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An analysis of medical futility dilemmas

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AN ANALYSIS OF MEDICAL FUTILITY DILEMMAS

by

Eloise A. Powell

**Bachelor of Science
University of St. Francis
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**A thesis submitted in partial fulfillment
of the requirements for the**

**Master of Arts Degree
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College of Liberal Arts**

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MASTER OF ARTS IN ETHICS & POLICY STUDIES


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ABSTRACT

An Analysis of Medical Futility Dilemmas

by

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Medical futility has caused serious dilemmas in the fields of medicine and bioethics recently. It has become more confusing due to the use of high technological equipment and medicines that are given to prolong life and interrupt the natural process of death.

Therefore, we have created a dilemma of medical futility. Until recently, not many steps have been taken to address futile or inappropriate care that is given to a large number of the population, but with healthcare costs rising substantially, the time has come when these issues must be addressed.

This thesis will include a short history of medical futility, the ethics of futility and how ethical principles are used in decision making. Patient rights and advance directives will be addressed and case law will be presented.

Finally, policy recommendations will be presented and the reason why these recommendations would be advantageous to the public will be discussed.

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INTRODUCTION

“There is an appointed time for everything, and a time for every affair under the heavens. A time to be born, and a time to die”(1). Yet, in the year 2000, the appointed time for a natural death to occur has become a controversial issue due to the use of futile treatment in the terminally ill, the elderly with multisystem failure, those in a persistent vegetative state, and neonates with no hope of survival. Life is being prolonged and sustained by artificial means due to the advancement of medical technology in the twentieth century. There are clinical, ethical and legal problems that exist when a life is being prolonged, as it is in the above populations, due to the use of advanced medical technology. I will present in this thesis how and why medical futility became an issue and where this issue stands in the year 2000. I argue that medically futile care should not be provided to the terminally ill, those in a persistent vegetative state, the elderly in multi-system failure and neonates with no hope of survival. I will make recommendations with the hope that public policy can be reformed or initiated to alleviate the problems that have occurred regarding the use of medically futile care.

For several years, the term ‘medical futility’ has caused and is still causing a serious dilemma in the health care field. The definition of futility has remained elusive and this problem has been and continues to be a serious and volatile topic of debate and controversy among physicians, bioethicists, other health care professionals and members of our society.

While the science of medicine was rapidly advancing, the area of medical futility became quite a thought-provoking issue in 1983. The increased use of advanced medical technology such as ventilators, pressure monitoring devices, renal dialysis, organ transplantation, and a vast array of medicines including vasopressors (medicines which increase the contractility of the heart) were used either one at a time or in combination to prolong life and replace the natural process of death.

Four cases will be presented here to exemplify medical futility in the 1990's. Two cases discuss the futility of care involving adults and two cases discuss neonates. One case portrays futility where the family member wants everything done in spite of the recommendation and prognosis of the physician. The other case portrays the physician wishing everything done in spite of the presence of a living will and the knowledge that there was no chance of survival. These two case histories were taken from the author's personal experience. The other two cases involve neonates: one case where the physicians again insisted everything be done in spite of the parents' wishes and the other where both physicians and parents agreed nothing should be done due to the condition of the infant.

The first case exemplifying medical futility treatment occurring in the 1990's involves a seventy six year old woman who had been comatose for five years. She was also a bilateral amputee (both legs amputated) due to long term diabetes. This patient had a history of cardiovascular disease and end stage renal failure which required hemodialysis (the process of cleansing the blood of accumulated waste products) at least three times a week to sustain life. Even though the prognosis given by the physicians was poor, with no hope of recovery, her son wanted 'everything

done' to sustain life. The patient was resuscitated five times, each time when her heart stopped. Her condition became worse with each resuscitation, until finally the fifth resuscitation failed, and the patient expired. The son filed a lawsuit against the physicians and the hospital for malpractice, but the physicians and the hospital were both exonerated. In this case, the next of kin was using his relationship with his mother to force the physician to provide futile care.

Another side of the coin is that case when the physician is the person who wants 'everything done' in spite of family wishes or the presence of a living will. Consider the case of a seventy-eight year old male admitted to the hospital who was alert and oriented but with multiple medical problems. The patient's heart stopped and he was resuscitated in spite of the presence of a living will. The patient was transferred to the intensive care unit and was in a comatose state for two weeks. The family wished to withdraw life support and have the living will honored, but the physician refused. The family eventually found a physician who would honor the living will. Life support was removed and the patient died within two hours. This case involved the physician using paternalism to provide futile care to an elder person with no hope of survival.

Medical futility is also present with the advent of the specialty of neonatology, (care of the infant within the first thirty days of life). Many years ago, those infants who were born prematurely or with severe congenital defects died shortly after birth; now, some of these infants are kept alive indefinitely and suffer while they receive futile care.

Consider the case of a twenty-five week fetus, born weighing no more than one pound, and with a very slight chance of survival. The baby was placed on life support and the parents waited a reasonable length of time (two months) before requesting that life support be withdrawn since there was no change in the baby's condition. Yet the physicians refused the request, stating that the baby would recover. Instead of respecting the parents' wishes, the baby was poked, prodded, and resuscitated time and again, always coming back, but the condition worsening each time. Eventually this baby did not survive a final resuscitation and the parents' nightmare was over. This case was portrayed in a book written by the parents of the infant.

On the other hand, there was a baby born with anencephaly (a condition in which some portion of the brain stem is present but the cerebral cortex, the largest part of the brain, is severely underdeveloped or is absent). Only one eye was present in the middle of the head (a condition known as cyclops), a slit representing a nose, and a slit representing the mouth. Physicians, nurses, and the parents all agreed that any medical treatment would be futile and the baby was kept warm and hydrated until her death a few hours later. This case occurred in a Catholic hospital and withholding treatment was considered ethically and morally acceptable. I was involved in the decision making process with the parents and medical staff. This last case is truly how families and the medical profession can work together for the best interests of the patient.

So, how and when did we, as the medical profession, begin trying to prolong the lives of those whose prognosis was so grave or non-existent?

Some idea of medical futility was acknowledged even in the time of Hippocrates. He noted that, “the functions of medicine are threefold: to relieve pain, to reduce the violence of disease and to refrain from trying to cure those whose disease has conquered, acknowledging that in such cases, medicine is powerless” (2).

For centuries, medicine offered little in the way of successful therapies, and the central function of medicine consisted of care rather than cure. In this country, American culture accepted the fact that death was the natural process that occurred when someone was grievously ill. Unfortunately, with the advent of high technology medicine, American culture has decided that seemingly unlimited life is an option and some people want “everything done” to prolong life even if it is to no avail (3). Therefore, this dilemma of medical futility has been heightened far beyond its earlier scope.

Physicians have been taught in medical school “to do everything” and many consider themselves a failure, especially interns and residents, if a patient does not survive an illness. Even though some disagree, physicians are being encouraged to limit the use of powerful therapies (such as resuscitation, ventilation, and dialysis) requested by patients and their surrogates. However, while this type of medicine is being discouraged, Emergency Medical Services must, unless documentation is provided, resuscitate anyone whose breathing has ceased or whose heart has stopped, regardless of the patient’s wishes. So some futile or inappropriate care is given in the field, in all states, by law.

While using all the advanced technology medicine has to offer, medical costs have risen substantially since 1960, and have caused a great concern among the

population and members of government. In 1960, national health care expenditures were only 3.5% of the gross national product, and by 1989; the cost had risen to 11.6% of the gross national product. These prices have risen at a far greater rate than any other consumer prices and increased again after 1989. Now, according to a study done by the National Center for Health Statistics in 1992, the cost for health care in the United States in the year 1990, had reached \$666 billion a year.(4) According to a study by the Healthcare Finance Administration published in Modern Healthcare on September 14, 1998, the projection for the cost of healthcare will increase from \$1.5 trillion in 1998 to \$2.13 trillion in the year 2007.(5) These figures may prompt a debate concerning non-beneficial or futile treatment to those who have a minimal quality of life, (e.g. those in a persistent vegetative state).

Statement of the Problem and Recommendations

Inappropriate or futile care is provided to a large portion of the population, yet policymakers have not really addressed it. Instead of addressing futile care at the bedside, it has become a problem that has been taken into the courtroom. Families are demanding inappropriate care and physicians are providing it because members of society have come to expect it and/or threaten lawsuits if it is not provided. On the other hand, some physicians provide inappropriate care because they have a need to use everything available in medicine to save a life if they feel a moral obligation to provide this care. Medical schools also play a part in this dilemma because they are guilty of not providing a curriculum that addresses the way physicians should deal with the death process. Communication, especially in this area of death, should be provided because it is of utmost importance among the health care team.

The media play an important role in the futility debate. Medical programs on television and those shown in movie theaters impress upon the public that if a cardiac arrest occurs, one shock with a defibrillator may bring a person back to life although this fact is highly unlikely.

In another case, the press depicted a former police officer who had been “in a coma” for eighteen years and miraculously began talking to his family continuously for twenty-four hours. Coma is defined as a state of profound unconsciousness from which the patient cannot be aroused even by painful stimuli. While the press reported the patient had been comatose, they showed a picture in the newspaper of this gentleman sitting in a wheelchair while someone instructed him to do some sort of project. A truly comatose person does not respond to instructions. Awakening from a comatose state is an extreme rarity. Obviously the media should investigate a case of this magnitude more carefully before it publishes something in the newspaper. A story like this can give so many people false hope when there is none.

All hospitals should establish a specific definition of futility and standard of care should be addressed. In 1987, the Hastings Center provided guidelines to provide an ethical framework for analyzing problem cases involving long-term life supporting technology, ventilators and dialysis, emergency interventions (cardiopulmonary resuscitation), nutrition and hydration of terminal patients, antibiotics and other life-sustaining medication, palliative care and pain relief. Some physicians have used these guidelines, but many have not, nor do many know of any guidelines in existence.

Physicians, nurses, ethicists, attorneys, policymakers and members of the community should be involved in a process, not unlike a grass roots movement or a community decision, to decide what definition, guidelines and policies will be established since the issues debated are so very serious and involve not only their lives, but the lives of all of us.

Purpose of the Paper

The purpose of this thesis is not to address rationing or withholding care from those who cannot afford to pay. It is to provide information and insight to advance my argument regarding the ethics and policies concerning futile and inappropriate care that is provided to the terminally ill, those in a persistent vegetative state, the elderly in multi-system failure, those newborns of extremely low birth-weight and infants who have birth defects not compatible with life. The other purpose is to make policy recommendations addressing this issue.

Many of us who are involved with families trying to come to a resolution regarding the care of their loved ones have watched them agonize over the decisions that must be made. Most of the staff presently working in acute care or transitional care hospitals wish there could be definitive policies regarding futile care as they watch patients suffer during the last days of their lives. Yet there is no national agreement as to define 'futility' or what ethics or which policies should be followed.

There are problems in the health care field regarding futile or inappropriate care that need to be addressed in the very near future. Is the medical profession going to continue to provide life-sustaining treatment to those patients who have no chance of survival or no quality of life? Futile or inappropriate care is not only expensive,

but an atmosphere of distrust is created among families, surrogates and physicians when there is indecision or lack of communication regarding treatment of their loved one.

To advance discussion of this issue, this thesis will explore the issue of medical futility as it is used to prolong the lives of those in a persistent vegetative state, those with a terminal illness, the elderly with multisystem failure and neonates with no hope of survival and the reasons why this type of care should not be provided. I will first examine the problem of defining 'futility' and consider the ethical issues involved. It will also touch lightly on neonates who weigh under 500grams and neonates, who are born with a birth defect that is incompatible with life, then consider case law on these questions, and will conclude with what should be guideline recommendations.

