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# GUIDELINES ON WITHDRAWAL OF LIFE SUPPORT

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# Abstract

Recent advances in medical technology have led to a gap between medical treatment and our ability to deal with the consequent situations. Life can be prolonged via life support to the point where it is of dubious quality, and no guidelines exist to indicate when it's withdrawal is legal or ethical. By examining the legal, ethical, social, and historical context of the debate over withdrawing life support, we develop a set of guidelines to deal with this issue.

## Executive Summary

Many of the most dramatic advances in technology in recent years have been in the area of health care. Unfortunately, legal and ethical thought has not kept pace with these advances, leading to a number of situations in which there is a lack of clear guidelines for proceeding. One of these areas is the withdrawal of life support. While large amounts of clinical data are available, and much has been written about the ethics of withdrawing life support, there have been few efforts made to integrate these two areas, as well as other areas that border on the issue such as religion, into a set of guidelines for dealing with the issue of withdrawing life support.

The legal context of the case is an important starting point for the exploration of this issue. The issue first gained the national spotlight in a legal sense with the *Quinlan* case, and since then numerous judgements in other states have been passed. Many of the judgements rendered are specifically narrow in scope, leading to a lack of broadly applicable precedents, while those judgements that were rendered in a broader sense often varied from state to state and failed to provide a functional set of criteria for withdrawing life support. Similar issues exist in competence cases, an area of legalities closely tied to the topic of managing life support.

In addition to legal concerns, there are personal concerns that need to be addressed regarding the patients. The clinical picture for those that go onto life support is in general fairly grim. Depending on the kind of life support required and the conditions of the individual patient, the quality of life of those existing on it is generally agreed to be

poor. Additionally, there exists no reliable means to predict the outcome of life support, either in terms of pure survival or in more subjective areas such as quality of life.

The additional issue of religion adds a volatile element to the discussion. The large amount of influence that religions have over the behavior of their members can be significant in influencing the decisions and recommendations of all involved. The guidance that religions can provide in the face of such difficult decisions as those relating to whether or not to continue life support is invaluable, but care must be taken to see that religious values of one person are not improperly imposed on others. While the primary concern is of doctors imposing their religious beliefs upon patients, care must be taken to see that doctors are not called upon to perform actions that are morally or religiously repugnant to them.

Finally, concerns about the high cost of medical care must be considered. Ideally, of course, everyone would have access to all necessary medical care, but the high cost of the machinery, drugs, and people necessary to maintain someone on life support severely limits who has access to these resources. The high cost of maintaining life support can also lead to the inclination to remove someone from life support for purely economic reasons.

The first step in constructing a set of guidelines is to look at the medical data available regarding survivability on life support. By quickly identifying those who can almost certainly be saved and expect a reasonable quality of life as well as those who are almost certain to die or suffer an extreme loss of quality of life regardless of medical intervention, the burden of making a decision can be greatly alleviated. Such data also allows for approximate chances to be given in those cases where the outcome is not so certain to alleviate in lesser part the difficulty of making such a decision.

Another important factor to consider in these guidelines is that of competence. Many of those who are on life support are either suffering from senile dementia or have suffered some sort or trauma leading them to be either clearly incompetent or partially incompetent. In either case, their competence with regard to a given decision needs to be established by some method and then their case handled appropriately to the results of that evaluation. In the case of a patient incompetent to make a given decision, some sort of surrogate decision-maker needs to be established within any limits that may exist by means of a living will or advance directive.

Advance directives and their ilk are coming into more frequent use in the United States, although there are some questions as to both their reliability in communicating the patient's real wishes and their applicability in some circumstances. A less common form of advance directive is the power of attorney, designating a specific surrogate decision-maker. The challenge with both of these items is to ensure that the advance directive is interpreted in accordance with the patient's wishes, or to make sure that the designee of the power of attorney makes decisions consistent with the value system of the patient.

As the person who has more knowledge regarding the situation as well as the person who is actually going to be performing whatever procedure is mandated by the decision-maker, the doctor is in a unique, powerful, and somewhat uncomfortable situation. Law has traditionally focused on prosecuting doctors who disconnect life-support rather than the people who actually made the decision. Additionally, the doctor may be put into a position where, in order to not provide an unwanted treatment, he may

be forced to do something that goes against his professional opinion. Finally, although this is a vanishingly small problem in terms of occurrence compared to the previous two, the doctor may be in a position where he can perform an unwanted procedure or pressure someone to give consent for an unwanted procedure. By clearly delimiting the areas of power and consequent limiting and defining the accountability of doctors, many of these problems may be avoided.

Finally, an outline of a decision-making process regarding withdrawing life-support, the rationale behind it, and peripheral issues is presented, along with recommendations for hospitals and long-term care facilities.

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# 1 Introduction and statement of problem

## 1.1 History of and background on life-support (cases etc.)

As befits such a complicated and important topic, the amount that has already been written on the topic of withdrawal of treatment fills books. From a legal perspective, however, there are a small number of important cases which can be looked to for both precedent and interpretation not only of the law, but of ethical implications of the law.

In the first formal acknowledgement of the problem, the American Medical Association issued a statement in 1973, reading in part: "The cessation of employment of extraordinary means to prolong the life of the body … is the decision of the patient and/or immediate family." This obviously shifted the responsibility of the decision from the doctors involved to the patients and family, but begged several important questions which would be factors in later cases. First and foremost, competence is never mentioned, either that of the patient or that of the family. Additionally, in cases of the patient's family deciding, there is no mention of the patient's best interests. It also fails to establish or obtain legal authority for either the doctors or the family of the patients to make such a decision. Finally, it does not address cases where the patient is clearly incompetent and there is no immediate family (or even extended family) to contact.

