine.[107] While this is certainly a more direct approach,

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[104]S.H. Miles. Informed demand for "non-beneficial" medical treatment. *N Eng J Med.* 1990; 325:512-515.
[105]R.L. Schwartz. Autonomy, futility, and the limits of medicine. *Cambridge Quarterly of Healthcare Ethics.* 1992; 2:159-164.
[106]D.H. Johnson. Helga Wanglie revisited: medical futility and the limits of autonomy . *Cambridge Quarterly of Healthcare Ethics.* 1993;2:175-184.
[107]Schwartz, p.161-162.

the question as to *why* this therapy was "beyond the limits of medicine" given its appropriateness in similar circumstances not so long ago would have to be addressed. In fact, less than twenty years ago, physicians considered it unethical and contrary to professional integrity to withhold such treatment.[108] Why the turnaround in medical thinking? Moreover, recent cases suggest that the medical profession has not reached a universal consensus on how these patients should be managed.[109]

Given that Mrs. Wanglie was technically alive, it would also be necessary to explain *why* maintaining her "living" body was beyond the realm of medical intervention. Ultimately, I believe, this discussion would distill out the major issue vexing health care providers. Namely, medical professionals consider it an affront to their integrity to be compelled to provide care for persons whose appreciation for life does not go beyond the maintenance of basic biologic function. The substantive issue would appear to be a conflict between the state's interest in helping to preserve the moral integrity of the medical profession and its interest in preserving life. The courts, however, have been reluctant to become involved in an analysis of the quality of life when determining state interests.[110]

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[108]*In re Quinlan,* p. 665.

[109]See *Brophy* and *In the Matter of Jobes*

[110]See *Brophy, Superintendant of Belchertown v. Saikewicz, In the Matter of Conroy, Barber v. Superior Court* and most recently *In re Cruzan. In re Cruzan*, the majority asserted that the state could assert "an unqualified interest in the preservation of in human life..." The dissenting opinions, however, emphasize that the state only had an interest in life in so far as the patient has an interest in his or her life. In particular, Justice Stevens in his dissenting opinion writes "...if they were *any* evidence that Nancy Cruzan herself defined life to encompass every form of biological persistence by a human being, so that the continuation of treatment would serve Nancy's own liberty, then once again there would be no conflict between life and liberty." He goes on to say, "Choices about life and death are profound ones, not susceptible of resolution by recourse to medical or legal rules .... Tomarrow, another State equally eager to champion an interest in "quality of life" might favor a policy designed to ensure quick and comfortable deaths by denying treatment to categories of marginally hopeless cases." It would appear, therefore, that the majority's pro-life stance and the dissenting opinion's view of defining the right to life in terms of the patient's interests would both support Mrs. Wanglie's right to continue life-support.

These issues, unfortunately, are likely to become more rather than less complicated. As patients are asked to consider their end-of-life treatment directives under the Patient Self-Determination Act, the uncertainty surrounding life-support decisions will be diminished.[111] Theoretically, patients could chose anything between "everything that can be done" to "withhold all care" when making end-of-life decisions. If patients are stating their directives in the form of a legal contract, is this a contract requiring that the patients' choices be carried out? If patient self-determination papers are to be meaningful, either medical professionals must be willing to accept decisions they may not necessarily agree with or guidelines need to be established delineating what may and may not be legitimately required or expected.

Until a uniform statute establishes guidelines concerning life-support and the incompetent patient or until the issue of obligation for "non-beneficial" treatment is adequately addressed by the courts, it is unclear whether or not physicians may, under protection of the law, withhold or withdraw life-sustaining therapy without the consent of the patient or appropriate surrogate.

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[111]The Patient Self-Determination Act requires that all health care facilities receiving federal funds provide their patients with information about living wills and durable powers of attorney.

Chapter 3:
Ethical Perspective

Although futility is frequently used as a rationale for withdrawing or withholding life-sustaining treatment, its practical application raises several questions. What is really meant when the term "futile" is used? Is this term objectively applied? How reliable are physicians at predicting the futility of further care in a particular patient? Is this determination absolute or is it contigent on an evolving set of circumstances. Is the concept of "futilty" culturally defined? Can the withholding or withdrawing of "futile" care be supported on grounds of justice? Does it represent a legitimate conflict between patient autonomy and professional integrity? This section will investigate these questions and demonstrate that the term raises several ethical concerns that threaten its legitimacy as a rationale for unilaterally withholding life-sustaining therapy.

A. Ambiguity:

Part of the problem with using "futility" as an ethical argument for withholding or withdrawing life-sustaining treatment resides in the ambiguity of the term itself. A "futile" treatment can either be a predictive evaluation of whether the treatment will work (e.g. physiologically, statistically, theoretically, etc.) or it can be a qualitative assessment of whether or not the therapy is "worth it". For some, treatment is considered futile if it does not satisfy or achieve its physiologic end. For example, it would be futile to perform dialysis on a patient who had inadequate perfusion pressure because the physiologic goal of dialysis, that of cleansing the blood of waste products, would not be achieved. In this narrow sense of the term, the proposed treatment and its physiologic goal are evaluated outside of the psychosocial context such that a simple equation of whether treatment "X" will achieve goal "Y" given certain physical and metabolic parameters can be addressed. The term, therefore, not only defines what can be potentially expected physiologically, but it also establishes the absolute limit of medical obligation. If a treatment is "clearly futile in achieving its physiologic objective and so offers no physiologic benefit to the patient, the professional has no obligation to provide it."[112] Once physiologic futility has been established, it seems illogical to ask physicians to do more than humanly possible.

In medicine, however, such clear-cut cases in which physiologic futility can be clearly delineated are few and far between. Decisions are often based on past experiences, published research, or clinical intuition. Accordingly, Schneiderman *et al.* propose a definition of futility that views probability and utility as independent thresholds. In terms of probability, if a physician

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[112]*Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying: A Report of the Hastings Center.* Briarcliff Manor, NY: Hastings Center; 1987:32.

concludes either through personal experience, experiences shared with colleagues, or in consideration of published data that the proposed treatment has been "useless" in the last 100 cases, the treatment should be considered futile.[113] This determination, however, raises several methodological questions. For example, how similar must the patients be? Does one examine the last 100 patients or should they be stratified according to age, etiologic agent, co-existing illnesses, etc.[114] Moreover, how similar must the physicians or medical center be? Should training, experience, or the level of care provided by the hospital be factored into the equation? Lastly, what temporal endpoint should be used when assessing the success or failure of the proposed treatment? Should the treatment be considered futile if the patient would survive only a few hours or a few days? Or would survival to discharge or some other date following discharge be a more appropriate end point for assessing therapeutic efficacy? Once the pertinent variables are accounted for, it is highly unlikely that a single physician would know of 100 cases that met the criteria necessary to make a "qualified" calculation of probability.[115] Outside of a large national computer network that continuously updated and recalculated statistics, precision in such a calculation is certain to be low. Therefore, when a doctor uses statistical probability to predict the outcome of a specific patient, he or she is acting on a sophisticated medical hunch -- a fact that Schneiderman's 100 person distinction disregards.

Schneiderman's utility distinction, on the other hand, evaluates therapeutic options in terms of effect and benefit. While an effective treatment is

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[113]L.J. Schneiderman, N.S. Jecker, and A.R. Johnsen. Medical futility and ethical implications. *Ann Int Med.* 1990;112:949.

[114]R.D. Troug, A.S. Brett, and J. Frader. The problem with futility. *N Eng J Med.* 1992;326:1560-63.

[115]A similar criticism of Schneiderman's probability calculation was raised in a recent article by David H. Johnson. See D.H. Johson. Helga Wanglie revisited: medical futility and the limits of autonomy. *Cambridge Quarterly of Healthcare Ethics*. 1993; 2:161-170.

limited to influencing some aspect of the patient's physiology, a beneficial treatment must appreciably improve the patient as a whole. If a treatment is effective but fails to be beneficial, the treatment must be considered futile. By this definition, futility is not judged in terms of physiologic objectives, but rather in terms of holistic benefit. Intuitively, this approach makes sense. A treatment should not merely influence the balance of electrolytes or tinker with serum pH levels, it should beneficially impact the patient's overall health and happiness.

The question then becomes who determines benefit and what criteria are used to define this concept? A "benefit" implies a result that is perceived as a "good". Because perception is inherently a subjective assessment, and therefore influenced by particular value systems, goals, and beliefs, the agent doing the perceiving becomes an important consideration. For example, a doctor may consider the placement of a gastrostomy tube in a patient with end-stage esophageal cancer beneficial because it would insure nutritional delivery, thereby delaying the development of cachexia and, thus, prolonging life. A patient, on the other hand, might not perceive such a an action as beneficial. The procedure itself is initially painful and carries potential side effects (e.g. infection, electrolyte imbalance, etc.); and while it may extend the patient's physical existence, it might also prolong the pain associated with cancer and diminish the patient's perception of the quality of his or her life. Moreover, it might compromise some other valuable end. For example, the terminal patient may place tremendous value on a death with dignity and feel that dependence on artificial nutrition would compromise that dignity. While the procedure would be consonant with the goals of the physician (i.e. preventing disease and prolonging life), it might not be in accordance with the patient's goals.