Chapter One gives a short history leading up to the time futility became an issue and touches on the ways different cultures and religions deal with futility. It will also include statements by Hippocrates and Plato stating why the lives of those who are terminally ill should not be extended. Chapter Two will discuss definitions of futility and work toward a simple, usable and defensible definition. Literature will be reviewed and arguments for and against providing futile treatment will also be presented.

Chapter Three will be devoted to patients' rights, including their legal right to refuse treatment. It will include the reason why advance directives became law and why the use and abuse of these directives has become an important part of health care today. It will also consider the fact that only ten to fifteen percent of the present

population have advance directives, and will discuss why these directives are not more widely used and whether or not or how they should be used.

Chapter Four will address case law. Several cases will be reviewed along with the reasons why these cases were presented to the court. Also covered in this chapter will be some of the reasons why physicians are pressured to provide futile or inappropriate care to patients and why families and surrogates demand care that is beyond curing a family member. It will also portray associations (one of which is the Americans with Disabilities Association) who try to promote their causes by impinging on the rights of patients and their families.

Chapter Five will present conclusions and provide policy recommendations. Some futility policies are in existence at the present time in the United States. However, due to the sensitivity of the subject of futility, the use of these policies is not widespread.

ENDNOTES

1. Ecc. 3:2.
2. Hippocratic Corpus, The Art. W.H.S Jones (trans) Cambridge, Mass., (1959): 11.
3. James M. Hoeffler with Brian E. Kamoi, Deathright, Culture, Medicine, Politics, and the Right to Die. (Boulder: Westview Press 1994): 26.
4. Lawrence J. Schneiderman, Nancy S. Jecker and Albert R. Jensen, "Medical Futility: It's Meaning and Ethical Implications," American College of Physicians (1990): 949-953.
5. Modern Healthcare. September 14, 1998:2.

CHAPTER ONE

HISTORY OF MEDICAL FUTILITY

Daniel Callahan, the noted bioethicist refers to medical futility as the “problem without a name”(1). Yet, this problem rears its ugly head almost daily in hospitals and extended care facilities throughout the country. Not only does this issue occur in the adult population, but also with infants in the neonatal intensive care unit.

Medical futility became a thought-provoking issue as early as 1983 when the Superior Court of Los Angeles ruled in favor of two physicians whose patient suffered a cardiac arrest after surgery. The patient was in a comatose state and placed on a ventilator. Five days after his cardiac arrest, the patient’s condition was deemed irreversible and with the permission of his wife, the ventilator was discontinued. However, the patient remained in a comatose state and a few days later his wife requested and gave the physicians written permission to discontinue nutrition and hydration. The patient received supportive care and died within six days. The reason the case went to court was to determine if the physicians were guilty of murder and conspiracy to commit murder (2). The court ruled that the conduct of the physicians was “one of omission rather than an affirmation...There is no criminal liability for failure to act unless there is a legal duty to act...A physician has no duty to continue treatment once it has been proven to be ineffective. Although there may be a duty to provide life-sustaining machinery in the immediate aftermath of a cardiopulmonary arrest, there is no duty to continue its use once it has become futile in the opinion of

qualified personnel. ...No precise guidelines as to when or how these decisions should be made can be provided by this court since this determination is essentially a medical one to be made at a time and on the basis of facts which will be unique to each case”(3). This decision was made in favor of the patient since no amount of medical care would save his life. At least here, the Court saw a clear case of futility.

How did medical futility find a place in our culture? There was no such problem in the world of primitive man, even though that culture did practice some form of medicine, which at that time was combined with magic. They believed that illness was caused by a supernatural force. Primitive man was knowledgeable in the art of using plants and herbs to relieve pain or to help with other symptomatology. They also knew how to set fractures, even though nothing was known of anatomy or science. Since medical knowledge was so very limited at that time, the problem of medical futility did not exist then or for many centuries (4). So, let us take a short journey in the history of medicine to find how medical technology evolved at first very slowly and then recently very rapidly when medical futility became a problem.

Medicine has always existed in the culture of man; for example, in 2500 BC, the Egyptians were treating burns with tannic acid and using compression to stop bleeding. In Babylonia and in Egypt, the use of surgical instruments to perform Cesarean sections to deliver babies has been documented. Treating fractures belonged to the Indian culture in 900 BC, and in 300 BC the Chinese invented acupuncture. One physician even used some form of anesthesia for surgical procedures (5). According to Hippocratic medicine in the Greek culture, physicians should use all the senses to make a diagnosis, and Aristotle encouraged the use of

observation and experimentation to develop a scientific basis for study. Hippocrates and Plato wrote concerning the futility of care in certain cases. Hippocrates admonished physicians to acknowledge when efforts will probably fail: “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 be overcome by medicine.” He further warned the physicians “in words too strong for modern taste that to attempt futile treatment is to display ignorance that is ‘allied to madness’”(6).

Plato states in The Republic that the “asclepian physician did not prescribe medicine to pamper a disease. For those whose bodies were always in a state of inner sickness he did not attempt to prescribe a regime...to make their life a misery...Medicine was not intended for them and they should not be treated even if they were richer than Midas”(7).

Socrates also argued against using medicine for those who were elderly or in a terminal condition.

His [Socrates] objective to [intensive] treatment...that it requires the patient to give himself over substantially and permanently to the management of his disease and so, in large measure, to give up the normal productive pursuits that characterize his prior life. Such a person, he says (407e12, 408b12), would benefit [lusitelein] neither himself nor other people by his mode of life; the treatment would lengthen his life but also make it a very bad one (cf407db-7), and it is an abuse of the art of medicine to use it for that end. He should be allowed to die a natural death untreated (8).

The Romans excelled in the field of public health. Two men, Celsus and Galen, made major contributions to the history of medicine. Celsus wrote books on the subject of surgery and was the first person to use a form of casting material to stabilize fractures. Galen made his contribution in the field of anatomy dissecting animals. Many of his contributions were in error due to the method he used (9).

Medical schools were established in the 8th century in Italy. The Islamic culture established hospitals in the 12th century. The first anatomy text was written during the Renaissance period, and as a result, surgery became less barbaric. The 17th century is noted for the discovery of the circulatory system by William Harvey and the invention of the microscope by Leewenhoek. Medical schools also flourished during this period. The 18th century saw the use of a vaccine made from a cow and injected into a human to prevent a person from acquiring the disease of smallpox. The sciences of microbiology and bacteriology were developed during the 19th century and the use of ether as an anesthetic during surgical procedures made these procedures safer and longer. Although these procedures were safer and longer, a number of deaths still occurred due to the unsanitary conditions in which they were performed. A physician named Semmelwiss, who practiced obstetrics in Europe, realized that childbirth fever was due to the fact that hands were not being washed before a delivery. When hand-washing was used the infection rate dropped almost immediately. At the same time, a scientist in the United States by the name of Lister also realized dirty instruments and dirty hands were causing problems following surgical procedures and started using a technique of washing hands and instruments

in a liquid substance called phenol. Infections following surgery and in the hospital wards dropped drastically (10).

While substantial progress was made during the 18th and 19th centuries, 20th century medicine progressed at a more rapid rate. With the use of various vaccines, the diseases of smallpox, diphtheria, and polio were virtually wiped out. Antibiotics came on the scene in the 1920's but were scarce at the time. But, by the 1960's, the use of penicillin and sulfa drugs worked miracles never before seen in the medical world (11).

In the 1960's, cardiopulmonary resuscitation also became a method to save lives, albeit not many. Basic life support, which included compressing the chest and using mouth-to-mouth resuscitation, extended into advanced cardiac life support which implemented the use of drugs and breathing tubes to extend a patient's life.

Ventilators or respirators, which were an extension of the iron lung used during the days of the polio epidemic, were being used during surgery or times when a patient was unable to breathe spontaneously. Vasopressors were now the drugs used in patients who had heart disease and were also used in cardiopulmonary resuscitation. Coronary angioplasty and coronary artery bypass surgery could fix the diseased vessels of the heart. Renal dialysis now became a player in extending the lifespan in those patients with end-stage renal disease. Organ transplantation also flourished and extended a person's lifetime, if only for a few years. Never before could human life be extended for prolonged periods of time!

Now one can begin to visualize a complication: in the early days of medicine, there was nothing one could do to extend the lifespan. Since there was no cure for

many diseases, many died at a young age from appendicitis, pneumonia, and strep throat. Those with a terminal illness, low birth-weight infants, severely deformed infants and the elderly with multisystem failure were allowed to die a dignified death. Now in the 20th century, almost any combination of medicines or procedures can be used to extend life for a prolonged period of time to the above mentioned populations.

Not only has advanced technology played a part in extending life, the American culture has denied the process of death and it almost seems that life can go on forever (12). We want everything done to prolong life, no matter what the cost.

Some cultures do not wish their population to suffer or to prolong their lives if they cannot function, so they agree to do nothing to extend that life and permit them to die a dignified death. Many non-western cultures seem to accept death more readily than those in the west. The African culture integrates children with adults in funeral preparations so they are more comfortable with the death process. The Japanese think that death is beautiful. This thought is closely linked to Buddhism, which regards death as the final stage in the continuum of life (13).

The Netherlands is the exception in western culture with regard to their acceptance of death. The Dutch accept euthanasia, mercy killing and the right to die. The reason for this thinking is that while 37% of the Dutch claim to be Roman Catholic, two-thirds of this population are not connected with a specific type of religion (14).

Clearly, religious aspects of futility should be addressed. According to the Jewish tradition in medieval times, a rabbinical commentary allowed the removal of anything hindering the soul's departure. This applies only when a terminally ill

patient is expected to die within three days. While it is not permitted to speed a person's death, nothing need be done to continue life in that state. On the other hand, in strict law, one must not do anything to hasten death but do everything to prolong life. Today in reform Judaism, Rabbi Solomon B. Frehof, the leading Reform authority on ethical issues, states that a "physician is not duty bound to force a patient to live a few days or hours. Thus, the physician may remove impediments to death such as artificial feeding"(15). In other words, the physician is not really hastening the death, he has simply ceased efforts to delay it. So a dichotomy exists in the Jewish tradition, the orthodox rabbis cannot sanction "pulling the plug" while the conservative and reform rabbis think differently.

The Catholic religion states that there is a right to die peacefully with human and Christian dignity. It absolves Catholic physicians from an obligation to use heroic measures on terminally ill patients. "When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life so long as the normal care due to the sick person in similar cases is not interrupted. In such cases, the doctor has no reason to reproach himself with failing to help the person in danger"(16).

Many of the Protestant denominations in the United States express the right to die with dignity. The Islamic tradition states "that when a person is old, very sick or has lost sentience, the doctor should not extend life needlessly, since such symptoms are a sign that God has willed death"(17).

Our exploration of the history of medicine comes to an end, and medical science continues to advance rapidly as we enter the twenty first century. Medical futility continues to cause controversy and remains a dilemma since many cannot agree on a definition of this term and continue to treat cases that are considered futile.

A definition of futility and the ethics of futility will be discussed in the next chapter.