The AMA's position regarding personal self-determination and right to refuse treatment has been upheld many times in court. In *Bouvia v. Superior Court of Los Angeles County*, the Court of Appeal held that "a person's right to privacy encompasses a virtually absolute right to refuse medical treatment, even when that treatment may be life-saving and its absence leads to an earlier death." [*Bouvia v Superior Court*, 179 Cal. App. 3d. 1127, 225 Cal Rptr 297 [Apr 1986]]. This case specifically pertained to the removal of a feeding tube which had been installed in Ms. Bouvia's stomach against her written orders. She was quadriplegic as a result of cerebral palsy and had been spoon-fed, refusing food when she felt nauseous. When doctors determined that her weight had dropped low enough to be potentially dangerous to her health, they installed the tube which she successfully petitioned to have removed in appeals court. As Justice Comptom put it, "If there is ever a time when we ought to be able to get the 'government off our backs' it is when we face death – either by choice or otherwise."*(Bouvia v.).* *Cobbs v. Grant* (8 Cal.3d 229, 1972) cited in the Bouvia case, held that "a patient has the right, in the exercise of control over their own body, to determine whether or not to submit to lawful medical treatment."

This right to refuse treatment stems in large part from *Pratt v. Davis* (224 Ill.1303, 1906), in which the doctrine of informed consent was first given legal form. Judgement in favor of the plaintiff, Pratt, was given in the amount of $3000 for trespass of person when a surgeon at the Kankakee state asylum removed her uterus without her consent. In the absence of clear evidence as to whether or not Mrs. Pratt was competent to give consent, the trial court "held a proposition of law stating that the burden of proof was upon the appellant [Davis] to show leave and license [to perform the operation]." In the absence of such evidence, it was held by the appellate court that Davis had indeed trespassed on Mrs. Pratt's person, and was liable for the damages from "pain and suffering from personal injury." Obviously, without the right to refuse to have a treatment, the right to informed consent is meaningless.

Perhaps the most comprehensive treatment of the various issues involved in substituting family judgement for a patient's was found in *Barber and Nejdl v. the Superior Court of Los Angeles* (147 Cal. App.3d 1006; 195 Cal. Rptr.484; 1983), in which two doctors (Barber and Nejdl) were charged with murder for complying with the wishes of a deeply comatose man's family by withdrawing life support from him and allowing him to die. The two doctors were to be prosecuted for murder until the complaint was ordered dismissed by a magistrate. A trial court ordered the complaint reinstated, and Barber and Nejdl then appealed to the Superior Court to obtain a writ of prohibition.

The initial dismissal of the magistrate held that since murder was defined as the "unlawful killing of a human being… with malice aforethought." (Pen. Code 187, from Barber/Nejdl v. Cal. Sup. Ct.), that since Barber and Nejdl did not kill the patient, but merely allowed the disease to continue its interrupted course, and because they did not act with malice when they withdrew the life support, they could not be charged with murder. The trial court judge ordered reinstatement of the complaint as a matter of law, holding that the conduct of Barber and Nejdl was in fact unlawful, his precise reasoning being that:

> "since everyone, sooner or later will die, homicide is simply the shortening of life by some measurable period of time and inasmuch as the petitioners' intentional conduct, which shortened Mr. Herbert's course of life, was not authorized by law, it constituted murder." (*Barber/Nejdl v. Cal. Sup. Ct.*1012)

The matter was further complicated by the fact that Mr. Herbert was not dead either by the older heart and respiratory standards or the newer brain death standards, but rather faced a continuing existence in a persistent vegetative state without any higher brain function. By California State law, he was alive and the law could be quite easily interpreted to show that Barber and Nejdl had in fact committed murder. The California Natural Death Act (Health and Safety Code §§ 7185-7195), which allowed for advance directives to remove life support, did not apply in this case, as Mr. Herbert had not filled one out, and the trial court judge, in light of this, held that the wishes of the family as a nullity. The superior court held that the Natural Death Act was limited in scope (for example, it is nonbinding on a physician if the patient executes it *before* being diagnosed with a terminal illness), and indeed the very language of the act states that

> "Nothing in this chapter shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such a respect the provisions of this chapter are cumulative." (Health and Safety Code, section 7193)

As was pointed out by Justice Compton, there was a "gap between technology and law" that forced patients, family, and doctors to make "intensely personal and painful decisions" without any clear indication as to what did constitute "effect[ing] the withholding or withdrawal of life-sustaining procedures in any lawful manner." (*Bouvia v.*) Insofar as the legality of withdrawing life support from a patient that was not legally dead was concerned, Justice Compton examined the Health and Safety Code, section

7186, and found it clear that a condition of brain death was in no way a "precedent to the cessation of such treatment." (*Bouvia v.*)

Concluding in a manner similar to the New Jersey Supreme Court in *Quinlan* (see below), Compton refused to differentiate between the withdrawal and withholding of treatment. Despite the fact that life support systems are to a certain degree automated, Compton ruled that

> "each pulsation of the respirator or each drop of fluid introduced into the patient's body ... is comparable to a manually administered injection or item of medication. Hence 'disconnecting' of the mechanical devices is comparable to withholding the manually administered injection or medication." (1016)

Similarly to *Cruzan* (also below), the distinction between tube feeding and other forms of life support was rejected, stating that the distinction seems "base more on the emotional symbolism of providing food and water to those incapable of providing for themselves than on any rational difference"(1016). (This observation has been supported by recent studies about the attitude of physicians to withdrawing life support measures, see section V-B.) The point that was returned to frequently in the decision was that the function of these life-support measures was distinct from traditional medicine in that while traditional medicine is targeted to treat a specific condition, life support measures are to maintain the life of the body while other means attack the condition.