Dr. Kate Christenson attempts to address the complicated issue of beneficence by advocating a definition of futility that is meaningful in relationship

to the patient's values and goals. She clarifies this position, however, by stating that only the "patient's realistic or appropriate goals" need be considered.[116] Once again, this distinction begs the question of what criteria are used to define "realistic" or "appropriate" and whose value systems are used to establish the criteria. A "realistic" goal can be one that is physiologically possible or it can be one that is hopeful given a certain statistical probability. The designation of "appropriate" is also goal dependent. In the case of Mrs. Wanglie, the physicians and family did not agree on the goals of medical treatment and, therefore, inevitably disagreed on what could be considered "appropriate" medical therapy. The medical staff perceived returning Mrs. Wanglie to a sapient form to be the end goal of medical intervention. Given the irreversibility of her condition, the respirator would not serve to attain this goal. Therefore, its employment would not be appropriate. The family, on the other hand, considered the preservation of life, in whatever form, the goal of medical intervention. The respirator was not only appropriate, but essential for Mrs. Wanglie's continued existence.[117] While terms like "realistic" and "appropriate" appear to be less value-laden, they merely sidestep the ambiguities raised by the term "futility" and we are no closer to determining who should make the decisions or how they should be made.

In essence, the debate over whether or not physicians should be required to provide futile treatment is obscured by the fact that there is no universal definition of what constitutes "futile" care. Aside from that which is physiologically impossible, the term "futile" can be understood only in relation to goals or valued endpoints. When the endpoint is life, physicians have no

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[116]K. Christensen. Applying the concept of futility at the bedside. *Cambridge Quarterly of Healthcare Ethics*. 1992; 3:242-248.
[117]M. Angell. The case of Helga Wanglie: A new kind of "right-to-die" case. *N Eng J Med.* 1991;325:511-512.

greater insight as to what constitutes a "good" or "benefit" than the average person. Issues of life and death and that "somewhere in between" state are complex because they touch the very core of what it means to be "living", "dead", "human", "spiritual", etc. "Physicians *qua* physicians are not expert on these philosophical questions, nor are they expert on the question of which physiological functions decisively identify a 'living, human organism'."[118] The question of what is "futile", therefore, is not merely a medical assessment. It is a question of serious philosophical, religious, and personal import.

B. Bias/inequity:

If the definition of what constitutes "medical futility" is ambiguous at best, its practical application in end-of-life decisions is even more problematic. Although medical futility is often cited as a primary reason for limiting medical care[119] , the assessment of "futile" may not be applied impartially. In fact, what one person considers "futile" may be influenced by one's attitudes and perceptions of different patients as well as different disease processes. In one study investigating DNR orders, Wachter *et al.* analyzed the frequency of DNR orders for four different diseases with similar prognosis (AIDS, unresectable non-small-cell lung cancer, cirrhosis with esophageal varices, and severe congestive heart failure with coronary artery disease). Even after adjusting for potential confounders (e.g. functional mental status, reason for admission, severity of illness, etc.), a strong association between DNR orders and specific

[118]A.M. Capron and L.R. Kass. A statuary definition of the standards for determing human death: an appraisel and a proposal. 121 *U.Pa.L.Rev.* (1972), p. 94.

[119]Bernard Lo, G. Saika, W. Strull, E. Thomas, and J. Showstack. "Do not resuscitate" decisions: a prospective study at three teaching hospitals. *Arch Intern Med.* 1985;145;1115-1117. This study investigated DNR orders considered at three different teaching hosptials. Of the 136 cases in which DNR orders were considered, physicians indicated that further medical treatment would be futile in 120 cases (88%).

disease persisted. DNR orders were discussed more frequently with patients who had AIDS or lung cancer than those with congestive heart failure or cirrhosis despite an accurate understanding of the similar prognosis by clinicians. Moreover, patients with AIDS and lung cancer who received DNR orders were less likely to be in an intensive care unit or have an in-hospital precipitating event than those with cirrhosis or heart failure who received DNR orders. The authors of this study concluded that physicians approach the issue of DNR status unequally in patients with different diseases despite their similar prognosis.[120]

Even when presented with the same case, variability in medical decision making and rationale exists among physicians. Residents, attending physicians, and private practitioners in internal medicine and family practice were asked to read a clinical scenario and then indicate their treatment preferences. The scenario described an elderly man with a long history of chronic obstructive lung disease who presented to the emergency room with acute respiratory compromise and presumptive bacterial bronchitis. Despite treatment (low flow oxygen, antibiotics, etc.), his condition worsened over the next few hours. Using an 11-point interval scale, the physicians were asked to make a decision to "intubate" or to continue "current therapy without intubation." They were then asked to consider 25 cards with additional information concerning the patient's physiologic status, his socioeconomic situation, and any professional consultations. The nature of the information (e.g. religion, insurance status, etc.) was printed on the front of the card with the patient's information hidden from view. The physicians were asked to arrange the cards on an 11-point scale ranging from "unimportant" to "very important". They were then asked to select

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[120]R.M. Wachter, J.M. Luce, N. Hearst, and B. Lo. Decisions about resuscitation: Inequities among patients with different diseases but similar prognoses. *Ann Int Med.* 1989;111:525-532.

8 cards they would want if they only had 2 hours in which to gather information necessary to make a final treatment decision. With the additional information, they were asked about intubation again and then asked to explain the rationale for their decision. The physicians were also asked to estimate the patient's expected survival time if intubated.

Examining the second treatment decision, it appears that different practice patterns influence both treatment decisions and the type of information considered necessary to make those decisions. Residents were more likely than attendings or private practitioners to forgo intubation and allow the patient to die. Private practitioners, on the other hand, were more inclined to intervene. Residents and attending physicians sought more socioeconomic information about the patient than did private practitioners, and they were more likely to place a higher value on this information. When asked to explain the rationale behind their treatment decisions, the nature of the acute problem and the patient's quality of life (as assessed by the physician) were the most common considerations. Of the ten most common reasons for treatment status, the interpretation of what the patient and/or family would desire ranked at the bottom. Estimates of life-expectancy also varied among physicians with residents and attendings estimating a shorter life-expectancy for the patient than private practitioners.[121]

Treatment decisions practitioners make are also influenced by variables that are not necessarily related to prognosis. Studies have shown that other factors such as race may influence the level of care patients receive.[122,123]

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[121]R. Pearlman, T. Inui, and W. Carter. Variability in physician bioethical decision-making: a case study of euthanasia. *Ann Int Med.* 1982; 97:420-425.

[122]Yergan J: Relationship between patient race and the intensity of hospital services. *Med Care* 1987; 25:592-603.

[123]S.M. Johnson. Students' sterotypes of patients as barriers to clinical decision-making. *J Med Educ.* 1986;61:727-735.

Clearly, different physicians perceive patients differently. This variation in perception may influence decisions to withhold or withdraw life-sustaining treatment such that therapy for some patients may be considered medically "futile" while for others it may not. This situation raises serious ethical concerns about justice. According to the principle of justice, likes ought to be treated equitably.[124,125] If physician bias influences treatment decisions such that similar patients are treated unequally, it is highly likely that the subjective term "futile" will also be applied inequitably.

C. Predictive Assessment:

The use of "futility" as an argument for withdrawing or withholding life-sustaining care is also a predictive assessment and is, therefore, dependent on whether or not the anticipated outcome actually comes to fruition. Consider for example, a eighty-nine year old man with a long history of chronic obstructive pulmonary disease who is found unconscious. The paramedics are called and CPR is initiated immediately. He is brought to the local emergency room and found to be in a coma. He is consequently placed on a ventilator and admitted to the intensive care unit. After seven days, the ICU staff believes that to continue respiratory support would be futile. The primary care physician disagrees. Life-support is continued against the protests of the staff. In a month the man recovers from the coma. Three months later he is weaned off of the respirator and he returns home to live a happy and productive life. If the

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[124] Wachter *et al.*, Decisions about resuscitation: Inequities among patients with different diseases but similar prognoses, p. 525-532.
[125] Beauchamp and Childress, Principles of Biomedical Ethics, p. 259.

treatment produced benefit, despite the predicted outcome, was it in actuality "futile" to continue care?

If the reliability of a futility judgment depends on prognostication, how accurately do physicians predict treatment outcomes? The issue of assessing outcome is complicated, as we have seen, because of variability in physician perception and treatment preferences exists.[126] Even when presented with the same patient, physicians vary in their predictions of life-expectancy.[127] Nonetheless, physicians are fairly accurate in predicting who will survive hospitalization and who will not, although they tend to overestimate the overall mortality risk when compared to more objective prognostic scoring systems.[128]

The disease process itself may make it difficult for the practitioner to anticipate treatment outcome. For example, while recovery from a persistent vegetative state is a relatively rare occurrence, the recovery from a cardiopulmonary arrest is less predictable.[129] After examining several papers investigating the success of in-hospital cardiopulmonary resuscitation (CPR), L. J. Blackhall reports that 16 to 45% of the patients in which resuscitation was attempted survived the procedure. Only 5 to 23% of the total patients, however, survived until hospital discharge. When survival is further broken down by disease category, CPR is virtually ineffective in reviving patients with concomitant cancer, gastrointestinal hemorrhage, sepsis, or acute stroke.[130] It therefore appears that not all CPR attempts are created equally and that underlying disease processes influence the potential success of the intervention.

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[126]The reader is referred to the previous section entitiled for a more in-depth discussion of bias and treatment inequity.

[127] Pearlman *et al.,* Variability in physician bioethical decision-making: a case study of euthanasia, p. 420-425.

[128]W.A. Knaus, D.P. Wagner, and J. Lynn. Short-term mortality predictions for crtically ill hospitalized adults: science and ethics. *Science*. 1991; 254:389-394.

[129]R.E. Cranford. The persistent vegetative state: the medical reality (getting the facts straight). *Hastings Center Report.* 1988:Feb./March p. 27-32.**

[130]L.J. Blackhall. Must we always use CPR? *N Eng J Med.* 1987;317:1281-1284.