ENDNOTES

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3. *Ibid.*, 12.
4. *Grolier Electronic Encyclopedia*. (CD-ROM)
5. *Ibid.*
6. *Ibid.*
7. *Ibid.*
8. *Ibid.*
9. James M. Hoefler with Brian E. Kamoie, *Deathright. Culture, Medicine, Politics and the Right to Die*. (Boulder: Westview Press 1994): 14.
10. *Ibid.*, 23.
11. *Ibid.*, 24.
12. Melvin I. Urofsky, *Letting Go: Death, Dying and the Law*. (Philadelphia: Charles Scribner and Sons 1993): 20.
13. *Ibid.*, 24.
14. *Ibid.*, 28.
15. Hippocratic Corpus. The Art. In: S. J. Reeser and A. J. Dyck, eds. *Ethics in Medicine: Historical Perspectives and Contemporary Concerns*. (Cambridge: MIT Press 1977): 6-7.
16. Plato. In: G. M. Gruber, trans. *Republic*. (Indianapolis: Hackett Publishing 1981): 17-27.
17. Kenneth L. Vaux, *Death Ethics*. (Philadelphia: Trinity Press International 1992): 3.

CHAPTER TWO

THE ETHICS OF FUTILITY

Literature concerning the subject of futility has dramatically increased since the passage of the Patient Self-Determination Act in 1991. Right to die issues such as withholding and withdrawing life support have also become prominent in the United States. A debate has evolved around these issues and the medically futile care given to premature infants and those with severe anomalies (abnormalities), the elderly with multisystem failure, and those who are in a terminal state. While some authors use the term 'futility' in their writings, others shy away from the term, stating that the concept of futility is too nebulous.

Ann Alpers and Bernard Lo state that futility is not just a medical issue (1). Indeed this is a true statement, because there are many facets to the term 'futility'. These include the medical, economic, ethical and moral aspects of futility. In this chapter of the thesis, I will discuss the definition of 'futility' and the problem of making futility judgments. I will also focus on the ethical principles used in judgments about futile care.

1. Definition:

How can one define the concept of futility? Although many clinicians may be unable to define this concept, they recognize it when they see it. These clinicians as well as members of the nursing profession know futile care and the term 'futility' not only from instinct, but also from their years of experience and expertise. According

to David F. Kelly, a professor at Duquesne University and author of the book, Critical Care Ethics, the best definition of medical futility is that of Stuart J. Younger, MD.

Younger suggests that ‘medical futility’ may be defined in many different ways, but his definition is stated thus:

“The treatment is clearly futile if it will fail in strictly physiological terms. The dialysis will not clear the blood, the vasopressor will not better the blood pressure, electric cardioversion will not start the heart, arrhythmia control (medications that control an erratic heartbeat) will not stop the fibrillation (a quivering heart). Or a treatment may be called futile if, while it works in the direct or local sense, it does not postpone death even by a few minutes. The cardioversion does start the heart, but the heart stops again immediately and this continues each time it is done. The dialysis does clear the blood, but since the patient is immediately moribund from the cardiac arrest, the dialysis does not postpone death from another cause”(2). Kelly argues that if the criteria presented above are those of futility, then medical futility does indeed exist.

In his article, “Medical Futility”, Steven Miles, a physician and ethicist, also provisionally defines ‘medical futility’ as a therapy that is of no value to the patient (3). The Hastings Center guidelines concur with Younger’s and Miles’s definition stating that if a treatment has no physiological benefit, it should not be provided (4). These definitions are clearly physiological in nature.

In this thesis, the definition of medical futility is also strictly physiological in nature. If a treatment cannot cure or provide a benefit to the following population, the terminally ill, the elderly in multisystem failure, those in a persistent vegetative

state or neonates with no hope of survival, that treatment should not be provided and palliative care should be instituted instead.

There are two types of physiological futility. First, is the qualitative type of futility that concerns the quality of life of the patient. It is a treatment that renders a patient permanently unconscious or that patient must rely on intensive care for the rest of his life, that treatment may be considered futile. In other words, that unconscious patient will never wake up and the patient in intensive care cannot survive outside the intensive care environment. Examples of qualitative futility would be those who are in a persistent vegetative state with no quality of life. The other type of physiological futility is classified as quantitative. If a treatment continually fails in the last one hundred cases, then it could be considered futile (5). An example of this type of futility could encompass the use of CPR in the terminally ill and the elderly in multi-system failure. I argue that these definitions, and the guidelines of the Hastings Center for applying these definitions should be followed since the issue here is that of providing futile treatment to those who have no hope of recovery.

Objections:

1. Truog, Frader, and Brett in their article “The Problem with Futility” state that “the rapid advance of the language of futility into the jargon of bioethics should be followed by an equally rapid retreat”(6). The authors believe that there are hidden agendas in the word ‘futility’, for example, conflicts regarding value judgments, rationing, and statistical probability.

In regards to the value judgments, the authors state that the physician's values and the family's values are not the same. In other words, in the case of futile care, we should probably resuscitate a person even though it might only be for a short time and the patient never regains consciousness.

In response, I would argue that the value judgment of the physicians and the families may differ, but most likely, the physicians realize that the patient will not regain consciousness, not even for a short time. If the physician knows this, then he should not provide futile care.

In reviewing the rationing question, the authors seem to think that using the term medical futility might cover up a form of rationing. However, as far as futility and rationing are concerned, medical futility is not used as a "cover-up" for resource allocation or rationing. Advanced medical technology is provided to most of the population, that is the reason why resources are becoming scarce in the year 2000.

2. Truog et al., regard futility as a matter of probability, that one can never say never, that a treatment would not work for a patient. However, I believe making that a blanket statement regarding futile treatment would not be a realistic point of view. Most patients who are terminally ill, in a persistent vegetative state, or the elderly in multisystem failure do not recover when they are provided with advanced medical technology, which in my point of view, I regard as futile care.

The medical profession is keeping people alive for an inordinate amount of time due to the advanced medical technology that is used today. Some in the medical profession believe that we (as medical professionals) have a moral responsibility to

keep patients alive at all costs. Yet if the patient has no quality of life, does not recognize anyone, or is unaware of his/her surroundings, we are certainly not acting in the patients' best interest to keep them "alive at all costs." Most of these patients have no quality of life, but just lay in the bed being (if you will) turned, watered, and fed. How can one justify the dignity of a person who was once a whole human being, possessed an intelligent mind and had feelings? I find that the degradation of that person is deplorable. All one has to do is take a tour through an intensive care unit or a long term care facility to witness this degradation of the human body.

Rationing, to save time and expense, has not been a factor in withholding care or treatment in the United States as it has in some European countries, namely, England and Holland. And if one looks at statistical probability in futility judgments, many of the cases where futile care has been provided have resulted in negative outcomes. Therefore, I believe the term 'medical futility' should be retained in the bioethics language.

3. Ethical Issues in Futility:

There are several issues governing the ethics of futility: a) trust combined with communication, b) economics and rationing, c) justice, beneficence, non-maleficence, and autonomy.

Advanced medical technology that is used today has proved to be life saving many times, but it has also failed in a large number of cases. Family members or significant others often request physicians to perform a 'miracle' for their loved one, many of whom have no hope for survival. These same technologies have also created ethical dilemmas that were unknown to medicine before this time (such as the use of

intubation and kidney dialysis). Even though the best medical procedures are being used and are not effective to the patient, families or others may request these procedures in the hope a 'miracle' will occur. These requests are often made due to a lack of trust in the physicians who are caring for the patient in the hospital.

4. Trust combined with Communication:

Gone are the days when families had just one physician to deal with their medical problems. These family physicians not only knew the patient's medical problems, but they knew the family dynamics as well. Many in the population of the United States can still remember the family physician and how he was thoroughly trusted. This element of trust was lost when physicians started to specialize and most of these specialists were strangers to the family. Not only were they strangers, but many did not seem to take an interest in getting to know the families or the problems they were facing while a family member was in the hospital. Many physicians, due to their caseload, still do not take the time to effectively communicate with the patient or their families, and a trusting relationship cannot be built with a physician who spends a short period of time with them. When questions are presented to the physician, he/she should take the time to answer these questions totally and honestly even if the answers are those that one does not wish to hear. Trust in the physician is such an important issue involving patients today, in part because there is such a large amount of medical information published in books, magazines, and on the internet today. The American population is no longer in awe of the medical profession as it was in the past; trust therefore needs to be earned and given, not taken for granted.

Another problem with the specialization of medicine was and continues to be that each body system has its own specialist and often times these physicians are not in total agreement with one another regarding the prognosis of the patient. There can be as many as six or seven physicians caring for one patient and the family/surrogate may hear a different prognosis from each one.

Under these conditions, families are often at a loss to make decisions regarding futile care because physicians do not communicate, not only with the families, but also with one another. The bioethical principle of veracity may be an issue in these situations. It is imperative for the physicians to provide one whole truth to families/surrogates in the cases that involve futile care.

As physicians make their hospital rounds, they write on the progress notes, but they do not have or take the time to read another physicians' notes (which may differ slightly from their own note). It takes only one physician to offer hope, when there is no chance of recovery, to cause confusion when the other physicians on the case feel that the case is futile. The intricacies and the prognosis of the patients' condition should be expressed truthfully as a whole, so a decision can be made. Communication and trust in the physicians combined with discussion is the key in these cases.

Judith Darr in her article "Medical Futility and the Implications for Physician Autonomy" states that communication is an extremely important part of the treatment plan and would obviously alleviate many conflicts concerning the care of patients, particularly those that are considered futile (7).

If this communication is lacking, then obviously it is up to one person (this is usually the nurse caring for the patient) to bring these physicians together and request a care conference so the family and the surrogate can reach a reasonable and morally acceptable decision for the family member who is dying. If some physicians are still in disagreement after a care conference has been held, then it is time for the hospital ethics committee to be involved. The committee will call family, physicians and staff together to facilitate discussion and enable them to reach a decision. Many cases that have been brought before the hospitals' ethics committee have helped the families reach a comfortable decision. It is very rare that these meetings fail in the goal of facilitation.

(b) Economics and Rationing:

Economics will become an issue in futile care very quickly, especially with managed care involved on the scene. Robert Veatch states in his article "Justice and the Economics of Terminal Illness" that twenty to thirty percent of all health care costs are devoted to the terminally ill. He defines terminally ill as "an illness in which, on the basis of the best diagnostic criteria and in the light of available therapies a reasonable estimation can be made prospectively and with a high probability that a person will die within a relatively short period of time." He also states that providing heroic care in the terminally ill is "only marginally beneficial" or "useless" at most (8).

There are two issues that I would like to discuss regarding terminal care and the economics of providing this care. One involves the care of the elderly who have multisystem failure. This person has diabetes combined with end-stage renal failure

and end-stage cardiomyopathy. Long term dialysis, possible heart surgery and possible long term use of a ventilator would be required to keep this patient alive but this treatment would not provide a cure. The cost of this type of care for a patient with this type of terminal illness would be prohibitive. Palliative care should be instituted in this case since it is a great possibility that the most advanced care would prove to be futile.

The other end of the terminally ill spectrum concerns infant futile care. Consider the case of an infant born with the chromosome disorder Trisomy 13. These infants suffer from profound retardation, seizures, apneic episodes (the infant stops breathing), feeding disorders, severe failure to thrive, visual and hearing defects and other brain disorders. Twenty percent of these infants are stillborn, fifty percent die by six months of age, and eighty five percent die by the end of the first year of life (9). These infants should be treated until the parents are informed of the prognosis, then decisions should be made (either palliative care or hospice) according to the infants' condition. Placing these infants into a Neonatal Intensive Care Unit would again be prohibitively expensive since the high tech treatment would not cure the underlying problem.

GUIDe (Guidelines for Intensive Care in Colorado) a group in Denver, Colorado, recently formulated guidelines regarding futile care in the neonatal intensive care unit. These guidelines state that babies who weigh five hundred grams and under or those who are less than twenty-four weeks should not be resuscitated. Other conditions included Trisomy 13 and 18 (in which death will occur without ventilator support), anencephaly, and other conditions of similar magnitude (10).