The final conclusion of the court was that for a treatment to be ethically continued, it must be "proportionate", meaning that treatment which has the best chance of providing benefits to the patient, when those benefits outweigh the problems inherent in the treatment. In *Barber*, it was found that the physicians had acted correctly in acceding to the wishes of the family despite the fact that no formal guardianship proceedings had taken place nor any other legal action that would give a person firm legal right to substitute their judgement for him.

Before the *Barber v. Superior Court* issue, problems with substituted judgement became first apparent with the first modern landmark case in withdrawing treatment: the *Quinlan* case. Due to a combination of depressant drugs and alcohol Karen Quinlan suffered severe brain damage, resulting in a coma. After several months her family jointly agreed that they believed that she would never regain consciousness and decided to disconnect the artificial respirator that was keeping her alive. The reluctance of the staff of St. Clare's hospital to withdraw Karen Quinlan from the respirator was compounded by the fact that in 1975 the AMA issued another statement essentially equating withdrawal of artificial respiration with euthanasia. Despite the clearly stated wishes of the Quinlan family, they would not withdraw Karen from life support.

This reluctance finally ended up in court, where their lawyer Paul Armstrong argued and lost the case on the basis of a right to privacy as set forth in *Griswold v Connecticut*. The judge, Judge Muir, ruled that Karen Quinlan should continue on artificial respiration and keep her court-appointed guardian. Furthermore he ruled that no constitutional "right to die" existed and that her parents' personal wishes *specifically* to end her life could not be acceded to. The case swiftly went to the New Jersey Supreme Court. Julius Korein, who had testified for the Quinlan family in the earlier trial, explained that, contrary to the testimony of the St. Clare's doctors, there existed an unspoken standard of "judicious neglect" among doctors, where less of an effort was made to save those patients who were apparently "hopeless cases". Without making a formal ruling about it, the NJ Supreme Court found that the distinction between withholding and withdrawing treatment was "flimsy". The final decision was that the right to privacy did extend in this case to cover the decision of a family to remove an incompetent member from artificial life support and also gave Karen's physicians legal immunity from prosecution if they did so.

This case clarified some boundary issues of the 1973 statement of the AMA. The "best interests" of the patient were in this case considered irrelevant. The right to privacy granted the family sufficient authority to remove Karen Quinlan from respiration, and by extension the right of surrogates to make medical decisions for those under their care, but it still made no definite statements about what rights the patients had. Additionally, while the ruling said that the Quinlan family had the right to remove Karen from the respirator, it gave them no way to enforce their decision on the hospital. Rather than being removed from the respirator entirely, Karen was first removed from the respirator by stages over several months and ended up sustained by artificial feeding and hydration, living and suffering for approximately another ten years.

A similar case with similar results was the *Spring* case in which Earl Spring, 79 and suffering from cancer and senile dementia, required frequent dialysis to live. He also needed to be sedated to receive this dialysis at times due to this dementia. His wife and son obtained judicial permission to stop this dialysis, and Earl Spring died shortly thereafter. As with *Quinlan*, this essentially allowed the substitution of the judgement of the family for the judgement of the patient. An extension to *Spring* was *Dinnerstein* which added a caveat to the precedent in *Spring*; it held that while judicial preview of decisions to withdraw life-sustaining treatment was not necessary, judicial review might be to decide "…whether the decision to withhold involved a good-faith effort to follow accepted medical standards [Nelson, 119]. While the elimination of the need for preview was a positive step for the rights of families to decide, the addition of the caveat in fact made things more difficult. The ambiguity of the phrase "accepted medical standards" combined with the fact that a doctor could be held to these standards *after the fact* made it a much more risky proposition for doctors to remove life support. Again, the problem was a lack of clear standards delineating the rights of the family versus the rights of the patient.

The Nancy Cruzan case complemented *Quinlan* in this respect. Where *Quinlan* established the rights of the family with regards to removing life support, the focus of *Cruzan* became the rights of the patient. The Missouri State Court, in reviewing a probate court decision that allowed Nancy's family to remove her artificial feeding and hydration held that the state had an interest in preserving life and, therefore, that there had to be clear and convincing evidence of Nancy's wishes to withdraw her from life support. This by extension granted competent patients the right to refuse treatment, which was recognized by the National Supreme Court when reviewing the State Court decision. It also challenged the distinction between artificial nutrition and other forms of life support, thus rendering unconstitutional a large number of state laws distinguishing between the two.

## 1.2 Background on competence (definition, brief overview of issues)

Depending on which source you reference and which standard of competence you use, the number of incompetent patients residing in the United States range from 3 to 6 million. Their decisions must made by surrogate decision makers, and they often die after life sustaining treatment has been applied. Many of these patients have lost their decision making ability because of substantial age-related dementia. This segment of the medical population is directly related to the age of the population and is one of the fastest-growing ones as the average age of the country increases. (Enc. 572-573)

When addressing the issue of how surrogate decision-makers should be make decisions for an incompetent patient, the first thing which must be clarified is what exactly is meant by competence and incompetence. Perhaps with some justification, judges and lawmakers have refrained from rendering broad judgements that attempted to define a single standard of competence, instead restricting their judgements to the competence of a given person.