While "prognostication will identify broad categories of patients in whom long-term survival after CPR is highly unlikely", it may be impossible to identify a particular person in whom CPR would be unquestionably futile. Because a successful resuscitation attempt depends on a variety of factors (timing, coordinated intervention strategies, patient characteristics, underlying disease processes, etc.), "(t)he empirical and individual nature of (a) survival makes it difficult to know beforehand whether a given patient is an 'ideal candidate' for CPR."[131] Factors not necessarily associated with the underlying cause of the arrest may also influence the likelihood of survival. In a study conducted by Taffet *et al.*, for example, patients were more likely to survive CPR if a witness was present during the arrest or fewer medication doses were given during the resuscitation effort.[132] In addition, other variables such as the patient's psychological state or the availability of a strong and caring support network have not been traditionally investigated, but may also influence whether or not a patient survives an arrest.

Prognostic scoring systems may provide a more objective and more reliable method of predicting which patients would most benefit from intensive, life-sustaining treatment. Many advocate the Acute Physiology, Age and Chronic Health Evaluation III system (APACHE III) as a method of accurately estimating therapeutic outcomes.[133,134] Drawing on the statistics of a large database of adults admitted to surgical and medical intensive care units, the APACHE III uses a multivariable analysis of physiology, age, and co-existing

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[131]D.L. Schiedermayer. The decision to forego CPR in the elderly patient. *JAMA.* 1988;260:2096-2097.
[132]G.E. Taffet, T.A. Teasdale, and R.J. Luchi. In hospital cardiopulmonary resuscitation. *JAMA.* 1988;260:2069-2072.
[133]W.A. Knaus. Ethical implications of risk stratification in the acute care setting. *Cambridge Quarterly of Healthcare Ethics.* 1993;3:193-196.
[134]D.P. Schuster. Everything that should be done - not everything that can be done. *Am Rev Respir Dis.* 1992;145:508-509.

conditions to derive a score that is combined with weighted coefficients for disease and selection criteria in order to predict the likelihood of death before hospital discharge. Because it uses a multivariate analysis approach, the many variables that describe a particular patient's condition can be considered simultaneously. With a more complete understanding of the clinical picture, the APACHE III provides a more accurate prognosis than does clinical impression.[135]

Unfortunately, while the APACHE III may be good at predicting whether or not a given patient is likely to die during hospitalization, it does not give a sense of how long the patient will live or what his quality of life will be like during the interim. Moreover, the application of the APACHE III in real time could actually compromise patient care. If patients' scores are continuously recalculated and displayed, it could potentially influence care in such a way as to become a self-fulfilling prophecy. Patients at moderate or increased risk for in-hospital mortality may receive less aggressive care because the staff may perceive that the patient's risk for demise has been pre-set or is unalterable. The staff may also believe that the patient's quality of life is not worth preserving and, although the patient's score does not indicate a serious risk of mortality, may interpret the score as heralding the beginning of the end.[136] If so, the staff may be less aggressive than they would be normally for the same APACHE score.

While the APACHE III provides one of the most reliable prognostic models, it is unable to predict with 100% certainty that a particular patient will die

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[135]Knaus *et al.*, Short-term mortality predictions for critically ill hospitalized adults: science and ethics, p. 389-394.

[136]For example, patients in persistent vegetative states can live for many years primarily because involuntary reflexes (e.g. gag and cough reflexes) continue to function normally. Although the patient is completely unconscious, the underlying clinical condition is not affected by the lack of cerebral cortical function and they might not have a low APACHE score. See RE Cranford. The persistent vegetative state: the medical reality (getting the facts straight). *Hastings Center Report* Feb/March 1988:27-32.

despite aggressive intervention. Given this element of uncertainty, as small as it may be, what role should prognostic scoring systems play in the futility debate? Could treatment deemed statistically futile be withheld against patient consent? Dr. William Knaus, one of the principal developers of the APACHE scoring system, considers it disadvantageous to use risk stratification as a litmus test by which certain treatments or therapies would not be offered once a specific risk level was achieved despite the patient's preferences or values. Instead, he stresses that the APACHE score could enhance physician-patient communication by providing the patient with sound data as opposed to clinical instinct or personal bias. By painting a more realistic picture of the clinical condition, the system could then make more meaningful end-of-life choices available to patients as they relate to their goals and values.[137] In my opinion, this approach is ethically valid in that it preserves patient autonomy and upholds the notion of informed consent. With more accurate information available, patients are more likely to give informed consent that is truly informed. While the APACHE score could play a major role in clinical decision-making, it should not be the *sine qua non* for withholding therapeutic interventions.

Nonetheless, some physicians may consider the APACHE score the evidence necessary to bolster a judgment of futility. With firm data in hand, they may consider it within the realm of professional discretion to unilaterally withhold treatment that is likely to be non-beneficial. Unfortunately, unless the APACHE system is applied across the board as a method of determining "futility", its sporadic application is likely to contribute to the confusion and confrontation already associated with the futility debate. Without a prior understanding between the physician and patient or proxy that statistically ineffective care will

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[137]Knaus W.A., Ethical implications of risk stratification in the acute care setting, p. 193-196.

be withheld or withdrawn, it would be unfair to patients for some practitioners to deny care based on APACHE scores when others took into consideration patient's desires and goals.

With the advent of highly sophisticated prognostic scoring systems, the determination of which treatments are likely to be non-beneficial will become more refined. Yet, even with the most sensitive system in place, the determination of futility is still a predictive assessment. While prognostic scores should definitely play a role in decision-making by providing patients and physicians with a more accurate understanding of the clinical situation, the patient-physician relationship will suffer if risk stratification replaces compassionate discussions and shared decision-making.

D. Static Judgment:

While illness is a temporal phenomenon, futility is a static judgment. That is to say, a judgment of futility is a snapshot assessment based on a specific set of circumstances that may or may not change over time. As the course of an illness waxes or wanes, the determination of what is considered futile will also change. Untoward events such as sepsis or pneumonia may complicate the clinical picture and increase the likelihood that certain therapeutic interventions will not prove effective. At other times, patients may find the strength to stave off death and return from the most doomed of courses.[138] Because the patient's

[138]This point is poignantly illustrated by Dr. Dunphy in "On Caring for the Patient with Cancer". In this essay, Dr. Dunphy descibes a patient that had histologically diagnosed cervical cancer that failed to respond to surgical and radiation therapy. At the time of discharge to the "Home of the Holy Ghost", a nursing home for terminal patients, she was moribound with severe anemia, cachexia, and profuse bloody vaginal discharge. The discharging physician noted in her chart that it was likely that the patient would live only the next day or two. Twelve years later, when Dr. Dunphy was making rounds at the nursing home in attempt to help update their medical records, he came across this woman who, except for the signs of heavy irradiation to her pelvis,

condition is continuously evolving, the futility of a particular treatment may also change and many people advocate reevaluating the patient's situation on a regular basis.[139] What was "futile" today may not be "futile" tomorrow; and what appears to be an improving course could always take a turn for the worse.

The set of circumstances dictating the "futility" of a treatment will also vary according to environment and resources. For example, the facilities and technical support available at a large teaching hospital in San Francisco make a liver transplant a viable option for someone in hepatic failure. If the same patient were at a small village hospital in Tanzania, on the other hand, the prognosis and the utility of available treatment would be very different. The likelihood of certain procedures and therapies producing benefit will vary according to location and access to resources in the United States as well. The futility of open chest cardiac massage, for example, will depend on whether the procedure is being done at a trauma center or at a rural emergency room, whether the attending physician is a thoracic surgeon or a podiatrist, or whether the patient was transported 60 miles by car or by a life-transport helicopter .

As technology advances, the criteria used to define futility will also change. In situations such as persistent vegetative states new advances occur extremely slowly so that what is perceived as "futile" today is likely to be futile for at least the next 10 years. Advances in neonatology, on the other hand, occur at such a rapid pace that what was considered "futile" five years ago may be standard practice today.

The determination of futility, therefore, is not an absolute definition and is contingent upon an evolving set of circumstances. As the course of illness

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had made a complete recovery and was in excellent health. See J.E. Dunphy. On caring for the patient with cancer. *N Eng J Med.* 1976;295:313-319.

[139]T.D. Kinsella and C.B. Stocking. Failed communications about life-support therapy: silent physicians and mute patients. *Am J Med.* 1989;86:643-644.

changes, as access to resources and technology improve, or as advances in medical management are made, the definition of what constitutes "futility" will also change in response to the changing circumstances.

E. Cultural views of illness

Illness is not merely a disease process. It is a cultural expression with "punitive or sentimental fantasies." Sickness says something about the person's character, moral fiber, and ability to cope within society. It can be the curse of unhappy gods or the body's manifestation of unexpressed passion. Whatever the underlying medical explanation, illness has cultural meaning and significance.[140,141] Likewise, medical decisions are not made in a scientific vacuum and are influenced by cultural values and beliefs.

Medicine itself can be viewed as a culture with its own distinct values and beliefs. Just as children learn cultural norms, students of modern medicine are acculturated as to what is valuable, appropriate, and acceptable. Advancing technology has blurred the lines between life and death, calling into question the traditional beliefs surrounding this transition. For those in medicine, it would appear that technology has teased out the subtle components of what constitutes "life". On the one hand, there is "organic" existence, a state of physiologic being in which the body continues to function but without cognitive awareness. In this state there is no hope for self-realization, pleasure, or pain. On the other, there is "personhood" -- an awareness of self and one's relationship to the external world. The concept of personhood embodies the

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[140]S. Sontag, Illness as Metaphor, (New York: Vantage Books, 1978).
[141]L. Romanucci-Ross and L.R. Tancredi. The Anthropology of healing. in In Search of the Modern Hippocrates, ed. by RJ Bulger, (Iowa City:University of Iowa Press,1987), p. 127-145.

experiential notion of a life with passions, dreams, and disappointments. While it was once considered unethical to withdraw life support from a permanently comatose patient, there is currently a common perception in medicine that the "organic" or "vegetative" state is not worth preserving.[142,143] To preserve such a state through artificial means would be morally wrong.[144] Rather than acknowledging that this view of "life" is as much a product of medical culture as any other culturally defined value, those in the profession attempt to frame the discussion outside the realm of values by using terms like "futile" or "medically inappropriate."