These guidelines should be communicated to the parents and decisions made concurrently with the physicians. Again, communication and discussion is the key in many instances.

(c) Justice, Beneficence, Non-maleficence and Autonomy:

In addition to communication and trust, discussed in Section (a), the four additional ethical principles that govern medicine are those of justice, beneficence, non-maleficence and autonomy.

Rosemarie Tong in her article “Toward a Just, Courageous, and Honest Resolution of the Futility Debate” states that the above principles come into play in the area of withholding or withdrawing futile treatment in hospitals (11).

The concept of justice means that fair and equitable treatment should be given to everyone. Distributive justice is the type of justice that is relevant to medical futility; and with justice, economics goes hand in hand in the field of health care. If one uses the definition of justice as fairness, then everyone should be treated equally. Therefore, a patient in a persistent vegetative state or one who is terminally ill would be given the same medical treatment as a patient who is acutely ill and not in the former state. However, due to the advanced medical technology, one really cannot justify treating all patients equally. It would not be economically feasible. We should then consider utilitarian justice as an alternative. Here the whole of society should be considered, not just the needs of a few or of an individual who would be receiving futile care. In other words, we should not perform heart surgery on a patient who would not benefit from that procedure which might only be prolonging his death and causing untold suffering. We could use the funds for those who would

benefit from the treatment, hence the principle of utilitarian justice, maximizing utility for the whole of society.

Another form of justice in the health care field is that of intergenerational justice(12). Resources are becoming scarce in the United States, therefore, the cost of care is becoming a problem. How can we equate the cost for care of a severely prematurely infant in the neonatal intensive care unit with a minimal chance of survival with the preventative care and rehabilitation of our elderly population (13)? Also to be considered is the allocation of funds to the elderly in total body failure, that would likely involve futile care, as opposed to the health care for children, young adults, and those in mid-life who are acutely ill and would benefit from the care given in an intensive care unit.

As care is given to these patients, the ethical principle of beneficence, acting in the patients' best interests or acting as the patients' advocate should be uppermost in the mind of the health care team. Beneficence is defined as the value of doing good. In medicine, it would mean improving the quality of the patients' life. It could mean that the burdens of the treatment do not outweigh the benefits to the patient.

One of the goals of medicine is to improve the quality of the patients' life. Advanced medical technology used many times when futile care is provided to a patient, inflicts pain or some severe form of discomfort. We are definitely not practicing this principle of beneficence or acting in the best interest of the patient when we provide this kind of care.

Sharing the principle of beneficence is that of non-maleficance. Non-maleficance is defined as 'doing no harm' and to provide competent care to the

patient. We must act in the best interest of the patient. Yet, if “do no harm” credo is used, can the withholding or withdrawing of treatment be said to be doing harm to the patient? Tom Beauchamp states, in his book, Principles of Biomedical Ethics that the principle of non-maleficence support more specific rules (14). One of these rules is “do not cause pain and suffering to others.” If we withhold treatments that will cause pain or suffering to a terminally ill patient, we are upholding the principle of non-maleficence.

Another one of these rules is “do not kill”. Would the medical profession be guilty of killing a patient if life-sustaining treatment is withdrawn from a terminally ill patient who is dying? The answer is no, because the patient is already in a terminal state and we are allowing him/her to die. We have just been prolonging a life with the use of advanced medical technology.

What is the difference between killing and letting die? How can we distinguish between them? Killing is the deliberate act of taking a life, while letting die permits a patient to die without the interference of advanced medical technology. An example of this concept is the case of Samuel Linares (15). Samuel was a toddler of fifteen months when he ingested a balloon and the obstruction of his airway caused the child to stop breathing. He was rushed to a hospital emergency room in Chicago. He was resuscitated and left in a persistent vegetative state that was due to a lack of oxygen to his brain. After admission to the hospital, the father begged the physicians to remove life support from his son and the physicians refused. The father finally held the hospital staff at bay with a gun; removed life support from his son and held the child until he died. The District Attorney stated that the father killed his son, but

the father stated that the balloon his son ingested killed him. The coroner ruled the death as accidental. The father did not wish his son to live in this persistent vegetative state. This example of letting die portrays a child in extremis when brought into the hospital emergency room.

As one moves from the principle of non-maleficence to autonomy, we must take the wishes of the patient or the surrogate into consideration. Autonomy has acquired meanings as diverse as self-governance (16). According to this principle, the patient has the right to refuse treatment, yet, many physicians refuse to honor these requests. These physicians are afraid of the legal ramifications if they do honor these wishes. Some physicians feel that the patient is making the wrong decision if they refuse treatment. One factor should be remembered; physicians are taught to cure and do everything in their armamentarium to bring about that cure and some physicians think they are performing physician-assisted suicide if they let the patient have the right to die.

When one makes a choice regarding medical care,"[a]utonomy is your right to determine what is done to you, to make decisions for yourself... Your right to personal liberty, privacy, and confidentiality, to be left alone and to be respected as a person, all flow from this principle, and your physician has an obligation to promote and respect your rights, values, preferences and choices" (17).

Can the physician be held liable when he allows a patient to die if he does honor that patient's wishes? Judicial precedent states no:

There can no longer be any question that our society and our law reject technological vitalism in treating the terminally ill, and that the contract model has triumphed at the points where it overlaps with criminal law norms. We do not violate the sanctity of life when we limit

technology's use to settings where it can provide benefit, understood by such, by those we claim to help (18).

I would like to present a case where these principles of ethics could have and should have been applied.

Consider the case of a male infant born in 1976 weighing eight hundred grams. The mother was only five and one half months pregnant and delivered early due to a placenta previa (a low-lying placenta). The infant survived for several days without any extraordinary means, then developed problems and was transferred to another facility many miles from his home.

The infant then developed respiratory problems and was placed on a ventilator. The parents objected and the physicians stated they would obtain a court order if the parents refused the ventilator. Complication upon complication developed and the parents felt they had no choice or voice in the decision-making process for their child. Not only did they feel they had no voice in the decision-making process, they also felt their infant would not survive. The parents felt their baby was an experiment and not their child. Trust was an issue and communication was a problem.

The parents wrote of their experiences in a book, The Long Dying of Baby Andrew (19). They hoped the book would provide some knowledge to other parents and would give decision-making back to the parents.

While the parents presented their side, the physicians presented their case in another vein. They stated that many of the concerns of the parents were with themselves and their financial situation. They (the parents) had few concerns for the

infant. The physicians failed to see the burdens of the parents traveling a great distance to see the infant or to realize the financial burdens placed upon them (20).

While reviewing this case, one can observe that the principles of autonomy, non-maleficence, and justice were lacking. Physician paternalism seemed to be paramount in this case. The physicians would not discuss the case or the prognosis with the parents. This infant was not brain dead so the ethical principle of non-maleficence was ignored, the treatments causing pain and suffering to the infant. The only way these infants can communicate is with a high pitched cry, so we do not know the degree of pain we are causing.

The parents knew instinctively that their child would not survive, yet, they were not consulted during the course of his treatment, nor did they have a voice in the treatment of their son. Autonomy was the issue here, this principle was not upheld.

If the physicians felt that the infant would not survive, why did they spend a large amount of dollars to keep the infant alive? How could they justify this treatment? The benefits of the treatment in this case certainly did not outweigh the burdens to the infant or to his family. The principle of justice was not upheld.

If these principles had been followed, trust in the physicians had been present, and communication had been open, this infant may not have suffered and instead died a peaceful death.

5. Applications of Ethical Decision Making:

Decisions concerning medical futility are quite often difficult and involve ethical dilemmas. Many of these dilemmas involve withholding and withdrawing treatment from a patient. And, whenever ethical issues are present in a case, there can

also be conflict. This conflict may exist among nurses, physicians, and families/surrogates. Refusal to treat due to a diagnosis and/or prognosis or the withdrawal of life support can cause the death of a patient. Some professionals and many families are reluctant to make a decision because death is so final. They may realize that the decision they make is really in the best interest of the patient, but they also feel guilty if they are part of a decision to take a life.

One way to resolve this conflict is to have open communication among the professionals and the families/surrogates involved with the patient. A conference should be held to determine the diagnosis, condition and prognosis of the patient. Is the treatment being provided to the patient a benefit or is it just band-aiding one problem before another part of the body fails? This band-aiding process is usually the course of action when futile care is being provided. One major system is the root cause of the patient's pending demise and since this system cannot be cured, the rest of the systems are failing one by one.

The wishes of the patient should be considered. If the patient does not wish to prolong her life due to her illness, that wish should be honored. The ethical issue occurs when the patient is no longer competent and has no advance directive. She has not stated her wished to anyone in the family. What will her quality of life be if the treatment is continued? The possibility is good that she will be admitted to a long-term care facility and her quality of life will be profoundly diminished. The benefit of the treatment would not outweigh the burden to the patient or to her family.

If this patient suffers from end-stage cardiomyopathy, it means no type of treatment can cure the heart and the patient will die. If the heart stops, we could

resuscitate the patient with various cardiac drugs until the respiratory and renal systems fail. Then a ventilator could be used in combination with the drugs and the patient could be dialyzed to keep the kidneys functioning. The fact remains; the heart cannot be cured, so we are providing futile care to the patient. The healthcare team should be negotiating with the family to provide palliative care to this patient so she can end her life with dignity.

Another type of ethical issue can occur when a patient is alert and can make decisions. This patient has a diagnosis that will eventually cause her demise, but she could live for a prolonged period of time if she receives extraordinary treatment.

Consider the patient with a diagnosis of amyotrophic lateral sclerosis (ALS), a degeneration of the upper and lower nerves leading from the brain to the spinal cord and from the spinal cord to the muscles of the body. Prognosis of the disease is very poor. Life expectancy from this disease is approximately three years. The mind is alert but the body has failed. Here is a patient who had a vibrant personality and led an active life, now she is chained to a bed and must have all her needs met. She can no longer swallow, so she has a tube placed in her stomach for nourishment, and the only way she can answer questions is by signal-blinking her eyes.

The patient develops a severe pneumonia and requires hospitalization but refuses treatment with antibiotics. She communicates that the burdens of living do not outweigh the benefits of the treatment to be provided. This patient does not wish to live in this dependent state any longer even though she has a loving family who would care for her.

The nurses, physicians, family members and other members of the healthcare team understand her decision but are having difficulty abiding with that decision. So, we go back to the diagnosis, condition and prognosis of the patient. The diagnosis of ALS will eventually take her life, her condition at this time is poor but she could recover. The overall prognosis of her disease is extremely poor. We would be honoring her autonomy if we honored her wishes; she no longer wishes to live in this debilitated state and considers her life to be a burden to herself and to her family. The principle of beneficence is honored because we would not be providing her with treatment that could be painful to her. Again, we should hold a care conference and reiterate the diagnosis, condition of the patient, prognosis of the patient and the quality of life of this patient. This care conference may enable everyone concerned with the case to understand the feelings of the patient so they can feel comfortable with her decision. We can provide palliative care and support the patient by upholding her decision.

6. Conclusion:

So, in conclusion, I have supported the physiological definition of futility and determined that medically futile care should not be provided to the elderly with multisystem failure, severely premature infants, infants with severe anomalies, those patients who are in a persistent vegetative state and those who are in a terminal state. I have stressed the importance of communication and trust between family members and physicians.

The ethical principles of justice, beneficence, autonomy and non-maleficence have been discussed and how they can be used to enable the medical profession to

come to decisions regarding futile care. Finally, conflict resolution and the decision-making process have been discussed using these principles.