Currently, the judicially popular definition of competence used is known a "process standard" of competence, in which the actual decision itself is not considered when competence is being evaluated, but rather the means by which the patient reaches that decision (see section 3.3 for more information regarding various standards of competence). If the patient employs a sound process to make a decision, then the patient is competent to make that decision. As with all definitions of competence, however, there are several questions begged: if a sound process is employed with faulty data (either delusionary in nature or simply errant), is that decision still valid? Furthermore, what exactly constitutes a valid process, and how can it be determined whether or not the patient is actually using one. Finally, in many cases of mental or neurological disorders, even though all relevant information may be possessed by the patient and the process may be sound, even by the most stringent standards, if the patient is exhibiting desires known to be inconsistent with their "healthy" mindset, the question remains of whether or not their judgement is respected.

The legal context that competence is placed into makes it difficult for doctors to come to "safe" conclusions about the competence of a patient. *Dinnerstein*, for example, held that judicial preview of a case was not necessary in terms of competence due to the prohibitive time constraints, but that judicial *re*view of a case was a legitimate option (Nelson, 119). In effect, the doctor is not required to gather a court opinion as to whether or not a patient is competent, but they can still be made fully to answer if the patient is found later to be incompetent. When in many facilities, especially long-term care facilities for the elderly, where competence is more often a question, the doctors alone make the determination of competence versus incompetence (Miller et. al., 1990), the burden they are placed under is that much greater.

Another consideration making the matter more difficult is the fact that competency is not considered to be a all or nothing proposition, in effect asking if the patient is "competent-to" rather than simply "competent". For example, a patient being asked to express a preference in treatment requires a much stricter standard of competence than one being asked to express a preference for dinner. The question which then needs to be asked is not "is the patient competent?" but rather "is the patient competent to make this decision at this time?" Establishing the answer to this question is the problem that confronts doctors, loved ones, and judges in dealing with patients.

## 1.3 Considerations of quality of life

Even for those patients whose lives can be saved, there remains the question of whether or not their lives *should* be saved. The picture of many patients that suffer from PVS is not pleasant, and even those that recover rarely make a full recovery in which they regain all lost function. *Quinlan* contains numerous images of Karen apparently in pain, trying to pull away from breathing tubes, and so on, even to the point where she is described by one doctor as a "monster". Of those unfortunate enough to end up in PVS, their outlook is poor.

The Quality Standards Subcommittee of the American Academy of Neurology performed a 1995 survey of traumatic and non-traumatic brain injuries, rating their recovery on the Glasgow Outcome Scale, which places each patient into one of five categories: good recovery, moderate disability, severe disability, PVS, or death. A good recovery is defined as one in which the physical or mental complaints remaining after recovery are negligible and do not impair the day to day function of the individual. A moderate disability is defined as one in which the disability or disabilities are sever enough to impair participation in some activities, but do not interfere significantly with the individual's ability to take care of themselves. A severely disabled person requires special day to day care to meet the necessities of daily living.

The outcome of the survey using this scale was not encouraging: after a year, only 52% of the adult patients who suffered traumatic injury to the brain had made any sort of recovery, 33% had died, and 15% were in PVS. Approximately half of those who recovered were subject to severe disability, and only about 13% made a good recovery. For nontraumatic injury the outlook for adults is even worse. 53% die, 32% enter PVS, and only 15% recover any sort of functionality. Only one percent of the adults who suffered non-traumatic brain injury made a good recovery after a year. As unhopeful as this looks, "for this category…the prognosis is poorer than that suggested by the data." (QSS of AAN, 1995)

The American Thoracic Society has said that "survival…completely lacking in cognitive and sentient capacity, may be regarded as having no value for such a patient." (ATS, 1991) Such a view would seem to indicate that death is preferable to PVS, but a lack of reliable indices for which patients may or may not make some sort of recovery makes the issue a very difficult one to decide. Even further, we may consider those patients with severe disability who require continuous care. Many advance directives indicate that people do not consider existence in a state such as that a desirable fate either, and certainly the cost of caring for such people is prodigious.

To some degree, the quality of life of the patient, as well as it may be ascertained, must be considered by the decision-maker when decisions regarding the removal or continuation of life support are being made. The challenge is to consider the quality of life of the patient first and foremost, and decide as best as possible in accord with any whishes that they made known.

## 1.4 Considerations of religion

The question of withdrawing treatment challenges a number of tacit assumptions held in many forms regarding the values of a society or culture. As one of the major influences on determining and socially enforcing those values, religion was almost certain to be – and indeed has been – closely linked to this debate almost since its creation. The high emotional strain involved in facing one's own death or the death of a loved one causes many to turn to religion for support and guidance as well, while politically the constituency of a church can wield much political power in determining legislation regarding this issue (witness the abortion debate).

As well as the volatile emotional element, adding to the confusion around the debate is the fact that the sacred writings of most religions contain a degree of ambiguity and even apparent internal contradiction that leads to great differences in interpretations. Additionally, the New and Old Testaments are both, in North America at least, typically not read in their original language but in some translation, which introduces further ambiguity and confusion.