The Wanglie case provides an interesting clarification of this point. Mrs. Wanglie was ventilator-dependent both before and after she fell into a persistent vegetative state. If the respirator continued to perform the same function in both states (i.e. ventilate the lungs and oxygenate the blood), why was the respirator considered appropriate in the former case, but not in the latter? Before suffering a cardio-pulmonary arrest, Mrs. Wanglie was in a state recognized as valuable by the medical culture even though she was ventilator-dependent. Once becoming permanently comatose, however, Mrs. Wanglie lost her "personhood" in the eyes of the medical community. Because an "organic" existence is not perceived as valuable, it was philosophically consistent to declare continued life-support inappropriate.

The medical dissection of what constitutes "life" and the value placed on "personhood", however, is not a universally accepted notion. In a recent study exploring the effect of values and culture on life-support decisions, J. Klessig asked 230 patients of different ethnic backgrounds living in Los Angeles to read

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[142] For example, Karen Quinlan's physicians argued that it would be contrary to the goals of medicine to discontinue respiratory assistance.
[143] A. Johnsen. What does life support support? *The Pharos*. 1987; Winter, p4-7.
[144] "Courts Continue to wrestle with the Wanglie and Lawrence cases," *Hospital Ethics*, Sept./Oct. 1991. p.12-14.

eight different clinical scenarios in which continued treatment was hopeless or the patient was terminal. Four scenarios dealt with starting life-support and four with stopping life-support. Only Jewish and Caucasian groups strongly objected to starting life support. The rest strongly agreed (Filipino, Iranian), agreed (African-American, Korean), or were equivocal (Chinese, Mexican-American) about initiating life-support. As to discontinuing life support, only the Jewish group strongly agreed that life-support should be stopped. The Filipino group, on the other hand, strongly disagreed with stopping life-support. The rest either agreed (Chinese, Caucasian), were equivocal (Mexican-American) or disagreed with stopping support (African-Americans, Iranian, Korean). It would appear that the desire not to use life-support (combining both decisions to start and to stop treatment) are primarily Caucasian and Jewish ideals.

Moreover, although the President's Commission found no moral difference between not starting treatment and stopping treatment, it appears that some groups do make a distinction.[145] If not starting and stopping life-support are considered morally equal, then one would expect the percentage of people who did not support initiating treatment to roughly equal the percentage of people who agreed that life-support should be stopped. This conclusion does not appear to be the case for all groups investigated. Looking at the African-American group, in particular, 40% did not believe life-support should be initiated. When withdrawal of life-support was considered, 60% believed that life-support should be terminated. It would appear that the African-American

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[145]President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions.* Washington, D.C.: U.S. Government Printing Office, 1983, p. 73-77.

group was more inclined to start the treatment, but that this treatment could be withdrawn later when the situation was shown to be hopeless.[146]

When considering life-support decisions, the clinician needs to be aware that "physicians, too, carry value systems that relate to their past experiences, upbringing, and ethnic identity."[147] What the medical profession considers important or morally compelling may not be held in high esteem by other cultures in the United States. In order to avoid episodes of miscommunication and potentially difficult and painful confrontations, it is imperative that the healthcare provider be attentive to cultural differences and seek expert advice whenever uncertainty exists. Because medicine as a culture influences what physicians perceive as valuable, it is important to remember that others may not define the same elements as "valuable" or label other things as "futile".

F. The limits of interpersonal relationships

The issue of medical futility raises serious questions and much confusion about what should and should not be discussed with patients and their families. Most often the question of whether or not to discuss "futile" treatment arises when considering the use of cardiopulmonary resuscitation (CPR) and do-not resuscitate orders (DNR's).[148] As with most ethical quandaries, there is no consensus on an obligation to discuss "futile" care with patients, and the

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[146]J. Klessig. The effect of values and culture on life-support decisions, In Cross-cultural Medicine - A Decade Later (Special Issue). *West J Med.* 1992;157:317.

[147]ibid. p. 319

[148]CPR is an emergency procedure in which consent need not be obtained from the victim in an unexpected cardiac arrest. It is a treatment that, in a limited sense has gone beyond the realm of purely medical intervention. Basic life support is taught to Girl Scouts, lifeguards, police, firefighters, and essentially anyone else who wants to learn its life-saving techniques. Atlhough the resuscitation effeort in the intensive care unit may look nothing like the simple chest-compression, mouth-to-mouth routine depicted on television, the public may not appreciate the difference. This misperception coupled with the fact that many may expect that CPR will be performed, makes CPR a difficult treatment to potentially withhold without consent.

spectrum of opinion ranges from complete nonobligation to absolute patient determination. If the treatment is truly futile, it is argued, then the physician is under no obligation to discuss the option with the patient or family.[149,150,151] It would be ridiculous, not to mention incredibly time consuming, to require physicians to discuss all non-beneficial treatment options with their patients or proxies. Other physicians appeal to the moral principle of veracity and suggest that offering futile treatment is deceitful because it implies a potential for benefit when none actually exists.[152,153] Still others recommend that even if futile treatment is not offered, the decision and rationale should be discussed with the patient and/or family, thereby providing more open communication.[154,155] Finally, advocates for patient's rights advise that the final decision regarding resuscitation should be made by patients in relation to their own goals, values, and beliefs.[156] Clearly, with so many different recommendations, it is no wonder

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[149] Schneiderman *et al.,* Medical futility and ethical implications, p. 949-954.

[150]J.C. Hackler and F.C. Hiller. Family consent to orders not to resuscitate: reconsidering hospital policy. *JAMA*. 1990;264:1281-1283.

[151]Tomlinson and Brody elucidate three rationales for do-not-resuscitate orders: no medical benefit, poor quality of life after CPR, and poor quality of life before CPR. For the latter two rationales, the justification for a DNR order is based on the individual patient's values. DNR orders based on no medical benefit, however, need not be discussed because "the justification for the order would not rest on information about the patient's values or preferences." See T. Tomlinson and H. Brody. Ethics and do-not-resuscitate orders. *N Eng J Med.* 1988;318:43-46.

[152]Once again the definition of what constitutes the potential for benefit is debatable. In this article, Dr. Blackhall argues that futile treatment should not be offered. She later goes on to say that when survival rates are low, but real (<5%), patient autonomy should be the overriding principle. There is no consensus, however, on the point at which the likelihood of a successful treatment moves from the "low" to the "futile" category. L.J. Blackhall. Must we always use CPR? *N Eng J Med.* 1987;317:1281-1284.

[153]K. Christensen. Applying the concept of futility at the bedside. *Cambridge Quarterly of Healthcare Ethics*. 1992;3:242-248.

[154]ibid., p. 242-248.

[155]G.R. Scofeld. Is consent useful when resuscitation isn't? *Hastings Center Report.* Nov.-Dec. 1991: 28-36.

[156]President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions.* Washington, D.C.: U.S. Government Printing Office, 1983.

that the question of discussing "futile" treatment creates confusion and anxiety for both physicians and patients.

Aside from believing that physicians are not obliged to discuss nonbeneficial treatment, why do some doctors refrain from discussing the futility of further interventions with their patients? Physicians may be hesitant to initiate end-of-life discussions because they fear these talks may be difficult for patients and their families. They may feel that they already know the patient's wishes or that directly addressing the issue would only create undue anxiety and psychological harm. By not talking about the futility of further intervention, the doctor may feel that he or she is "doing the right thing."[157]

Yet, the decision not to discuss futile care may also give physicians a means of avoiding difficult conversations. Although physicians encounter death on a regular basis - caring for patients who struggle with their chronic illnesses until the end, rushing to aid the victims of senseless and irrational violence, comforting those left behind to grieve the tragic loss of loved ones - death remains an uncomfortable topic. Doctors often feel uneasy and awkward talking to patients and families about death.[158,159] Death is perceived as the antithesis of all that medicine is trying to accomplish; to discuss its possibility is to admit, if only transiently, that the physician may fail. Although the majority of physicians endorse the notion of patient participation in resuscitation decisions, few physicians actually discuss this issue with their patients before an in-hospital

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[157]In a study designed to investigate the extent to which private physicians and house officers discussed CPR with patients and/or their families, Bedell and Delbanco report that physicians in general tend to form an opinion about a patient's desire for resuscitation *a priori* of direct conversation. In addition, private physicians are more likely to believe that it is the physician's responsibility to make decisions about resuscitation for their patients. Many suggested that direct discussion would be too threatening to patients and would impose unnecessary guilt on the family. See S.E. Bedell and T.L. Delbanco. Choices about cardiopulmonary resuscitation in the hospital: When do physicians talk with patients? *N Eng J Med.* 1984;310:1089-1093.

[158]A.L. Peters. Death and medicine: A personal account. *Am J Med.* 1990; 89:81-82.

[159]R.P. Durand, G.E. Dickinson, E.D. Sumner, and C.J. Lancaster. Family physicians' attitudes toward death and the terminally-ill patient. *Family Practice Research Journal.* 1990;9:123-9.

arrest occurs.[160,161] Physician insecurity and reluctance to talk about death may partially account for this paradox.

Physicians may also fear that if they do discuss "futile" care they may be forced to perform a ritual that is not only futile but "dehumanizing". In a study investigating do-not-resuscitate decisions, DNR's were considered in 136 out of 3,282 patients. Of the 87 cases in which patients did not contribute to the discussion, family participation was only possible in 75 cases.[162] In 14 of these cases, however, family participation was not sought. Physicians did not seek family participation because they feared that the family would disagree with the DNR order (2 cases), they had difficulty with talking to the family (2 cases), they considered the medical indications for DNR order decisive, therefore, did not feel family input was necessary (2 cases), or they feared legal repercussions (1 case). In 6 of the cases where family participation was available but not invited, no reason for nonparticipation could be identified.[163] It would appear that physicians may opt to shun a discussion of the futility of CPR with families in order to potentially avoid a confrontation.