Many of these ethical issues could possibly be resolved if the patient had a living will or a durable power of attorney for health care as is posited in the Patient Self-Determination Act, the subject of the next chapter.

ENDNOTES

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CHAPTER THREE

PATIENT RIGHTS AND THE PATIENT SELF-DETERMINATION ACT

Patient rights and the Patient Self-Determination Act have had an impact on patient autonomy but not one the proponents of this Act would like. This Act is known as the Danforth Amendment and stresses patient autonomy, specifically the right to refuse treatment. But the public has been very wary of the use of advance directives, which are supposed to give them the right to have a choice in determining their medical care. This chapter will explain how patient rights and advance directive came into being and how if these directives were used properly, many cases involving medical futility would be avoided.

These directives consist of a living will or a durable power of attorney for healthcare. Yet, even when patients have advance directives, many physicians or family members have not honored these directives. In some cases, the lack of the advance directive has saved the patient's life. Consider the case of a patient with an acute exacerbation of chronic obstructive pulmonary disease that might require the temporary use of a ventilator. If the patient had a living will that stated they did not wish any type of life support to be administered in any case, that patient might be allowed to die without any treatment.

A short history of the Patient Bill of Rights and the Patient Self-Determination Act will provide insight to the reasons why these laws are important and why they are not widely implemented in the healthcare field today.

The Patient Bill of rights was the result of a study done by the National Welfare Rights Organization in 1970(1). This organization investigated hospitals and the way patients were treated, especially in the admission process and the right to privacy (2). The report published in that year contained a list of twenty six items concerning patients which was then presented to the Joint Commission on Accreditation for Hospitals. The Joint Commission adopted a number of these items regarding patient rights and then published these rights in their manual. At that time, the Joint Commission manual was a document of a more or less philosophical nature and the hospitals were not forced to comply with the contents. Some of these rights included access of care to all persons regardless of race, color, creed, national origin, or ability to pay. One of the most important rights stated that the patient had the right to be told the truth about their medical condition and to give informed consent for their treatment. Informed consent is that type of consent whereby a physician must inform the patient of the benefits or the side effects of any treatment provided. In the 1970's and until this decade, paternalism was the dominant way physicians practiced medicine and patients were not told of the seriousness of their condition, nor were they allowed to have a decision in the care they were to receive. While the list of rights in the 1970's was long and the Joint Commission expected compliance, it is now mandated that the hospitals have a specific list of rights and they (the hospitals) must comply. The list of eleven rights, which includes the right to refuse treatment, must be enforced in the year, 2000. If compliance does not occur by the hospital, it may forfeit Medicare funding.

Senator Edward Kennedy headed a Commission named “Quality of Health Care and Human Experimentation” in 1973. While Senator Kennedy’s Committee began by investigating research, it later turned to the field of medical ethics. The issues in this field now became public knowledge. The Commission then became the President’s Commission for the study of Ethical Problems in Medicine (3).

So despite physician opposition, a Commission was formed by the United States Congress in 1978, to examine and scrutinize the field of medical ethics. It was the use of advanced medical technology and the quality of life of the patients that was at the root of the movement (4).

Patient rights were becoming an issue in the 1970’s when Ralph Nader’s group, “The Public Citizens Health Research Group” continued to spotlight patients’ rights as public policy (5). The Quinlan and Cruzan cases brought forward the way these rights were contested in the healthcare field and are cited as landmark cases in the field of bioethics in the 1970’s and 1980’s.

The right to refuse treatment became a public issue in 1975 when Karen Ann Quinlan, a seventeen year old, collapsed at a party, possibly from a combination of drugs and alcohol, and was taken to a hospital where she lapsed into a coma. She suffered from a lack of oxygen to the brain and gradually regressed into a persistent vegetative state from which she would never recover. The term “persistent vegetative state” was coined in the The Lancet, a British Medical Journal, in 1972. The patient is awake but unaware of himself or anything around him. The patient has periods of sleep and wakefulness, moves, but not voluntarily, and exhibits no emotions. This

state is more common due to the advanced technology that was used and is being used today.

After Quinlan existed a few months in this state, her parents requested that the respirator be removed from their daughter. The physician agreed, but then decided it would be morally wrong for him to perform this act. The hospital concurred, stating that Quinlan did not meet the Harvard brain-death criteria and thus she was still alive.

We must remember that during this time, advanced medical technology was now being used with greater frequency; especially in the field (e.g. by emergency medical personnel). For example, it was used as a result of car accidents, or in the case of Quinlan, being admitted to the emergency department due to an unknown cause. When Quinlan was admitted to the emergency department, the physicians were not quite sure of her specific diagnosis.

In addition to the advanced care in the field and in the emergency department, critical care units were now an integral part of the hospital. While nurses and physicians were already making life and death decisions, withdrawing life support from a patient, especially one so young, was not a commonality. There were also legal aspects to consider: would the physicians or nurses lose their license because they caused a patient to die? These were the questions that remained to be answered in this case, so those involved in the case were very uncomfortable with making the decision to withdraw the ventilator. Not only were there legalities to consider, but also many of the staff did not think it was ethical or moral to withdraw life support even though there was no quality of life for Quinlan.

The Quinlans took their case to Court and the New Jersey Supreme Court ruled in their favor (6). The respirator was removed, but not the feeding tube. Quinlan lived for eight more years in this persistent vegetative state until her death in June, 1985.

While cases such as Quinlan had existed in hospitals for years, none had received much publicity. Right-to-die issues became quite prominent surrounding this case. In 1976, before the Quinlan case, five states had legislation introduced regarding the right to die issue, but it was defeated in all five states (7).

After the Quinlan case, in 1976, seven states (Nevada, California, Arkansas, Idaho, New Mexico, Oregon, and Texas) signed bills into law regarding right-to-die issues (8). "Quinlan stands out as the first right-to-die case heard by a state Superior Court in which the Court freely injected itself into the sacrosanct doctor-patient relationship as an arbiter of rights and wrongs. In other words, the Quinlan case personalized issues such as this and brought to the forefront that medical issues such as the right-to-die issue should be considered family affairs, not decided by the state in the Court system. The Court argued in ground breaking fashion, that the Quinlan case raised questions that transcended the medical hegemony that had traditionally existed"(9). In other words, physician paternalism and one-sided decision making was finally becoming an issue in the care of patients.

The Cruzan case is the second landmark case in the quest for patient rights. In 1983, at age 25, Cruzan was involved in a car accident where her brain was deprived of oxygen for 20 minutes or longer. She was resuscitated but was left in a persistent vegetative state due to irreversible brain damage. Cruzan's body eventually assumed

a fetal position and she was kept alive by feeding her through a gastrostomy tube (a tube surgically inserted into her stomach). After five years in this state, in 1988, the family requested that the feeding tube be removed. Judge Charles E Teel, who presided over the Probate Division Court in Jasper, Missouri, agreed with the Cruzans, but there was a debate in Court whether this act would honor Nancy Cruzan's request (she had previously stated that she would not wish to live if she had no quality of life) under informed consent or if it would be criminal homicide (10). Appeals were immediately filed by the state and the case was moved to the Missouri Supreme Court. The Court refused the Cruzans' request. They (the Court) agreed that Nancy Cruzan's wishes were not known. According to the state law in Missouri, clear and convincing evidence that the patient did not wish to live in a persistent vegetative state must be present to terminate life-sustaining treatment.

The Cruzans again appealed and the case was taken to the United States Supreme Court, which recognized a right-to-die but also stated that the states have a right to set "reasonable standards" to guide the exercise of that right (11). The state of Missouri again demanded clear and convincing evidence of the patient's wishes before the Cruzans' request to remove the feeding tube would be honored. In the Cruzan case, two friends came forward and stated that Cruzan did not wish to live if she must depend on artificial means to sustain her.

The Cruzan case is cited as the most important bioethical case decided by the United States Supreme Court (12). In a 5-4 decision, the Supreme Court's ruling established a constitutional right to refuse treatment under the Fourteenth Amendment's guarantee to liberty. The Fourteenth Amendment is a guarantee of

freedom of choice and action. Before the case, the right to refuse could be changed by statute or case law. The Supreme Court decided that a prior judgment of a competent person could be taken into consideration (13).

Chief Justice Rehnquist wrote the majority opinion. Concurring Justices Scalia and O'Connor presented other opinions in this case and Justices Brennan, Marshall, Blackmun, and Stevens presented the dissenting opinions.

The opinion of Justice Sandra Day O'Connor stated that liberty guaranteed by the Fourteenth Amendment must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment including the artificial delivery of food and water (14). The state must honor the decision regarding the medical treatment of a surrogate appointed by the patient. In my opinion, Justice O'Connor is establishing a right for anyone to refuse care if they so desire.

On the other hand, concurring Justice Scalia presented this opinion stated thus:

A state has the power to ignore an individual's refusal of treatment, even if proven by clear and convincing evidence, because of its interest in preventing suicide (15).

Justice Scalia also believes that the state has the power to prohibit by force if necessary that right of patients to refuse treatment even if they are in a terminal state of dying. Scalia does not differentiate between removal of life support and ordinary suicide. Justice Scalia also believes that the state has the power to prohibit by "force if necessary" that right to refuse treatment even if the patient is in an imminent state of dying, those with no hope of cure, and those who are racked with pain due to a terminal condition (16).

Suicide is defined in the Encyclopedia and Dictionary of Medicine and Nursing as the act of taking one's life. While Justice Scalia seems to have the patient's interest in mind, he is taking away the right for a patient to refuse no matter what the case. With all due respect to the Justice, I will argue against Scalia's opinion of equating suicide and the removal of life support. Suicide is the deliberate act of taking one's life, while a person who is in a persistent vegetative state such as Cruzan cannot actively take her own life because she has no thought processes to make that decision. Nor do most of the patients who have life support removed.

If we go back to the 1960's, there were few means to sustain a person's life and the person was allowed to die a dignified death. I firmly believe that this should be the case today: let the patient die a dignified death without being prodded with tubes, needles, and other treatments to sustain a life when there is no hope.

The dissenting Justices were sensitive to the "individual rights of patients and the realities of medical practice". Justice Brennan observed "that the Missouri rule is one that transform human beings into passive subjects to medical technology".

Justice Brennan's words in his closing statement are as follows:

Missouri and this Court have displaced Nancy's own assessment of the processes of dying. They have discarded evidence of her own will, ignored her values, and deprived her of the right to a decision as closely approximating her own choice as humanly possible. They have done this disingenuously in her name, and openly in Missouri's own. That Missouri and this Court may be truly motivated only by concerns for incompetent patients is no matter. As one of our most prominent jurists warned us decades ago: 'Experience should teach us to be most on our guard to protect liberty, when the government purposes are beneficent...The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well meaning, but without understanding (17).

Since the Cruzans' request failed to satisfy the state's evidentiary standards, the United States Supreme Court sent the case back to Missouri and the case was presented again to the Probate Division courtroom of Judge Teel. The Judge heard testimony of friends who had conversations with the patient in the matter of sustaining life in a terminal condition or in a persistent vegetative state. The physician, who at first refused to remove the feeding tube, finally changed his mind. Even the Court appointed guardian sided with the Cruzans stating "to be kept alive in a persistent vegetative state would be living hell"(18). On December 14, 1990, the feeding tube was removed from Nancy Cruzan and she died within eleven days. As an aside to this case, Nancy Cruzan's father committed suicide in 1997. He was never able to completely resolve the emotional problems that occurred during the years his daughter lived in a persistent vegetative state.