For example, the well-known sixth commandment, "Thou shalt not kill" (Exodus 20:14, King James Version) can be compared to the version found in the New International Version, "Do not commit murder." (Exodus 20:14, New International Version). The first version could be interpreted to state that withdrawing life support is against religious law, regardless of secular law, if removing life support is equated with killing someone. The second one could be interpreted as saying that if withdrawing life support is legal by secular law (i.e. not murder), then withdrawing life support is allowable even if it *is* equated with killing someone. Neither translation, it could be argued, captures the cultural nuances of the original Hebrew in which it the oldest extant versions are written.

While internal debate within the various religions continues, the conflict between the religions themselves must also be considered when a physician is unwilling to observe the separation of church and state and will neither act in accord with the wishes of his or her patient nor step down to allow another to do so. Furthermore, the conflict between the interest of the state in preserving life, especially the life of children, and the interest of members of a religion in adhering to practices that may forbid the use of certain medical technologies must able dealt with.

## 1.5 Financial concerns

The administration of life support is an expensive proposition, to such a degree that the costs involved cannot be ignored. The care of a patient in PVS, or an elderly patient in a similar state, is an immense financial burden on most families, especially when insurance only pays a portion of it or when the family has no insurance. This can lead to an inclination to remove a patient from life support for purely economic reasons.

Alternatively, in many cases due to the way that hospitals fix prices, maintaining a patient in PVS can actually be a profitable proposition for a hospital, especially in those cases where the patient needs limited life support, such as mere ventilation. This can lead to cases where the physicians may have pressure put on them to continue life support even when it is not indicated for the patient.

When money is weighed against the life of a patient, it is easy to give a glib answer to the effect of human life being priceless, but when maintaining a life of questionable quality leads to measurably deleterious effects on the lives of others, then the question becomes cloudy once more. Methods should be developed to weigh the economic necessities of the healthy against the ill, and find ways to alleviate the financial burden of an ill family member.

## 1.6 Scope of paper and narrow statement of problem

Recent advances in medical science and technology have brought about the need for radical revision in our thought about the processes of life and death. Those who would have been considered dead (under the cardiac/respiratory failure criteria) in earlier years are now quite routinely resuscitated. Social, legal, and ethical thought has failed to keep pace with these developments, leading to a set of circumstances where a patient is in a kind of legal gray area. Issues such as the need for harvestable organs have blurred the boundaries even further. Cases such as “Roe vs. Wade” established that there can be such a legal entity as a viable body that is not a person, but failed to back it up with criteria for making a distinction between such an entity, not an object of legal or moral concern, and a person, who is.

Further clouding the issue is the fact that there is no longer as high a degree of surety about which patients can and can not be expected to regain a desirable quality of life as there once was. Those in a so-called "Persistent Vegetative State" (PVS) are in a largely unknown area as far as modern medicine is concerned. Despite many attempts, doctors are still unable to determine precisely what the eventual outcome for any given patient will be. Even for those patients who survive, there is the further question of how much brain or nervous system damage they sustained, the atrophy of their muscles while in PVS, and various other factors which raise serious question as to whether their life was worth saving, in terms of the suffering of both the patient and their family.

While many of the ethics of prolonging life were settled as far as competent patients are concerned by the Supreme Court review of the Cruzan Case, there are numerous issues involved in the case of incompetent patients on life support which make the decision even more complicated. Even more, there are frequent questions as to what exactly constitutes competence and incompetence. Various theories of competence, such as some "process standards" of competence have been attempted to be applied in a hospital setting, but often fall short in some form or another. The most commonly applied standard today is derived from the "doctrine of informed consent" rule, namely, the patient must be able to understand what choice is being made, what the possible, probable, or definite outcome of that choice will be, and what it means to the patient. This in itself can have problems, however, such as in the case of patients suffering from senile dementia where periods of lucidity alternate with periods of extreme confusion.

Some attempt to compensate for a lack of clarity regarding the issue of competence has been made in the issuing of "advance directives", which are now accepted almost universally as binding. These are of only limited effectiveness, however, because as they are currently filled out, they are often ambiguous and difficult to interpret. In one study by Kathy Faber-Langendoen, only 20% of the patients included in the study had advance directives. Furthermore, there are serious concerns about the competence of people who are healthy to accurately predict their wishes should they become seriously ill. Whereas many fill out Do Not Resuscitate (DNR) orders, a study by Owen et. al. found that those most likely to request action that would probably lead to death were those being offered potentially curative treatment, while the spouses of many of those who had not opted for some sort of self-willed death and instead died of illness opined as to how an earlier death would have been better for the patient. This suggests that those who have the most to lose by dying – i.e. those more likely to recover – are paradoxically the most likely to request death, indicating that advance directives filled out by healthy or recovering people (which tend to more often indicate a desire to be allowed to die rather than undergo treatment) may not be indicative of their true desires once ill or beyond reasonable hope of recovery (when the directives filled out at that time are more likely to indicate a desire to live) (Owen et. al.,).

Even once those who are competent and those who have advance directives of any sort are removed from the pool, there still remains a substantial number of those who are not competent to make their own decisions who have not formally expressed their desires in the event of illness. Faber-Langendoen's study found as well that in addition to the fact that only 20% of the patients had advance directives, only 35% of the patients were judged competent to make their own decisions. Even assuming that there was no overlap at all between the two groups (somewhat unlikely), there remains 45% who required surrogate decision-making.