If discussions about resuscitation and life-sustaining measures do occur, they are often delayed until the patient is no longer able to communicate clearly their desires.[164] Unfortunately, this wait-to-the-last-moment approach makes investigating and carrying out the patient's treatment choices extremely difficult.

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[160]Bedell, Choices about cardiopulmonary resuscitation in the hospital: When do physicians talk with patients? p. 1089-1093.

[161]L.J. Blackhall, J. Cobb, and M.A. Moskowitz. Discussions regarding aggressive care with critically ill patients. *J Gen Int Med.* 1989;4:399-402.

[162]In 76 of these cases patitnt participation was no possible because of coma or severely impaired mental function. Of those capable of participation (N=60), 11 patients did not partke in discussion because the physician believed the patient's desires were already known (7 cases), the family requested the patient not be involved (2 cases), or for unkown reasons (2 cases). B. Lo, G. Saika, W. Strull, E. Thomas, and J. Showstack. 'Do-not-resuscitate' decisions: a prospective study at three teaching hospitals. *Arch Intern Med* 1985;145:1115-1117.

[163]Lo B *et al.,* 'Do-not-resuscitate' decisions: a prospective study at three teaching hospitals, p. 1115-1117.

[164]ibid., p.1115-1117.

Although the standard of substituted judgment is frequently used as a method of carrying out a patient's wishes, the practice is problematic in that neither physicians nor proxies appear to be especially good at predicting patients' desires for end-of-life treatment. When comparing the attitudes of patients who survived resuscitation with the physicians' opinions of their attitudes, Bedell and Delabanco found that the doctor's opinion about a patient's preference for resuscitation only weakly correlated with the patient's expressed desire.[165] When choices are left to surrogates, on the other hand, patients may receive more aggressive care than they would want. In a study that asked designated family proxies to make treatment choices for a patient in a hypothetical coma, proxies tended to overestimate the older patients' preference for life-sustaining treatment.[166] Advanced directives have been promulgated as means of improving communication by providing written documentation of the patient's treatment desires. Yet, strictly following advanced directives may not truly represent the patient's treatment preferences either.[167]

The only real means of avoiding the pitfalls of substituted judgment or the ambiguities of directives is by actually communicating, and continuing to communicate, with the patient. Most patients support collaborative decision making regarding the use of CPR.[168] And in general, patients want to discuss cardiopulmonary resuscitation and end-of-life decisions with their doctors, although only a few have actually done so.[169,170,171,172] While it is feared that

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[165]Bedell, Choices about cardiopulmonary resuscitation in the hospital: When do physicians talk with patients?, p.1089-1093.
[166]N.R. Zweibel and C.K. Cassel. Treatment choices at the end of life: a comparison of decisions by older patients and their physician-selected proxies. *Gerontologist*. 1989;29:615-621.
[167]A. Sehgal, A. Galbraith, M. Chesney, P. Schoenfeld, G. Charles, and B. Lo. How strictly do dialysis patients want their advance directives followed? *JAMA*. 1992;267:59-63.
[168]R.H. Shmerling, S.E. Bedel, A. Lilienfeld, and T.L. Delbanco. Discussing cardiopulmonary resuscitation: a study of elderly outpatients. *J Gen Int Med*. 1988;3:317-321.
[169]K.S. Schonwetter, T.A. Teasdale, and G. Taffet. Educating the elderly: cardiopulmonary resuscitation discussions before and after intervention. *Journal of the Amercan Geriatrics Society*. 1991; 39:372-377.

these discussions will produce negative psychological stress, most patients are left with a positive impression when they think about or discuss life-sustaining treatment. Many felt more in control of the situation, relieved or cared for. Even those patients who had negative emotional responses to end-of-life discussions (e.g. feeling nervous, sad, hopeless, etc.), still wanted to talk about the issues with their physicians. Moreover, many of those who wanted to talk about life-sustaining treatment wanted physicians to initiate the discussion.[173]

In addition, not discussing life-sustaining treatment that might be considered futile promotes distrust. Patients and their families may have expectations or preconceived notions of what ought to happen at the hospital. When the anticipated care fails to materialize, they may feel betrayed, especially if CPR is withheld without previous knowledge or consent because of its general acceptance as "non-invasive" and "non-medical". If CPR is withheld, a family may feel that the patient might have fared better outside of the hospital where some concerned citizen would have at least attempted a resuscitation. Thoughtful discussions would help reveal when patient expectations do not jibe with actual treatment strategies, thereby decreasing the likelihood of patients and families feeling hurt and betrayed.

More importantly, when physicians fail to discuss the "futility" of care with their patients, an opportunity for greater understanding and clarification is lost. Why do patients and their families request treatments that are likely to be ineffective or even harmful? It is suggested that these requests are "often

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[170]B. Lo, G. McLeod, and G. Saika. Patient attitudes toward discussing life-sustaining treatment. *Arch Int Med.* 1986;146:1613-1615.
[171]D. Frankl, R.K. Oye, and P.E. Bellamy. Attitudes of hospitalized patients toward life support: a survey of 200 medical inpatients. *Am J Med.* 1989; 86:645-648.
[172]R. Steinbrook, B. Lo, J. Moulton, G. Saika, H. Hollander, and P.A. Volberbing. Preferences of homosexual men with AIDS for life-sustaining treatment. *N Eng J Med.* 1986;314:457-460.
[173]Lo *et al.*, Patient attitudes to discussing life-sustaining treatment, p. 1613-1615.

signaling a different type of need, the need not to be abandoned."[174] Patients and families may not necessarily want the treatment they so vehemently request; rather, they may fear that failing to ask for "everything that can be done" will result in abandonment. Patient-physician discussions can often clarify misunderstandings, address concerns, and allay fears. They also serve to reinforce that the patient is cared for and that he or she will not be abandoned to face his or her illness alone. Discussing the "futility" of further technical intervention can provide an opportunity to stress the physician's dedication to providing compassionate comfort care.

Other requests for "futile" care may stem from a commitment to certain religious or cultural beliefs. While the physician may be speaking in a language of statistics and medical facts, patients may be coming from an entirely different perspective. In the face of medically determined "futility", patients may turn to hope or miracles for strength. Talking with the patient affords an opportunity to address the patient's concerns and to gain a better understanding of goals, values, and belief systems. Talking can also expose differences in understanding so that the physician can acknowledge the limits of his or her own expertise and personal bias and seek outside help. For example, a meaningful dialogue is unlikely to occur if the doctor is functioning in a construct of technology when the patient operates from one of spirituality. In such a situation, the most appropriate person to be discussing end-of-life-treatment decisions with the patient may not be the doctor. Instead, a spiritual guide, psychiatrist, grief therapist, social worker, or medicine man may provide greater insight and support. This person could also serve as a liaison by helping the physician gain a better appreciation of the patient's value systems. Although

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[174]Christensen, Applying the concept of futility at the bedside, p. 242-248.

infrequently practiced, the solicitation of outside expertise may help put the patient's request for "futile" care in context.

Patients and families may also disagree about the "futility" of certain life-sustaining measures. If the issue of "futility" is never raised, the patient and/or family does not have the opportunity to challenge the doctor's conclusion, get another opinion, transfer care, or look for alternatives.

Lastly, postponing talks about DNR's until the situation is "futile" perpetuates the myth that DNR orders are the hallmark of a dismal prognosis. When attempting to account for the observed disparity in DNR rates for diseases with similar prognosis, Wachter *et al.* suggest "caregivers may consider DNR orders only when they feel they have no effective therapies to offer."[175] This hypothesis is supported by the fact that DNR's are discussed more frequently with groups of patients that might be perceived as "on the fringe", namely older patients, patients who are severely ill, and patients who were estimated to have a poor prognosis.[176] Unfortunately, this attitude may serve only to reinforce the belief that DNR orders herald an imminent demise or that because the physician has nothing "medical" to offer, he or she has nothing to offer and, therefore, checks out. Moreover, the practice of not discussing DNR's until "nothing more can be done" entirely discounts the patient's perspective. Patients may consider resuscitation efforts futile even when their physicians would not. Limiting discussions to those for whom CPR would be "medically futile" denies patients the opportunity to refuse resuscitation efforts they may consider "futile".

In conclusion, physicians ought to discuss life-sustaining measures, "futile" or not, with all patients. The moral requirement of honesty not only

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[175]Wachter *et al.*, Decisions about resuscitation: Inequities among patients with different diseases but similar prognoses, p. 532.
[176]Blackhall *et al.*, Discussions regarding aggressive care with critically ill patients, p. 399-402.

requires disclosure and open communication, it promotes "professional self-scrutiny".[177] The physician is forced to examine whether the treatment is "futile", and if so, why? What are the underlying biases and assumptions? How does this determination influence the patient's goals and values? How will it improve patient care and quality of life? Moreover, if the physician feels further intervention would be futile and dehumanizing, more communication, rather than less, would help the physician get a better sense of the patient's goals, values, and beliefs so that the dying process would be more humane for that particular patient.

If physicians do not want to be forced to provide "futile" care, it behooves them to improve their communication skills, address their own insecurities about death, and seek outside consultation whenever a patient's world construct and belief system does not correspond with their own.

G. Resources:

While using the argument of futility as a rationale for withholding or withdrawing care is clearly problematic, the use does raise an important question of resource allocation - although indirectly. There is a growing belief in this country that people have a right to basic health care. At the current rate of spending, however, it is highly unlikely that universal coverage of basic care will be a reality unless steps are taken toward cost containment. If the healthcare budget needs to be trimmed, the most obvious place to begin is with care that offers no benefit.