As a result of this case, Senator John Danforth of Missouri introduced and pushed through Congress the Patient Self-Determination Act , which now plays a prominent role in patients' rights and the right to refuse treatment.

The Patient Self-Determination Act (PSDA) was part of a 1990 amendment to the Medicare law. As mentioned previously, it was written by Senator John Danforth of Missouri and is named the Danforth Amendment. It stresses patient autonomy and specifically the right to refuse treatment. In order to receive Medicare funds, the law states that a hospital must ask if the patient has an advance directive and record that answer on the patient's chart. If the patient does not have an advance directive, the hospital must provide information to the patient on how they can obtain that directive. In the event the patient does have an advance directive, a copy must be obtained and

placed on the chart. If a copy is unavailable, the substance of the directive must be obtained and recorded in the chart. The substances of a directive are the wishes of the patient should he/she become incapacitated and unable to make decisions regarding their care. The law also requires hospitals to have policies regarding these directives and a mechanism to educate the staff and the community concerning these directives.

The intent of the Danforth Amendment is as follows:

More and more it is arguable that we play God by subjecting people to unwanted and sometimes unnecessary treatment, treatment that unnaturally prolongs the dying process. Our health care system has become, with extending life, at times neglecting the caring component of medicine and trampling on the rights of patients (19).

The passage of this act was passed as an important milestone for patient rights, enabling them to specify treatments they will refuse or those they will accept should they become incapacitated and unable to make decisions.

The two most common forms of advance directives are living wills, also called a declaration, and a durable power of attorney for health care. A living will is a document whereby an individual can specify those treatments he would refuse if he were to become incapacitated and unable to make a decision. A durable power of attorney for health care authorizes a spouse, significant other, a relative other than a spouse, or another person to make decisions concerning life-sustaining treatment if the patient becomes incapacitated. This document may or may not be notarized. It is extremely important to instruct the patient that there is a difference between a power of attorney and a durable power of attorney for health care. Many do not realize the difference between the two documents. A regular power of attorney is a document that concerns money and property while a durable power of attorney for healthcare is

a document that concerns health care only. Even though the Danforth Amendment was passed, the impact of this bill has not been what the proponents expected or hoped would happen with its passage. When the bill was passed, approximately 4% of Americans had what constituted a living will or an advance directive. Even though the community and the staff of hospitals have been educated, the numbers of Americans who have advance directive remains low, at eight to fifteen percent (20).

At this writing, the District of Columbia and forty-six states authorize both the living will and the durable power of attorney for healthcare. One state, Alaska, authorizes only the living will and three states, Massachusetts, New York, and Michigan authorize only the durable power of attorney for health care (21).

Also as a result of the publicity that highlighted the Quinlan and Cruzan cases, the Joint Commission mandated that hospitals educate the public, on admission to the hospital, that they have a right to refuse treatment. The hospital must also inform the patient that they have a right to have an advance directive or to have a surrogate decision maker.

What seems to be the reason that advance directives are not a success in the United States, or for that matter in any other country in the civilized world? When I lecture to the community in Las Vegas on the subject of advance directives, the consensus of the listeners seems to be that they are afraid if something does happen to them, say an acute illness, an advance directive may be the cause of their death. In other words, if they had an advance directive, the staff of the hospital would not resuscitate them. Others fear that even if they had an advance directive and they were incapacitated, the physician or the family would not honor the directive and they as a

patient would suffer for a long period of time. Numerous members of the population have observed relatives or friends go through this process.

Karen O. Kaplan, who is executive director of Choice in Dying, is proposing legislation to encourage physicians to speak of advance directives as part of patient care instead of approaching this subject only in a medical crises. Karen Kaplan also states that the threat of lawsuits may force hospitals to pay more attention to the wishes of patients, their relations or surrogates. As a case in point, a family successfully won a lawsuit against a hospital for refusing to follow a mother's directive that her daughter not be resuscitated. After the resuscitation, the daughter was left in a persistent vegetative state and this cost the hospital \$16,000,000. So even though the patient had advance directives placed on the chart, the physician and the hospital refused to honor the directive (22).

Care that is provided to a patient contrary to their written wishes can be construed as battery. At this writing, the Courts are becoming more willing to consider battery to the patients if advance directives or a durable power of attorney for health care are not honored.

On the other hand, Arthur Caplan, director for the Center of Bioethics at the University of Pennsylvania, predicted "that the act would be a failure", and the SUPPORT study (Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment) seems to support his thinking. It found many shortcomings in the treatment of the terminally ill. Many physicians were unaware that their patients had signed advance directives, so many of these patients had painful deaths when their wishes were not honored in the ICU. In many cases, even if the directive was

placed in front of the chart, the physician did not honor it. Even though nurses were appointed to intervene in the cases where the patients had an advance directive, it did not make a difference, since the physicians did not honor those directives. Some ethicists feel that since the SUPPORT study shows advance directives are failing, that physician-assisted suicide will become more common. Joseph J. Fins, a physician and director of medical ethics at a New York hospital, states that he sees suicide as a symptom of the problem and not a solution. He also states that physicians should focus on palliative treatment instead of trying to cure an incurable disease.

Daniel Callahan states “that these problems can be resolved only by bringing about profound changes in the way the medical profession and the society at large think about dying, we thought at first all we needed was reform, it is now obvious that we need a revolution” (23).

Another perspective on advance directives is that of Christopher James Ryan, a psychiatrist in New South Wales, Australia. He states that he feels there are problems with advance directives. Ryan feels that there are unnecessary deaths due to the use of the directives: if a patient is temporarily incapacitated, he should be resuscitated until he can wake up to make another decision (24).

Ryan begins his article with a mythical story. A king introduces a new law and “this law allowed his subjects to enter into a mysterious wager”. The participants had to answer a certain question given beforehand and the entrance to this contest was strictly voluntary. If the contestant won, he was rewarded, however, if he lost he was put to death. Many lost their lives needlessly due to the participation in this contest.

He equates participation in the contest with signing an advance directive.

Ryan states that those who sign advance directives when they are well may not be making the right choice for end of life decisions. In other words, you may think you know the right answer to the question, but you do not. The other analogy he makes is to imagine yourself in a state of terminal illness, a temporary confused state, or unconscious but having a chance for survival—will you be treated aggressively or will you just receive palliative care?

He does clarify one point, that he does not oppose all forms of advance directives. He only opposed those cases where the directive states that only palliative care will be given to one in an incompetent state that is potentially reversible, because unnecessary deaths may be the result.

While autonomy is the goal of the advance directive, the author objects to the fact that the choices are different between a real situation and when an imaginary scenario is presented to one who must make a life or death decision.

Ryan stresses that the “utilitarian argument draws its strength from the hope that the existence of advance directives will end the suffering of people with a terminal illness who have decided that they would be better off dead”. However, it also presumes that these individuals make this decision when they are healthy and not balancing a decision from the state of ill health at the present time. This could possibly undermine the utilitarian argument since people might die when they do not want to due to the presence of an advance directive.

The author's main argument applies only to those directives which are made by people who are in a healthy state and who wish the withdrawal of life support in a situation where their "inability to consent is potentially reversible".

While the author is trying to provide a safety net for those who have written advance directives, there are some problems with his argument. If an eighty-five year old man is resuscitated so he can make a decision because his condition is potentially reversible, it may take months or years for the person to reach that state; so we could potentially have rooms full of persons waiting to come around to make a decision while the body deteriorates. Many directives made are also very specific as to the treatments that should be withheld. They also specify that the directive may be used only if the person is permanently unconscious or in a terminal state of illness.

Therefore, I argue against Ryan by stating that in his argument the patient's right to make a decision regarding his health care is abolished. My other argument is that even though a patient has a directive, that patient can rescind that directive at any time prior to incompetence. In other words, a patient may have a directive when he enters the hospital but he may change that directive at any time after admission.

So while the use of advance directives does have problems, many people have been saved a life of degradation because these directives have been honored by the health care team involved in their care.

Case law is the subject of the next chapter. If advance directives or a durable power of attorney for healthcare had be present, some of these cases may have been settled at the bedside and not in a courtroom.

ENDNOTES

1. James M. Hoefler, and Brian E. Kamoie. *Deathright: Culture, Medicine, Politics and the Right to Die*. (Boulder: Westview Press 1994): 105.
2. *Ibid.*, 105.
3. David Rothman, *Strangers at the Bedside*. (New York: Basic Books 1991): 188.
4. *Ibid.*, 188.
5. *Ibid.*, 189.
6. *In re Quinlan*, 70 N.J. 10,355 A 2d647 (1976).
7. Hoefler, 131.
8. *Ibid.*, 131.
9. Jacquan Hall, *Nursing Ethics and the Law*. (Philadelphia: W.B. Saunders Co. 1996): 455.
10. Lawrence J. Nelson, *Clinical Ethics Report-Bioethics in the Courts: Summeries of Selected Judicial Decisions 1989 to 1995*. (Spring/Summer 1995) vol.9 no.122: 2.
11. *Ibid.*, 2.
12. *Ibid.*, 2.
13. *Ibid.*, 2.
14. *Ibid.*, 2.
15. *Ibid.*, 2.
16. *Ibid.*, 2.
17. *Ibid.*, 2.
18. Hall, 455.
19. *Ibid.*, 455.
20. James Horgan, "Right to Die," *Scientific American*. (May 1996):12-14.
21. *Ibid.*, 13.
22. *Ibid.*, 13.
23. *Ibid.*, 14.
24. Christopher James Ryan, "Betting Your Life: An Argument Against Certain Advance Directives," *Journal of Medical Ethics*. (April 1996:22): 100-4.

CHAPTER FOUR

CASE LAW

Everyone has the right to make decisions with regard to his or her medical care whether to accept that care or refuse it. This issue was discussed in the previous chapter. This right is derived from several sources: “(1) the Fourteenth Amendment guarantees that no person will be ‘deprived of liberty...without due process of law’; (2) the constitutional right to privacy; (3) the constitutional right to religious freedom; and (4) the common law of body integrity and self-determination and the doctrine of informed consent” (1).

These rights, however, are being curtailed by other interests such as the desire to “1) preserve life, 2) to prevent suicide, 3) to protect third parties, and 4) to safeguard the integrity of the medical profession”(2). In other words, outside agencies, such as the ADA (American with Disabilities) or other persons are attempting to become involved in making decisions regarding medical care for those who are strangers to them. Some of these groups regard withholding or withdrawing treatment from patients as pro-euthanasia. The case law presented in this chapter represents the different ways the Courts view medically inappropriate or medically futile care.

The medical profession, particularly, does not wish to be accused of making decisions that would include passive euthanasia. Passive euthanasia could be defined as withdrawing treatment from an individual who has a terminal condition or removal

of life support from a person who has no hope of survival and is in a comatose state. Even though these are cases of futility, we live in a highly litigious society where “pulling the plug” if you will, could be considered a form of euthanasia.

The Massachusetts high Court has found that there is a “critical distinction” between insisting that life be sustained when an affliction is curable as opposed to the state interest in preserving life where that ‘prolongation’ incurs a ‘traumatic cost’ for the individual. The Court found in Eichner v. Dillon (1980) “that a terminally ill patient maintained by life support has no health and in the true sense, no life for the state to protect” 436 N.Y.S. 2d 517 (3).

Consider the case of Baby K, an infant born in October, 1992, in the state of Virginia. The infant was born with anencephaly, a condition in which some portion of the brain stem is present, but the cerebral cortex, the largest part of the brain, is severely underdeveloped or absent. No treatment can correct this condition and Baby K was blind, deaf and could not feel any pain. She could breathe and suck but she remained in a permanent unconscious state. Many of these infants die within a few days after birth, but Baby K was resuscitated after birth and was placed on a ventilator.