The two remaining parties to such a decision, the doctors and the families, occasionally come to disagreement over what decision is in the best interests of the patient. Both the *Quinlan* and the *Cruzan* case forced the policy of "judicious neglect" (the tacit and secret agreement among doctors to withhold some treatments from patients who could not medically benefit from them without consulting the families of those patients), which had been practiced previously, out into the open, making it a matter of public policy. The case of *Griswold v. Connecticut*, which established the right of private citizens to make personal decisions without government interference, was successfully invoked in the *Quinlan* case, resulting in the family of Karen Quinlan being allowed to withdraw her from life support. In *Cruzan*, however, it was found that a preponderance of evidence that the patient desired death in the case of a PVS was needed to disconnect the life support of a patient. As the family of Nancy could muster no such evidence, she remained on the respirator. This ruling did pave the way for advance directives, however, and in later cases an advance directive was accepted as a preponderance of evidence, but this led back into the difficulties attendant to an advance directive.

**2** Contradictory and confusing rulings, different laws from state to state, and a lack of unambiguous precedents have made this issue quite difficult to resolve. When the differing agendas that doctors, patients, and families may have are considered as well, the issue seems nearly insoluble. In the end, a firm policy, consisting of a hierarchy of individuals and values, is needed to make a proper decision regarding the end of life that will be in the best in

# 2 Purely medical concerns

Death, even in this age of advanced medicine, is still a frequent phenomenon, with approximately two million deaths year in the United States alone. Chronic illness accounts for approximately two thirds of these deaths, with approximately 70 percent of them after some form of artificial means of life support has been applied. Such a high incidence of life support indicates the need for developing clear guidelines for managing life support (http://www.echonyc.com/~choice/issues.htm#Facts).

## 2.1 Terms and definitions

### 2.1.1 PVS- Definition some facts

The definition of a persistent vegetative state is a chronic state of "wakefulness without awareness."" (http://www.geocities.com/HotSprings/Oasis/2919/). The term PVS is used to describe patients who have sustained severe brain damage and injury. Normally such patients would have died with their injuries, but with the technological and medical advances of recent times, they are able to be kept alive in a persistent vegetative state. In the United States, there are about 14,000 patient in a PVS. (http://www.geocities.com/HotSprings/Oasis/2919/) This is not to be confused with coma; in a PVS, patients are subjected to go through cycles of sleep and wakefulness (http://www.geocities.com/HotSprings/Oasis/2919/ ). A coma, unlike the PVS, is a "profound or deep state of unconsciousness" (http://healthlink.mcw.edu/content/article/921394859.html). Patients in comas may still retain cognitive neurological function. A PVS may follow a coma. (http://www.geocities.com/HotSprings/Oasis/2919/ ) Patients in a PVS awaken sometimes but are not "aware" since they have no cerebral function. Since many humanly functions such as emotions and sensations are controlled by the cerebral cortex, patients in a PVS lose all of these functions and display mainly "vegetative functions and reflexes" (http://www.geocities.com/HotSprings/Oasis/2919/). Patients do however have some autonomic brain functions that come from the brain stem. (http://www.geocities.com/HotSprings/Oasis/2919/ ) Functions such as smiling, shedding tears, breathing, swallowing, and even screaming are controlled in large part by the autonomic system and therefore may be exhibited by a patient in a PVS. (http://www.geocities.com/HotSprings/Oasis/2919/) Patients are still capable of looking around but are unaware. (http://www.geocities.com/HotSprings/Oasis/2919/)

### 2.1.2 Consciousness

What exactly does it mean to be conscious? According its definition, a person is conscious when he or she is aware of his or herself, and when he or she is aware of the environment. (http://www.geocities.com/HotSprings/Oasis/2919/) Patients in a PVS are aware of neither. (http://www.geocities.com/HotSprings/Oasis/2919/) If one were to hold a mirror up to a patient, they would not be able to recognize themselves since they have lost their self awareness. Any movements displayed by patients in a PVS, whether it be a look around the room or even a groan, are only reflexes that are possible through the autonomic system. The mental state of a patient in a PVS is best summed up by this quote:

"the absence of any adaptive response to the external environment, the absence of any evidence of a functioning mind which is either receiving or projecting information in a patient who has long periods of wakefulness" (http://www.geocities.com/HotSprings/Oasis/2919/ et. al.)

### 2.1.3 Irreversibility

A persistent vegetative state is considered irreversible and permanent when it is clear that the patient's chance of recovering consciousness are minimal (http://www.geocities.com/HotSprings/Oasis/2919/ ) A rule of thumb that is contended, is that any patient who remains in a PVS for a period of time longer than a month or so, is most likely not to regain consciousness. (http://www.geocities.com/HotSprings/Oasis/2919/) This does not however rule out any chances of consciousness, it merely suggests that it is highly unlikely. Patients who have metabolic and degenerative diseases rather than brain injury, have no potential of regaining consciousness. (http://www.geocities.com/HotSprings/Oasis/2919/) The state of the patient after recovery

In the event that a patient does recover from a persistent vegetative state, it is a given that they will never regain normal and complete functions. (http://www.geocities.com/HotSprings/Oasis/2919/ ) Patients who do recover from a vegetative state, sustain some severe disabilities. (http://www.geocities.com/HotSprings/Oasis/2919/) Oftentimes, they are unable to walk right or even at all, they can not see well and they can not speak well. (http://www.geocities.com/HotSprings/Oasis/2919/)

"with all the support that medical technology can provide, it cannot 'resuscitate a brain'. Thus, even the extremely small likelihood of "recovery" cannot be equated with a return to a relatively well-functioning state"

(http://www.geocities.com/HotSprings/Oasis/2919/ et. al).