[177]Scofeld, Is consent useful when resuscitation isn't? p. 28-36.

Because physicians, by virtue of their professional role, have firsthand knowledge of healthcare needs and what medicine can offer, many advocate that the medical profession take an active role in shaping health care reform.[178] Others envision the role of the physician as going beyond that of an expert consultant. In particular, Dr. Steven Miles, the ethics consultant to the Wanglie case, asserts that physicians have a duty of "stewardship" that "rests on fairness to people who have pooled their resources to insure their collective access to appropriate health care."[179] According to Webster's Unabridged Dictionary, a steward is "one called to exercise responsible care over possessions entrusted to him." If society has indeed "pooled their resources" and entrusted them to physicians, it has not elected to elaborate on exactly how these resources should be used in order to "insure collective access" or what defines "appropriate health care." Therefore, by claiming the duty of stewardship, physicians assume that society has not only conferred the medical profession the responsibility of using resources wisely, it has entrusted physicians with the task of rationing resources fairly and in a manner that will maximize benefit for the group.

The assertion of "stewardship", however, raises serious ethical concerns. First, does placing the physician in a position of making direct cost-benefit calculations compromise the therapeutic relationship? Second, is the proper role of the physician in healthcare rationing one of "stewardship"?

Under the Hippocratic tradition, the physician comes to the therapeutic relationship with the purpose of benefiting a particular patient. It is with this understanding and assurance that patients can allow themselves to be vulnerable and exposed, trusting that they will not be harmed. Under the

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[178]C.J. Dougherty. Ethical values at stake in health care reform. *JAMA*. 1992;268:2409-2412.
[179]Miles, Informed demand for "non-beneficial" treatment, p.514.

"stewardship" model, doctors are being asked to be in the precarious position of having to consider what is best for society and not just what is best for the individual patient *when* they are making therapy decisions. Unfortunately, what is good for the individual may not be good for society in general; and what the individual patient wants and the what the public needs may be strikingly different.

Applying a utilitarian calculus in an attempt to produce the greatest good for the greatest number, however, negates the basis of the therapeutic relationship. Consider the example of Sam who has the unfortunate luck of being homeless and without health insurance. On the way to the local soup kitchen, Sam is hit by bus while crossing the street. Unconscious, he is brought to the nearest hospital and admitted under the care of Dr. Bob, the local utilitarian physician. During his physical exam and evaluation, Dr. Bob concludes that aside from a few scrapes and bruises the unconscious Sam is in relatively good health. Dr. Bob then remembers that he has five other patients in the hospital who are dying of organ failure. If Sam's organs were transplanted, only one person would die instead of five. Furthermore, because no one knows Sam is there, no one would be the wiser. Suddenly, Sam starts to have difficulty breathing, but Dr. Bob is so preoccupied with his utilitarian thoughts that he does not notice Sam gasping for air. When Dr. Bob realizes what is happening, he is a little slower intubating than usual. Sam suffers anoxic damage to his brain and his organs are later transplanted. Five people leave the hospital healthier than when they first entered.[180]

While no one could imagine a physician really behaving in such a manner, the example is purposefully a hyperbole in order to illustrate that

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[180]Example used in Ethical Theories, Philosophy 104, Spring Semester, 1992, University of California, Berkeley

utilitarian calculations potentially violate the trust necessary for a therapeutic relationship to work. If it became standard practice for physicians to weigh the potential benefit of one patient against the potential benefit of others while making therapeutic decisions, a patient could never be certain that his best interests were being pursued. The foundation of the therapeutic relationship would be on tenuous ground.

Furthermore, there is no paradox in caring for patients on one hand and working for healthcare reform that would modify or limit that care on the other. In matters of healthcare reform ...

> "...physicians serve best as expert witnesses providing the basis for informed public decisions. They must lead in pointing out deficiencies and raising the painful matter of choices. At the same time, each doctor must honor his or her traditional contract to help his or her own patient. Doctors cannot allow the larger social issues to undermine that solitude."[181]

The concept of physicians participating in rationing decisions at the macrolevel is not problematic. In fact, physician participation is absolutely necessary if rationing is going to reflect the concerns of the medical community in addition to those of the general public. It is ethically dubious, however, to take a vigilante approach. To apply a set of rationing beliefs at the bedside despite the current system and its accepted standards is unacceptable.

Second, the assertion of "stewardship" implies that physicians are uniquely qualified to make healthcare rationing decisions. While medical information and opinion are obviously important for prudent policy, the rationing of scarce resources is a complex process that not only relies on facts but also the value society places on these facts. Even in the unlikely event that society granted the medical community the privilege of developing a rationing scheme,

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[181]E.D.Pellegrino. Toward an expanded medical ethics: the Hippocratic ethic revisited. In In Search of the Modern Hippocrates. ed. by R.J. Bulger. (Iowa City:University of Iowa Press, 1987), p.52-53.

the decisions reached would represent only the values of the medical profession; they would not reflect a societal consensus by any stretch of the imagination. If decisions are going to be made for society, society at large should come to some consensus on how best to ration health care.

However, if one acknowledges that the "futility" controversy is at least partially a debate about resource allocation, certain assumptions require substantiation. First, there is an erroneous belief that resources saved by denying or withdrawing futile care will find their way to those who could most benefit. Consider for example the following argument used to support implementing the APACHE III:

> With the enormous costs of healthcare spiraling out of control while millions are denied access to the healthcare system, there is ample reason to seek an improvement in the efficiency of intensive care. If physicians and nurses could identify which patients' illnesses were not severe enough to warrant an expensive stay in an ICU, which patients had much to gain, and which patients had no chance of recovery, a substantial amount of healthcare resources could theoretically be saved or diverted to those in greater need.[182]

Theoretically, the resources saved by eliminating futile care could be diverted, but such a step is highly unlikely. Given our current healthcare system, the resources saved from withholding futile treatment from the patient with private insurance cannot be channeled into a child immunization program, breast cancer screening program, or any other under-supported area. This shifting of funds could occur only in a "closed-system" in which universal health coverage is funded by a national budget.

Second, in order to support a hypothesis that eliminating "futile" care will divert resources, the cost of "futile" care must be a calculable figure. Although a large percentage of federally allocated funds goes to provide care during the last

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[182]K. Sasse. Prognostic scoring systems: facing difficult decisions with objective data. *Cambridge Quarterly of Healthcare Ethics*. 1993;2:185.

days of life, exactly how much money is spent on "futile" care?[183] It is deceiving to look solely at the end sum and the end result and attempt to derive some retrospective assessment of cost-benefit. A major variable missing in the calculation is at what point during care did it become obvious that the patient was imminently and irreversibly near death? How much money was spent on care that was considered heroic after it became clear that the dying process was well underway? What percentage of that sum was spent without open consultation of what the patient would want, that is, practicing "heroic" medicine without explicit consent? Lastly, how much money was spent on comfort care? Without addressing these variables, the end sum gives very little information regarding the "futility" of care.

Nonetheless, recognizing that the question of futility is in part a question of finances is more straightforward because it forces the critical examination of resource allocation. As such, the hidden judgments concerning quality of life and differences in beliefs are revealed and addressed in a more honest forum. Setting aside the question of whether issues of distributive justice can be addressed in an environment that does not promote the "just" distribution of health care, can a redefined notion of futility be supported on grounds of justice?[184]

According to Beauchamp and Childress, justice is a complex concept that is closely linked to issues of entitlement, fairness, and desert. If the discussion is limited to fundamental needs, that is needs that if not met would detrimentally affect or harm a person, what characteristics should a theory of distributive justice take into consideration? Should the goods and services required to meet

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[183]One particular study found that 46% of all Medicare charges in the last year of life were spent within the last 60 days.

[184] For the purposes of this argument, the definition of futility excludes that which is physiologically impossible.

fundamental needs be distributed equally, according to individual characteristics (e.g. need, effort, contribution, or merit), or as a function of free-market exchanges? Three major theories of justice --utilitarian, libertarian, egalitarian-- approach these questions very differently.[185] How do these theories purport to distribute healthcare and how would the concept of futility fit into the proposed rationing scheme?

Under the utilitarian theory, distributive justice must conform to the over-arching principle of utility. Any method of distributing healthcare resources must take into consideration the predicted private and public benefit, anticipated savings and potential risks. If the resources spent on futile care would be better used elsewhere, then under the principle of utility, futile care ought to be withheld.[186] Moreover, the definition of what constituted "futile" care could be considered broad enough to encompass any treatment that did not contribute to the greater good. Provided a general definition of what constituted "futile" care could be reached and it could be shown that eliminating this care would enhance the greater good, withholding or withdrawing "futile" treatment against the desires of the individual would be morally permissible under a utilitarian model of distributive justice.

The libertarian theory of distributive justice, on the other hand, places high value on personal liberty. Implementing policies founded purely on principles of utility or equality would sacrifice personal liberties because such policies coercively redistribute financial resources from one group to another. Healthcare, like any other commodity, ought to be a function of the free market and not a matter of social planning. If people choose to provide for their healthcare by purchasing health insurance, that is a personal decision. If people

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[185]Beuchamp and Childress, p. 256-265.
[186]Beuchamp and Childress, p. 265-266.

cannot afford healthcare, the situation is unfortunate, but not unfair because society is not morally obligated to care for the poor and unhealthy. That is not to say that the libertarian would oppose utilitarian or egalitarian health care policies if they were freely chosen. The problem is, with a diverse population, it is highly unlikely that all people would freely choose a policy that required certain groups to sacrifice for the benefit of another group.[187] Given a system that prizes personal freedom, it is unlikely that the concept of futility would play a major role in allocating healthcare resources. Under a libertarian model, people ought to have the right to purchase the goods and services they value -- even if some might consider this care futile.