Hospital personnel, physicians, and nurses requested permission from the mother to remove the ventilator, stating that the child would not live. The mother refused and the hospital attempted to transfer Baby K to another hospital with a neonatal intensive care unit, but no other hospital would accept her as a patient. Her mother cited her right to religious freedom to demand treatment. It was God’s choice when the baby would die, not that of the medical profession. The baby remained in

the hospital for six weeks and eventually was weaned from the ventilator, a process where demand breathing is decreased for the patient and the patient will finally breathe on his or her own.

The infant was readmitted twice more with respiratory distress and was placed on a ventilator each time. Baby K received a tracheostomy (an opening into the trachea to facilitate the passage of air) in March, 1993. This procedure was still only a measure to prolong her life. Health care professionals made repeated attempts to dissuade the mother from asking for any more treatment that they considered futile. The mother refused each time, stating that her religious belief required that all life was considered sacred.

The hospital filed a suit with the United States District Court in Virginia, asking if refusal to treat would be in violation of any existing law. The hospital also requested a Guardian Ad Litem. This is a court appointed person, made during the course of a proceeding, in order to protect the interests of the alleged disabled minor. The baby's father and the Guardian Ad Litem agreed that all care was futile due to the underlying condition of the infant and agreed with the hospital that no further ventilatory treatment be given. The Court cited three federal statutes that the hospital would violate if it refused treatment to Baby K: 1) the Emergency Treatment and Labor Act (EMTALA), 2) The Rehabilitation Act of 1973, and 3) the American with Disabilities Act of 1990 (ADA). The Court also ruled in favor of Baby K's mother, citing Constitutional and common law principles. In the Matter of Baby K. 832F Supp.1022 (E.D. Va.19930) (4).

EMTALA requires that a hospital treat anyone who enters that hospital seeking emergency treatment in order to stabilize the condition of that person. The mother of Baby K requested such treatment, since the baby was in respiratory distress. The hospital argued such treatment was inhumane, considering the condition of the infant and requested an exception in this case.

The Court argued otherwise. It stated it is up to Congress, not the Court to make an exception, and if any treatment would stabilize the baby's condition that it be given, even though it is considered futile.

In regard to violation of the Rehabilitation Act, the Court considered the baby a handicapped person since she was born with a congenital defect. Under Section 504 (of the Rehabilitation Act of 1973) it is unlawful for a recipient of federal financial assistance to withhold from a handicapped infant, nutritional sustenance or medical or surgical treatment to correct a life-threatening condition if: 1)the withholding is based on the fact that the infant is handicapped; and 2)the handicap does not render the treatment of nutritional sustenance medically contraindicated (5).

The Court noted that refusal to treat Baby K by withholding the use of a ventilator would violate the ADA, since ventilatory support would be given to other children if it were requested by their parents. The ADA prohibits discrimination against disabled persons in "public accommodations operated by private entities" such as hospitals. (sec.301) (7) (F) (6).

The Court also found Constitutional and common law rights that prevent the hospital from refusing treatment to Baby K. It focused on the right for parents to

make medical decisions for their minor children. It also found that there is an explicit guarantee of a right to life in the United States and the Virginia Constitution.

The District Court rejected the right of health care professionals to withhold treatment in some cases, especially those cases when the parents opposed withholding treatment.

Two opinions (somewhat narrow) were stated:

It is beyond the limits of our judicial function to address moral and ethical propriety of providing emergency stabilizing medical treatment to anencephalic infants. We are bound to interpret federal statutes in accordance with their plain language and any expressed Congressional intent.

...EMTALA does not carve out an exception for anencephalic infants in respiratory distress any more than it carves out an exception for comatose patients, those with lung cancer or those with muscular dystrophy—all of whom may seek emergency stabilizing treatment of respiratory distress and also possess an underlying condition that severely affects their quality of life and ultimately result in their death. Official Report Citation, in the matter of Baby K. (4Circ 1994). [16F.3d590@598](#) (7).

The dissenting judge had a broader view of the case. EMTALA was intended by Congress to prevent “dumping” of patients from one hospital to another. A hospital must treat a patient even if that patient is indigent. In other words, if an indigent patient was in distress and requested treatment, treatment must be given and the patient is stabilized before transfer to another facility. This judge did not interpret EMTALA to mean that Congress should decide ethical and moral issues in medicine.

The hospital petitioned the United States Supreme Court and they refused to hear the case. Baby K died before any other appeals could be made to the Courts, so there was no legal resolution in this case. However, if Baby K had lived, she would have had to be resuscitated on every admission to the hospital for the condition of respiratory distress.

Another case where the Court ruled for the patient is that of Helga Wanglie. Wanglie fell and fractured her hip in December, 1989. The fracture was repaired and she was discharged to a nursing home. While in the nursing home in January, 1990, she went into respiratory distress, and was taken to a hospital where she was placed on a ventilator. She was unable to be removed from the ventilator and was placed in a facility that specialized in the care of that type of patient. While in that facility, she had a heart attack and was resuscitated. She was deprived of oxygen for several minutes and as a result, she was left in a persistent vegetative state.

There were repeated visits to the hospital for bouts of pneumonia and physicians made repeated attempts to have the family withhold any further treatment, stating that any and all treatment in her case was futile. The family refused and the hospital filed suit in the Court system of Minnesota.

The New England Journal of Medicine supported the hospital's suit stating in an editorial that "the hospital's pleas [was] born of realism not hubris...it advances the claim that physicians should not be slaves to technology any more than the patients should be its prisoners. They should be free to deliver and act on, an honest and time-honored message: 'Sorry, there's nothing more we can do'" (8).

Mr. Wanglie filed a counter suit against the hospital since the hospital no longer wished to provide medically futile care. There was a hearing in May, 1991 before Probate Judge Patricia Belois. The physician consultant for the hospital, Dr. Steven Miles, (the author of many articles in the field of bioethics) acknowledged that family members are definitely the preferred surrogate for a patient in a persistent vegetative state. However, he also stated:

Physicians have a duty to overrule a family in certain circumstances and that a doctor cannot be obligated to provide medical care that cannot serve a patient's personal interest (9).

The attorney appointed by the Court for Mrs. Wanglie stated that "he couldn't disagree with the family more, but I feel even more strongly that the right of the individual is paramount"(10).

The Court appointed Mr. Wanglie guardian for his wife and ruled in favor of the family. Mrs. Wanglie died shortly thereafter in July, 1991, of multisystem failure. In re Conservatorship of Wanglie, (No. PX-91-238 Minn. Dist.Ct.) (11).

While the Courts ruled favorably on behalf of providing futile care in these two cases, there have also been decisions in favor of withholding or stopping life-sustaining treatment in other cases.

In the state of Indiana, the Court ruled against the National Legal Center for the Medically Dependent and Disabled (a pro-life group) in the case of Sue Ann Lawrence in 1991.

Lawrence had been in a debilitated state since suffering from a brain tumor in childhood. As she grew older, her disabilities increased. When she fell from a wheel chair in 1987, she lapsed into a persistent vegetative state. After a year in this state, the family decided that life support should be withdrawn. They felt that Lawrence would never recover and never have a chance for any kind of life.

The National Legal Center for the Medically Dependent and Disabled (a pro life group) challenged this action. This organization cited the fact that Lawrence was in a persistent vegetative state and therefore considered disabled. They further argued that it would be a violation of her basic human rights to withhold nutrition.

The family agreed to resume the feedings until the Indiana Supreme Court reached a decision. The Court ruled “that the family had the authority, without judicial intervention, to stop any artificial nutrition.” Chief Justice Randall T. Shepherd wrote, “The law of the state permits the family to decide in consultation with their physicians, that the tube feeding of a loved one in a persistent vegetative state should be ended.” In re Lawrence, 578 N.E. 2d. 32 (Ind. 1991) (12).

The ethical principle of autonomy was honored and the principle of substituted judgment was used. The parents felt that their daughter would not wish to live in a persistent vegetative state.

The Courts also ruled in favor of removing life support in the case of Claire Conroy. Conroy was an eighty-four year old resident of a nursing home who had lapsed into a persistent vegetative state. A nephew, who was her legal guardian, petitioned the Court to remove life support. The Court weighed the benefits of treatment, comparing them to the burdens imposed by those treatments, (e.g. “the degree of the treatment’s invasiveness, the degree of humiliation, and the extent of uncontrollable discomfort or pain.”) The Court reviewed the case and agreed with the nephew to stop life-sustaining treatment, but Conroy’s court appointed attorney filed an appeal.

In an Appellate decision, the New Jersey Court:

“equated artificial feeding thru tubes with artificial breathing through the use of a respirator, and ruled that naso-gastric tubes, gastrostomies and intravenous infusions...are medical procedures with inherent risks and possible side effects, instituted by skilled health professionals to compensate for improved physical function. It further explained that “once one enters the realm of complex high-technology medical care, it is hard to shed the emotional symbolism of food. However, artificial

feedings are significantly different from spoon-feeding. They are medical procedures...and can be seen as the equivalent to artificial breathing.” In re Conroy, 98 N.J. 321, 486 A.2d 1209 (1985) (13).

All four of these cases are ones in which there was no chance of a cure nor was there a chance of a return of any quality of life. The death process was just being prolonged by our advanced technology. Yet there are attorneys, judges, and other groups with their own agendas in mind, who are afraid to face reality with the dying process. One cannot expect the human body to function forever. Granted there is always hope, but in these four cases, there was no hope and the decisions should have been made at the bedside and not in a courtroom. Hopefully, with the use of the Ethics Committees and increased communication, some of these issues will be resolved at the bedside. If perchance, one would view these cases with cost in mind, there were not only medical costs of sustaining a person with no quality of life, but there were legal costs as well.

Let me return to the problem with the ADA. The ADA was not written to intrude into family concerns regarding medical care or to interfere with medical decision-making. It was written to eliminate discriminatory as well as physical barriers to the participation of people with disabilities in employment, public services, public transportation, accommodations and telecommunications. The ADA also stresses independence in the disabled population. Yet, the portrayal of a disabled person is usually one of a frail, elderly person who is chronically ill and “only marginal to society”.

Many of the handicapped and disabled are truly frightened of health professionals not providing treatment to them if they become ill or withdrawing

treatment just because they are handicapped and their life may not be considered worth living. This is simply not realistic. Any person who enters a hospital emergency department must be treated or it is a violation of EMTALA. The hospital will not withhold or withdraw treatment from a handicapped person until it has family permission if the patient is unconscious. Each hospital has policies and procedures to cover instances such as this. Therefore, it might behoove the ADA to spend money educating the public and their own members that treatment will not be withheld from those who are disabled or handicapped.

The futility issue is not about this population, it concerns those who lay in hospital beds with no hope of leaving the intensive care unit and those being in a comatose state for the rest of their lives. Therefore the ADA and other groups previously mentioned who try to intervene in the cases brought to court should not try to interfere in a family decision; but they, as an organization should become familiar with the process used in hospitals when a treatment of life support is being withdrawn from a patient.

All the health care team members take each case of medically futile care seriously while caring for the patient. No one is trying to end a life needlessly. But as problems do develop, every effort should be made to solve them at the hospital level instead of in a courtroom.