### 2.1.4 Care and cost of care for patients in PVS's

Care for patients in PVS's is not easy for the family. It can create a severe financial and psychological crisis for the caretaker since the technology is fairly expensive and patients can remain in a vegetative state for a long period of time. (http://www.geocities.com/HotSprings/Oasis/2919/) In 1994, the annual cost of care for a patient in a PVS, was 50,000 dollars. (http://www.geocities.com/HotSprings/Oasis/2919/et. al) Since the patient is capable of living in such a state for a long period of time, the cost will add up to an extremely large amount.

### 2.1.5 The financial burden of PVS patients

The cost of prolonging life through artificial means can get fairly expensive. The cost of end of life medical care alone, accounts for up to 12 % of the overall health care cost. On top of this, end of life care makes up 27% of the Medicare budget. In fact the use of advance directives and the lower use of high technology intervention can lower the end of life costs by 25% to 40% (Emanuel, 1907). This is not a clear cut case though. It hasn't actually been proven that advance directives lower medical costs, though there is circumstantial evidence that they do. Hospices also can help reduce the cost of end of life care. According to one study, there was a net savings of $.68 for every dollar spent among cancer patients who spent their last moments in hospices rather than in hospitals. (JAMA, Emanuel)

Studies have been done to determine whether or not advance directives and hospices actually decrease the cost of end of life care. According to these studies, three randomized trials of hospice and advance directives indicated no cost savings whatsoever. This is in contrast with the findings of the nonrandomized trials. According to these trials, savings ranged from zero percent to 63%. In general, however the savings were small. (JAMA, Emanuel)

Sometimes a major factor influencing a family's decision is cost. Economic factors can play a substantial role in the decision process for those with out medical insurance or those with bad insurance. The expenses of prolonging life and extending the hospital stay and use of technology can be costly. Admittance to a hospital adds on a number of costs including, physician fees, pharmaceutical costs, home health costs, and technology and machinery costs. Outpatients do however save a little more than in patients. Patients who use hospice or advance directives may have a lower cost, studies have been done on this matter but with inconclusive results. A large gap exists between true costs and charges and payments made on the patient. True costs are much lower than what patients are charged.

"...caring for terminally ill patients imposes significant financial and caregiving burdens on families and, at least for hospice, much of the savings is an exchange of inpatient care for care by families and friends" (Emanuel, JAMA).

According to one study, patients who chose home care over hospital care tend to create less financial burden. (Emanuel, JAMA)

Medical insurance is a big part of cost for the family. Medicare parts A and B only cover up to 50 percent of the medical care costs. This is for patients over the age of 65.

### 2.1.6 Should the PVS be maintained?

"Treatments that offer no benefit and serve to prolong the dying process should not be employed" (http://www.geocities.com/HotSprings/Oasis/2919/ ) This is the general consensus of experts on the issue of continuing treatment. Experts contend that the money and resources that go into prolonging a PVS are better spent on others who actually stand a chance of survival. (http://www.geocities.com/HotSprings/Oasis/2919/ ) Chances of survival are slim as it is, and even with survival, a normal life is not to be expected. Quality of life diminishes severely. (http://www.geocities.com/HotSprings/Oasis/2919/) Most patients in a PVS are mere "biological existences" (http://www.geocities.com/HotSprings/Oasis/2919/) and should not be considered the same human they were prior to their vegetative states. They lose most functions which make them who they are. (http://www.geocities.com/HotSprings/Oasis/2919/) They lose their consciousness and awareness and are merely existing as biological forms. "Author Robert Wennberg agrees that to end life-supporting measures when faced with neo-cortical death is to act responsibly, and that the slim chance that one might recover, albeit blind, deaf, or even paralyzed, is not sufficient to sustain life" (http://www.geocities.com/HotSprings/Oasis/2919/).

### 2.1.6.1 Maintenance and Prognosis

Lying in one position for a long period of time is not good for the body. Lack of movement can cause pneumonia and bed sores. For this reason it is important that health care professionals apply treatment to prevent the development of pneumonia and bed sores. Patients are also provided with balanced nutrition and undergo physical therapy to prevent "permanent muscle contractions" and "orthopedic deformities" (http://healthlink.mcw.edu/content/article/921394859.html).

Prognosis and outcome differs with each case and each individual. It is most dependant on the place of injury and on the amount of brain function lost. Patients in PVS's and comas can go through a range of recovery to death. (http://healthlink.mcw.edu/content/article/921394859.html)

People who do recover exhibit "physical, intellectual, and psychological difficulties". (http://healthlink.mcw.edu/content/article/921394859.html) For this reason, recovery is a slow process which requires much work and therapy. Those who recover may gain "full awareness" (http://healthlink.mcw.edu/content/article/921394859.html) or not even reach the point where they are able to carry out normal functions on their own. Comas usually don't last more than 4 weeks. (http://healthlink.mcw.edu/content/article/921394859.html)

> "Some patients may regain a degree of awareness after vegetative state. Others may remain in a vegetative state for years or even decades"
>
> (http://healthlink.mcw.edu/content/article/921394859.html).

Pneumonia is most often the cause of death for patients in a PVS or coma. (http://healthlink.mcw.edu/content/article/921394859.html)

## 2.2 Factors influencing survival rates

Most often, mechanical ventilators and related technology are used to prolong the life of a person in a coma or a vegetative state. As studies show, the removal of ventilators is often a somewhat difficult experience and the outcome of those on ventilators does not usually look good.