Lastly, under an egalitarian model of distributive justice, people should have equal access to the goods and services necessary to meet fundamental needs. This "decent-minimum" standard would ensure that each member of society would have an adequate level of health care regardless of ability to pay. Patients could also have the option of purchasing better services (e.g. private rather than shared hospital rooms) or expensive, but optional, medical care (e.g. orthodontics).[188] Although this standard would promote a two-tiered health care system, it would at least guarantee that basic health care needs would be met -- an improvement over the current two-tiered system of those who can get care and those who go without.

The egalitarian model of distributive justice would be well-tolerated in this country because it strikes a balance between the American ideals of equality and personal liberty. As already mentioned, there is a growing belief in this country that people have a fundamental right to healthcare. Providing a "decent minimum" standard of healthcare would be consistent with our tradition of

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[187]Beuchamp and Childress, p. 266-268.
[188]Beuchamp and Childress, p. 268-279, 275-280.

providing for those who cannot provide for themselves.[189] This model also respects the notion of personal liberty in that people would retain the right to purchase goods and services that go beyond the basics.

While society may be obliged to provide or subsidize basic care under the egalitarian model, it certainly is not required to provide everything that medicine can offer. According to R. M. Veatch and C.M. Spicer, equitably funded care can be limited by society (or an insurance carrier) such that certain care is given higher funding priority. Care that may be considered futile by some (e.g. long-term care for patients in a persistent vegetative state) can be limited or not funded if a collective decision is reached regarding its low priority. It is important to recognize that the substantive issue is how the community prioritizes equitably funded care and not whether the community considers the treatment "futile" per se. If patients have access to other methods of financing care that is considered low priority by the community, they should be allowed to receive such care as long as it does not use resources needed by others who have a higher priority claim. A commitment to equity requires that basic care be provided: it does not prohibit individuals or groups from funding care they value because that care exceeds the decent-minimum standard.[190]

A second method of rationing under the egalitarian system of distributive justice would be to institute the APACHE III or some other prognostic scoring system universally. That is, as a matter of policy, any care deemed statistically futile according to a predetermined prognostic score would be denied categorically. Once again, however, the two-tiered approach to healthcare would not necessarily be eliminated under this policy. Only care of questionable

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[189]For example, Social Security, Medicare, and Medicaid programs attempt to provide the basic necessities for those who cannot provide for themselves.

[190]R.M. Veatch and C.M. Spicer. Medically futile care: the role of the physician in setting limits. *American Journal of Law and Medicine.* 1992;18:15-36, p. 30-31.

benefit on the fringes of life and death would be affected. Therefore, care of questionable value (e.g. long-term care for patients in PVS) would not be categorically withheld unless such care also had a poor prognostic score (i.e. statistically futile). Moreover, without a "closed-system", this egalitarian model would not necessarily lead to more equitable distribution of healthcare resources.

If the critical question is how to devise an equitable plan of rationing health care that will accommodate a diverse population with different value systems and beliefs, futility serves as a backwards method of addressing this complicated issue.[191] The concept of futility represents more than an assessment of statistical probability or physiologic possibility -- it is an evaluation. As such, society must come to a consensus about how "futile" care should be prioritized in a rationing scheme. Physicians can contribute to the discussion, but to apply individual rationing beliefs at the bedside would be morally problematic. If "futile" care is to be categorically denied without patient consent, the directive must come from those who will feel the impact of this policy -- namely, from the society at large.

H. Patient Autonomy versus Professional Integrity:

As noted earlier, the question of limiting life-sustaining therapy on the basis of futility has often been portrayed as a struggle between patient autonomy and professional autonomy and integrity.[192] By requiring doctors to provide care they believe to be "futile" in the name of patient autonomy, the physician's role

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[191]This question, however, reflects a personal bias on my part and presuspposes that basic health care is a right. If it were not, the question of rationing would be entirely one of economics - - those able to afford medical care would receive it.

[192]Schneiderman *et al.*, Medical futility and ethical implications, p. 949-954.

becomes one of mere technical advisor.[193] Moreover, because futility is a medical conclusion, it is argued, "...physicians can judge a treatment to be futile and are *entitled* to withhold a procedure on this basis."[194](emphasis mine) Practicing medicine, however, is a privilege and not a right *per se*. If such a moral entitlement exists, it can only originate from a set of rights and responsibilities granted by society. Does the question of futility represent a legitimate conflict between patient autonomy and the rights granted to the medical profession?

When investigating the morality of the patient-physician relationship, we might do well to take a step back and ask what ethical principles characterize all human relationships. After all, before doctors and patients acquire their respective roles, they are first human beings. One would assume that any ethical premises guiding this fundamental state would also be applicable to the more specific medical relationship. Whether one begins from a deontological vantage point or prefers to view moral interactions from an axiological perspective, one can appreciate the inherent value of human dignity as a good worth preserving.[195] A universal principle governing human interactions, therefore, might go something like "all human beings should treat each other such that human dignity and the capacity for that dignity is respected."

With this principle in mind, we can imagine a thought experiment in which rights and entitlements are assigned *a priori* of specific roles and relationships. In this thought experiment, originally proposed by Rawls as a hypothetical

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[193]C. Pierce. "Whether to Give Futile Care has become a Topic of Legal Dispute". *Internal Medicine News and Cardiology News*, Feb. 15, 1993 p.2, 48.

[194] Schneiderman *et al.*, p. 949.

[195]Although "human dignity" is a difficult term to explicitly define, the notion connotes an image of the human condition -- physically, intellectually, and spiritually -- as unadulterated and pure. It is this state of being that is inherently noble and worthy of high esteem. Each person, by virtue of their "human-ness", is valuable and worthy of respect -- respect that honors the human mind, body and spirit.

"original position", we can imagine a group of individuals who, without insight as to their position in the real world, construct social rules and assign rights collectively. They have no idea whether they will be rich or poor, in the majority or in the minority, the doctor or the patient. Under this "veil of ignorance", the patient-physician relationship can be examined in the abstract.[196]

The patient-physician relationship is unique in that the encounter is inherently asymmetric: ideally, one person is motivated by genuine compassion and love of humanity to use special skills and knowledge for the sole purpose of healing or helping another. The other person desires health, but is made vulnerable by illness and lack of medical expertise. This person turns to the physician for comfort and restoration. Because of the disproportionate power and vulnerability, Kass argues that the physician must be held to high values such that the dignity of another human is not violated. Indeed, the Hippocratic Oath is not merely a statement of prohibition, it is a reaffirmation of the need to uphold human dignity.

> The Oath's specific restraints on deed and speech recognize the inherently degrading and dehumanizing aspects of illness and the vulnerability and exposedness of the sick person's body, soul, and intimate relationships. Accordingly, they address the danger that the physician might, in deed or speech, take advantage of the vulnerable and exposed and that he might contribute further to the degradation and shame of those he seeks to lift up.[197]

By virtue of this unequal partnership, the physician must be keenly aware of what respect for human dignity requires. If integrity is defined as "an uncompromising adherence to a code of moral ...values"[198], professional

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[196]John Rawls, A Theory of Justice (Cambridge, Mass: Harvard University Press, 1971).
[197]L. R. Kass. Professing ethically: on the place of ethics in defining medicine. *JAMA*. 1983;249:1309.
[198]Webster's New World Dictionary, Second College Edition, ed. by David Guralnik, (New York: The World Publishing Co., 1972), p. 732

integrity is founded on practicing the Art in a manner that respects human dignity.

The principle of autonomy also has its roots in the duty to respect human beings. Allowing people to make decisions that influence and shape the character of their own lives shows respect for people as ends unto themselves. Unless patients mistakenly claim in the name of autonomy care that is beyond the realm of what medicine can provide, or if physicians consider "medicine" their *primae facie* obligation, losing sight of their primary commitment to dignity, it is difficult to imagine how patient autonomy and professional integrity could be at odds given their descent from the same overarching moral obligation.

Moreover, given that society allows only a few to enter the medical profession and partially subsidizes their education, would a rational group of people grant this minority the right to exercise a monopoly over life-prolonging techniques that each may need or want one day? R.M. Veatch and C.M. Spicer argue that "under the veil of ignorance" a rational citizenry would not unless there was a promise to use it when patients desire it, especially in circumstances in which there was no a consensus about the value of the intervention.[199] Accordingly, physicians would not be *entitled* to withhold treatment they considered "futile" against the patient's request.

[199]Veatch and Spicer, Medically futile care: the role of the physician in setting limits, p.15-36.

Chapter 4:
Redefining the Argument: Redefining the Relationship

When envisioning the ideal patient-physician relationship, a dialogue of rights does not immediately come to mind. In fact, if one has to appeal to a theory of rights and correlative duties in order to describe the interactions within the intimate relationship of physician and patient, chances are the relationship has already gone awry. In a relationship where the physician has characteristically been considered dominant, it is paradoxical that vulnerable patients and grieving families are now depicted as "demanding" or "controlling" when a disagreement arises. Can treatment conflicts be resolved in a manner that fosters a compassionate therapeutic alliance?

When conflicts over the "futility" of care are discussed, solutions focus primarily on what physicians have the right to do (or not do as the case may be). If a treatment or procedure is considered "futile" from the outset, a physician may choose not to become involved. Such is the case when a cardiac surgeon refuses to perform a coronary artery bypass on a poor surgical candidate. Once involved, however, the physician can either provide the care he considers futile, transfer the patient to the care of a more compatible provider, or deny care against the patient's or family's desires. Many, however, find the latter option disturbing and consider discontinuing life-sustaining treatment over the objections of the family on a case-by-case basis callous.[200] Even if "futile" care were not capriciously terminated, it would be inhumane to refuse life-prolonging treatment *before* a patient or family had the opportunity to come to terms with the inevitability of the situation, seek outside counsel, or get another professional opinion. When treatment conflicts arise, flexing one's medical "right" to deny

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[200]M. Angell. The case of Helga Wanglie: A new kind of "right-to-die" case. *N Eng J Med.* 1991;325:511-512.

care does not appear to be the most compassionate method of reaching a solution.