ENDNOTES

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4. In the matter of Baby K. 832F Supp. 1022 (E.D. Va. 1993).
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6. Wendy Parmet, "Discrimination and Disability: The Challenges of the ADA." Law, Medicine and Health. (1990): 18.
7. Official Report Citation, in the matter of Baby K. (4Circ 1994). 16F.3d590@598.
8. James M. Hoeffler, and Brian E. Kamoie, Deathright. (Boulder: Westover Press 1994): 61.
9. Ibid., 62.
10. Ibid., 63.
11. In re Conservatorship of Wangle, No. PX-91-238 Minn. Dist. Ct. June 28, 1991). Reviewed in 16 (1) MPDLR 46.
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CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

We have now entered the year 2000, and the futility debate remains an issue in bioethics. It is evident that some guidelines and decisions need to be discussed, and public policy should be addressed. Medicine has progressed at a rapid rate since the 1960's when patients were allowed to die in peace and dignity, now, they are poked, prodded, and invaded bodily, sometimes against their will, to avoid the process of death.

So, in review, we have covered the history of medicine from primitive times to modern times where the advancement of high tech medical care is used to provide futile care to the terminally ill, the elderly in multi-system failure, those in a persistent vegetative state and neonates with severe anomalies or extremely low birth-weight.

I have supported the physiological definition of futility as the one that should be used in making decisions regarding futile care and my definition is: *If a treatment cannot cure or provide a benefit to the following population; the terminally ill; those in a persistent vegetative state; the elderly in multi-system failure; or neonates with no hope of survival (those of extremely low birthweight or those with severe anomalies) then that treatment should not be provided and palliative care should be instituted. There are two types of physiological futility. First is the qualitative type of futility that concerns the quality of life of the patient. It is a treatment that renders a patient permanently unconscious or that patient must rely on intensive care for the*

rest of his life, that treatment may be considered futile. In other words, that unconscious patient will never wake up and the patient in intensive care cannot survive outside the intensive care environment. Examples of qualitative futility would be those who are in a persistent vegetative state with no quality of life. The other type of physiological futility is classified as quantitative. If a treatment continually fails in the last one hundred cases, then it could be considered futile. An example of this type of futility could encompass the use of CPR in the terminally ill and the elderly in multi-system failure. I argue that these definitions, and the guidelines of the Hastings Center for applying these definitions should be followed since the issue here is that of providing futile treatment to those who have no hope of recovery.

The use of communication and trust combined with the ethical principles of justice, beneficence, non-maleficence and autonomy are paramount in the decision making process concerning the provision of futile care, for without the use of the above principles, there can be no discussion among the physicians, staff and family. It is of utmost importance that we uphold these principles in the decision making process.

The importance of having an advance directive (living will or durable power of attorney for healthcare) and how these directives are used to prevent providing futile care has been discussed. The use of these directives could prevent cases, such as the ones presented in the case law section, from being handled in a court of law instead of at the bedside.

So, in conclusion, I would like to present the following six recommendations that could lessen some of the conflict in the futility debate. Each will be elaborated in

in what follows.

1. **Education of the public concerning the death and dying process, focusing on the reasons why advanced medical technology should not be used in certain cases.**
2. **Mandatory education in medical school for physicians in communication, ethics, and advance directives.**
3. **Guidelines for the treatment of neonates weighing less than 500 grams and those with severe anomalies not compatible with life.**
4. **Public policy to prevent interference from outside agencies from interfering with family decision making concerning the removal of life-sustaining treatment.**
5. **Public policy in the area of pre-hospital resuscitation.**
6. **Specific guidelines for withdrawing life support such as those at Valley Hospital Medical Center should be in place at every acute care hospital and long term care facility.**

Patient Education:

The first issue that must be discussed in the education process of the public is to state that death is a natural process. It is an impossibility that anyone can live forever. Yet, our culture with the use of high tech medicine, seems to think that life can last indefinitely. The public should face this issue with reality and not expect the use of high tech medicine to prolong life when that is not possible. This education can be provided by those of us who lecture in the community on the use of advance directives.

In 1994, there were approximately 14,000 individuals in a persistent vegetative state being cared for in nursing homes and hospitals at the cost of \$50,000 to \$100,000 per year, per person.(1) Specific guidelines should be in place

concerning the use of CPR for this population. There is no quality of life here and it would be charitable to let a disease, usually pneumonia in this population, follow its natural process into death, while providing the best possible pain management.

Can we continue to treat patients who have no knowledge of their surroundings by using antibiotics to cure infections, feeding tubes for those who have no knowledge that they are being fed, and having breathing tubes to help them breathe? With the cost of health care rising at an astronomical rate, will we be able to continue to funnel health care dollars to this population? And will this population be able to continue to be admitted to an acute care hospital for a diagnosis of sepsis or to receive a blood transfusion for internal bleeding? The answer is no, because it is becoming too costly. I believe that health care dollars to those in a persistent vegetative state will be reduced and admission to an acute care facility will be denied, so this population will be directly affected by futility, one way or another.

It would be advantageous for the American people to come together at a grassroots level, possibly as a community project, to discuss these problems, not only among themselves, but also with physicians, attorneys, and those persons who have knowledge of bioethics. Also included in this group should be acute care and long term care administrators. This community group could research and discuss these issues, come to a decision and then present them to public policy makers.

Mandatory Education in Medical Schools:

Education in communication should be mandatory for those attending medical school. Many physicians cannot or do not know how to communicate with families. If physicians do not communicate with families, patients and staff, they will not earn

the trust that is so extremely important and so sorely needed in the medical profession today. Classes on death and dying should be mandatory for physicians rather than be an elective that is canceled due to a lack of interest. Attendance at these classes could possibly be a benefit to physicians' level of comfort concerning this subject.

Physicians also need to learn how to be articulate in the use of advance directives. Medical school education in this area would be especially helpful to those physicians going into family practice so they could initiate the use of advance directives in their offices.

Guidelines for Neonates:

Specific guidelines should be discussed and put in place regarding the resuscitation of a neonate who weighs less than 500grams or one who is so profoundly handicapped with severe congenital anomalies that there is no hope of recovery. These infants cannot speak; therefore, we have no idea of the amount of pain they are suffering.

The guidelines from the GUIDe group should be adopted by all hospitals that have a neonatal intensive care unit. These guidelines are as follows:

Lethal birth conditions affect only a small number of newborns. In this context, the word lethal implies that death is expected to occur in infancy. Examples of conditions included in this group are: Trisomy 13 or Trisomy 18, requiring life support, renal agensis, anencephaly, and thanatophoric dwarfism.

Supportive care is provided for all babies. This includes family contact, oral feedings, hospice or home care when possible, as well as warmth and pain control. Medical professionals will provide appropriate pain control with these patients, even though some medications carry risks, including respiratory or cardiac arrest

Intermediate care decisions are best made by the baby's family in consultation with the professional caregivers. Examples of

intermediate care are intravenous fluids (IV), oral medications, supplemental oxygen, and nasogastric tube feedings.

Aggressive care for these babies is inappropriate. Examples of aggressive care can include ventilator support, medications to maintain vital signs, CPR, total IV nutrition and gastrostomy tubes.

A physician in the delivery room may be able to make a diagnosis of a lethal condition. In these cases it would be appropriate not to institute ventilator support. In cases in which the professional caregiver is not sure of the delivery room diagnosis, it is appropriate to begin aggressive intervention, obtain the proper studies and then withdraw the intervention if the diagnosis of a lethal condition is confirmed.

Bereaved families deserve the highest level of human support, one that recognizes cultural, ethnic and religious differences.(2)

At the present time, Valley Hospital is forming a committee to address these guidelines for use in our neonatal intensive care unit. If these guidelines had been in place, the Baby K case probably would have never been presented in court. The absence of guidelines must be remedied.

Public Policy for Outside Agencies:

Policy defining the specified role of the ADA (i.e. discrimination on the basis of a disability for a person to perform "essential" job functions with or without reasonable accommodation) should also be in place to prevent any lawsuits from such agencies as the ADA and the National Legal Center for the Medically Dependent and Disabled against families who wish life support withdrawn from loved ones because there is no quality of life for them (3). One must remember that this population is, if you will, fed, watered and turned. However, these agencies look upon those in a persistent vegetative state as handicapped.

There are other causes for the ADA and the National Legal Center for the Medically Dependent and Disabled to defend. In these cases, I argue that they should defer to the families who wish to withhold or withdraw treatment from their family member. These agencies may not realize the burdens placed on the families, not only financially but also, emotionally.

There may be a time, if policy is not made, that these agencies may not only pick and choose those they wish to save, but will advance toward acute care hospitals and try to involve themselves in every case. Granted this probably would not happen, but there is always the possibility. An example of such a policy that could be initiated is for the ADA not to interfere in family decisions regarding futile care.

Public Policy for Pre-hospital Resuscitation:

When CPR was instituted as a life-saving measure, it was a wondrous thing and in some cases it did save lives. Yet, while it was a well meaning procedure, the use of CPR left some of our population in a persistent vegetative state. Mental hospitals in the 1960's had wards where those in a persistent vegetative state were cared for. When one entered such a ward as the one in Norristown State Hospital in Pennsylvania, one observed beds containing persons in a fetal position. The patients' arms, legs and fingers were contracted. Their hair was sparse and dry, their eyes were open and moving side to side but unfocused. They had movements but none were purposeful. Many would remain in this state for years to come. Now in the year 2000, CPR combined with Advanced Cardiac Life Support (CPR combined with drugs and intubation) has saved more lives than in the 1960's. But, there are many who are left in that 'no-mans land' of existing, not living.

Public policy in the area of pre-hospital resuscitation should be addressed and quickly. One must remember that when a person's breathing stops or a heart ceases to beat, others in the home become frightened and call an ambulance even though they (the patient) want nothing done. In the state of Nevada and some other states, it is the law that a person must be resuscitated when the paramedics arrive unless written evidence is presented that the patient has an advance directive. Seventeen states do have laws that allow a paramedic not to resuscitate a person when the ambulance arrives. These laws cover the cases of the elderly person as well as those who are terminally ill and those people who stand little or no chance of surviving resuscitation. Laws such as these would also have an impact on the overall cost of medical care; therefore, Nevada and the thirty-two other states without such provisions should enact them.

So, such a policy would state that whenever a person had signed a Do Not Resuscitate paper, the paramedics would lawfully have to honor that paper, even though the family objected. Another part of the policy would allow the paramedics not to resuscitate a person who is terminally ill, an elderly person or one who stands little chance of surviving resuscitation. Again, the public needs education in this area to support such legislation.

Specific Guidelines for Withholding and Withdrawing Treatment:

Specific guidelines for withdrawing or withholding life support should be in place at every acute care hospital and every long term care facility.

All medical facilities must recognize the right of every patient to accept or refuse medical care even if it ends his/her life. Decisions to forego treatment are guided by the benefits/burdens principle. If the treatment has no benefits for the patient and the burdens become unbearable, then ethically that treatment does not need to be provided.

If death results from the withholding or withdrawing of treatment, it does not constitute a suicide or homicide.(NRS449.650#1) There is no moral or legal obligation to provide futile treatment. The physician is not mandated by law to provide futile treatment. If futile treatment is withheld or withdrawn, then palliative care is provided. These are only a few of the guidelines. The entire policy is in the appendix.

In conclusion, medical futility according to a physiological definition does exist, but futile care is practiced in hospitals and long term care facilities every day. I argue that this care should not be provided to the population frequently mentioned in this thesis. I cannot stress enough the importance of communication in cases of medical futility and how dialogue with one another can make a difference. But, if the recommendations presented above, combined with a grassroots movement and town meetings were discussed and presented through the proper legal channels, they could be used in hospitals, Emergency Medical Systems, and so could withstand the litigious scrutiny of today's legal system. These guidelines and recommendations would also solve some of the dilemmas of 'medical futility' that are present in society today.

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