While most of the literature has examined the issue of futility from the medical perspective, it is interesting to note that the question of *why* patients and families demand futile care has not been investigated. Although there is no typical futility scenario, perhaps the following case shared by Dr. Guy Micco can shed some light on the patient experience and provide some insight as to why some patients and families "demand" futile care:

> While preparing dinner, a 57 year old woman suffered a cardiac arrest. Her husband called 911, but neither he nor his daughter knew how to perform CPR. The paramedics arrived and started resuscitation efforts, but it was estimated that the women had been without oxygen for more than five minutes. She was admitted to the ICU in a coma. The next day the husband was told that his wife had suffered irreparable brain damage and that "there was no hope." At different times during the day both the cardiologist and neurologist requested that the ventilator be turned off. The family resisted feeling that it was too soon to make such a decision. The pressure to withdraw care continued for the next few days and came from a variety of sources. One morning the husband was called at 6:30 in an attempt to "show him the light ". Finally, out of sheer frustration and need for guidance, the husband turned to their primary care physician. Knowing the family's strong religious convictions and genuine concern and love for one another, the primary care doctor was able to provide an atmosphere where the family could air their frustration, grieve, and come to a solution that reflected their moral convictions. The ventilator was later turned off and the woman peacefully died surrounded by her family.[201]

This situation, however, had great potential for becoming even more adversarial. From the perspective of the patient, several factors could easily be at play. The husband may be feeling an enormous amount of guilt for having not been able to perform CPR. Having witnessed a loved one experience such a traumatic event, he may still be in shock. He may be experiencing an intense

[201]This example was presented by Dr. Guy Micco, the details have been slightly altered in order to protect the patient's privacy.

sense of loss and confusion in the medical chaos as he attempts to understand the medical "facts" and their implication for his wife's health and their future life together. Because his wife does not appear "dead" in the classic sense, he may be experiencing psychological distress as he attempts to understand the physicians' advise to withdraw life-support in the context of his own morality. To the family, the situation is new, catastrophic, and emotionally intense. Uncertain and insecure, he turns to the physician for compassionate support and guidance. If confronted with unsympathetic and austere counsel, the natural response is to resist; to err on the side of status quo; to hope for the best in spite of the worst. If the physician approaches the family with the intention of "showing (them) the light", failing to recognize their precarious and vulnerable position, confrontation and conflict are likely to result. Although doctors are now willing to admit that there are limits to what medicine can accomplish, this revelation does not necessarily translate into more empathetic care.

If futility and the conflict from which it seems to emanate are ill-suited concepts in the therapeutic alliance, then the focus of the modern patient-physician relationship needs to be re-evaluated. Modern physicians are taught how to provide intensive care, but they are not educated or encouraged to care intensively. When the limits of "high-tech" medicine have been reached, or the ends they produce are no longer considered valuable in the medical community, the doctor may not recognize an obligation to continue providing care. Yet, the duty to attend the sick goes beyond administering appropriate science.[202] The practice of attending also includes elements of attentiveness and devotion. It is

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[202]According to Webster's New World Dictionary, "attend" has the following description, " *vt.* 1. to care or charge of; look after 2. a) to wait on; minister to; serve b) to serve as a doctor to during an illness 3. to accompany; go with 4. to accompany as a circumstance or result 5. to be present at 6. to await 7. to pay attention to --*vi.* 1. to pay attention; give heed 2. to be in readiness; wait 3. to devote or apply oneself 4. to give the required care or attention 5. to wait or delay." Webster's New World Dictionary, Second College Edition, ed. by David Guralnik, (New York: The World Publishing Co., 1972), p. 89.

this attentiveness and devotion -- to the frailty of the human condition, to the needs of the *whole* patient, and to the respect owed to persons in general -- that appears to be missing in the modern medical relationship. I contend that in a compassionate therapeutic alliance where the physician considers it his primary duty to respect the dignity of human beings while attending them in times of illness, a conflict over "futile" care would rarely arise. Furthermore, in the rare circumstances when a patient did persistently request "futile" care, I highly doubt that the language of rights and correlative duties would be invoked. Instead, the "conflict" might be described in terms of the patient's psychological, cultural, or spiritual needs; rather than attempting to determine whose rights should prevail, the discussion would focus on what would be the most compassionate and respectful method of addressing these needs.

By restructuring the medical paradigm such that the concepts of attentiveness, devotion, dignity and respect play a more integral role, the patient-physician relationship would reflect a more humanistic experience. Moreover, because the redefined therapeutic relationship is more holistic, it can account for a broader definition of "patient" and the use of symbolic treatment -- two concepts that traditional ethics have had difficulty reconciling.

When a person is in the process of dying, what constitutes "patient" is appropriately expanded to encompass the dying person's circle of loved ones. The duty to respect and attend is extended to the group of individuals intimately affected by the patient's illness. As such, the doctor should allay fears, maintain open communication, and be a present, empathetic counselor for both patient and support network. Because the ritual of dying is profoundly personal and potentially involves a vast array of medical interventions,

> (c)onversations about death and dying are exchanges in which the teaching role of the physician must be preeminent ... the challenge

> of the exchange is to recognize and respect the uniqueness of each patient's values and concerns.[203]

The challenge, however, includes recognizing and respecting the uniqueness of the patient's support network; and end of life treatment plans need to be developed within the context of the values and concerns shared by the patient and loved ones.

Given that the redefined patient-physician relationship embraces a broader definition of patient, it can account for the use of symbolic treatment at the end of life. As mentioned, the duty to respect and attend requires the physician to compassionately devote himself to providing care in a manner that reflects the patient's values and goals. Symbolic treatment is considered treatment that offers no perceived medical benefit but is employed because it satisfies another legitimate end. Consider for example parenteral nutrition. In many cases artificial nutrition does not satisfy a medical goal in that it will not reverse the underlying pathology nor restore a patient to a more comfortable state. In fact, artificial feeding may even extend the agony associated with the dying process. Yet, the concepts of "feeding" and "starvation" have tremendous cultural significance. If, after explaining the potential risks and benefits of parenteral feeding, this type of "futile" treatment is requested, it should be instituted or continued. To refuse to provide this care would be invalidating the other person's definition of what is considered valuable and significant -- it would, in essence, be denying the respect owed to another person. Symbolic treatment, therefore, has an ethical basis in that it demonstrates both compassion and respect for persons.

Some, however, would argue that while physicians may provide symbolic treatment, they are not ethically compelled to do so. For example, a physician

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[203]T. Duffy. When to let go. *N Eng J Med.* 1992;326:935.

should not be required to transplant a kidney in a patient in order to treat a brain tumor or amputate the arm of a patient requesting religious purification in the name of honoring compassion or patient dignity. I agree, but not because the physician is not required to provide symbolic treatment. Rather a physician only has the duty to compassionately provide treatment for which the treatment was intended. For example, a patient who has a brain tumor can ask for steroids or even an attempt at surgical resection, but cannot "demand" a renal transplant as a cure for the tumor because the purpose of renal transplant is to restore renal function. Moreover, an amputation serves to remove a diseased limb. If the man has a physiologically healthy arm he cannot expect medicine to surgically remove it. If it is spiritually "diseased", then he must turn to those who are concerned with spiritual as opposed to physical illness.[204] A physician's actions can be further constrained by what society will and will not provide under a chosen rationing strategy.

Second, because the redefined patient-physician relationship strives to uphold and respect dignity, it acknowledges diversity and differences without assigning evaluations. "(P)hysicians must constantly guard against confusing their own values as the 'good' to which all must subscribe if they desire to be treated."[205] Religious beliefs, for example, cannot be swayed by medical dogma and it is critical that patient's views are not considered "wrong" because they do not correspond to those considered legitimate by Western medicine.[206] By

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[204]If honoring human dignity requires respecting the human body, mind and spirit, it can be argued that removing the healthy limb would be akin to mutilation and would violate human dignity in that the physician would be failing to respect the human body.
[205]E.D.Pellegrino, oward an expanded medical ethics: the Hippocratic ethic revisited, p.45-64.
[206] The conflict of beliefs concerning Mrs. Wanglie's care appears to be a case in point. Dr. Steven Miles, an ethics consultant for the Wanglie case, was quoted as saying that people with religious convictions similar to those of the Wanglies' should form a "church of the Holy Respirator" and collect tithes to pay for "non-beneficial" care. While he raises an interesting point about health care resources and equitable allocation, his tone lacks a certain respect for those with different religious beliefs and values. Moreover, by attempting to wrest the control out of the familial domain, a conflict over values was turned into a caustic legal battle. Following the

respecting the dignity of others, physicians are more likely to recognize the limits of their own understanding and provide better patient care by consulting other members of the healthcare team (e.g. clergy, nursing staff, social workers, etc.).

Lastly, when one expands the role of the physician from the one who holds the cure to the one who heals by attending the sick, patient autonomy and professional integrity are not at odds. Both should, after all, gain their moral legitimacy from the duty to respect the inherent dignity of the human condition. In the crisis of illness, people need time to accept, adjust, and reconcile. By attending to the uniqueness of the experience for each patient and family, by heeding the mandate of compassionate care, and by remembering that devotion to the Art begins with devotion to the patient, futility need not be an issue.

Court's ruling, Mrs. Wanglie's daughter was quoted as saying, "We won, and we beat the doctors." Clearly, the nurturing therapeutic bond in which patients, physicians and families work together had disintegrated into a relationship of adversity and contempt.
See C. Pierce, "Whether to Give Futile Care has become a Topic of Legal Dispute," p.48.

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