### 2.2.1 Survival rates as a function of intubation time

It has been estimated that about five thousand patients' lives are sustained through the use of ventilators and artificial feeding tubes. Many of these patients are in a persistent vegetative state (PVS). A good case study of those kept alive through the use of artificial life support are patients who have undergone a bone marrow transplant. These patients, due to the extremely invasive nature of the surgery involved in bone marrow transplant as well as the need for powerful immunosupressants to prevent rejection of the transplanted marrow, very often require at least ventilation if not further means of life support. Survival rates of bone marrow patients on ventilators can range from zero percent to eleven percent as indicated by a study of 979 patients (Ryan, 100).

Death on the ventilator can result from a wide range of factors, such as organ failure or septic shock. The most common killer, however, is pneumonia, the incidence of which is tightly correlated with the amount of time spent on a ventilator increases. In the study mentioned above, patients were considered survivors if they survived more than thirty days after extubation. 82% of those studied died while on the ventilator, and the remaining 18% died approximately 18 days after extubation. (*Id.*)

The discontinuation of mechanical ventilation in patients suffering from respiratory failure is often a painful and sometimes a morally objectionable procedure. Physicians try to create new painless methods of removal. Removal first starts with identifying tactics to help reduce the patients' needless time spent on ventilators. These can be as basic as counting and measuring breaths. Many methods exist which help determine whether or not the patient is ready for extubation. (N.E.J.M, 335, 1864)

Removing artificial ventilation early is not necessarily fatal, however; "as many as half of patients who remove their breathing tubes prematurely do not require reintubation within 24 hours" (N.E.J.M, 335, 1864). As a shorter intubation time is correlated with a better survival rates, early removal of artificial ventilation may actually improve the chances of survival in some cases.

In a study supporting this conclusion (the promotion of early removal of ventilation), 300 patients who were being mechanically ventilated were divided into two groups; the intervention group and the control group. The intervention group was made of 149 individuals while 151 composed the control group. The patients in the intervention group received their normal daily care along with frequent screening of respiratory function. The control group only received regular care, with consequent infrequent screenings. Patients in the intervention group who passed the regular screening were taken off the mechanical ventilator and allowed spontaneous breathing for a matter of two hours; their physicians were notified accordingly. Repeated trials of spontaneous breathing continued for them with every successful screening. Patients in the control group did not go through these spontaneous breathing trials. (N.E.J.M, 335, 1864)

The outcome of the study reflected what was hypothesized; that the patients with repeated trials of spontaneous breathing would breath on their own sooner. The median for the duration of mechanical ventilation in the intervention group was 4.5 days, but was 6 days for the control group. The duration of mechanical ventilation was smaller in the intervention group (N.E.J.M, 335, 1864). Only 103 of the 151 patients in the control group were actually successfully screened, while 113 patients of the intervention group had successful screenings. Forty eight of the patients in the intervention group were extubated the same day they endured successful trials of spontaneous breathing. Overall, 65 of the intervention group patients were successfully removed from their mechanical ventilators. Only 24 patients in the control group had the same fate. Surprisingly, the number of days spent in intensive care did not differ greatly between the two groups (N.E.J.M, 335, 1864).

Mechanical ventilation is the most difficult type of intervention to withdraw, causing great pain and discomfort to those patients whom it is withdrawn from (N.E.J.M, 336, 653). The most common method of removal is to stop other treatments with the hope that the patient will die on their own while still on the ventilator (*Id.*). "In a survey of critical care physicians, 15 percent reported that they almost never withdraw ventilator support from dying patients who are forgoing life-sustaining treatment, and 26 percent believed there was a moral difference between not initiating treatment with a ventilator and withdrawing one already in use" (*Id.*).

There are two typical ways of removing mechanical ventilation. First is the removal of the endotracheal tube. The tube is removed after suctioning, and the airway is exposed to oxygen and humidified air to prevent dryness. The second method is terminal weaning. In this method, the ventilator rate is slowly reduced, along with the oxygen levels. This is done without removing the endotracheal tube (*Id.*). Terminal weaning can take anywhere from 30 to 60 minutes. Terminal weaning is the preferred method, according to a survey done, it can be used up to 67 percent of the time by physicians (*Id*) despite the fact that data shows that there is not a large difference in comfort levels between the two methods (N.E.J.M, 336, 9).

### 2.2.2 Resuscitation

A significant facet of end of life issues is the DNR order. Unless contraindicated by such an order, some form of cardiopulmonary resuscitation (as opposed to CPR proper) is performed on all patients who go into cardiac arrest. Cardiac massage is one such form of resuscitation. According to a study done, the survival rate of patients was 70% , 14 of every 20 patients survived. This study was performed only once, however, and the results have never been reproduced. The rates of survival until hospital discharge range lie between 5 to 23 percent, with the mode at 15 percent (N.E.J.M, v 325). These statistics do not include patients with cancer, repeated arrests, and other chronic illnesses.

A correlation exists between the survival rate after administration of CPR, and preexisting illness. Patients suffering from chronic illnesses seldom survive. According to a study conducted on 294 patients who had suffered cardiac arrest, 44 percent were revived by CPR. However, only 14 percent of those patients survived until discharge. In fact, overall, only 2 percent of the patients who had severe cardiomyopathy and prolonged hypertension, survived. Also, only 3 percent of patients with renal failure survived, and no patients requiring dialysis survived. These findings suggest that such modes of resuscitation are not always effective. (*Id.*)

The results of another study yielded results quite similar to the first. They showed that while 32.4 percent of the patients responded to the CPR, only 8.7 actually made it long enough to be discharged. In general, the common findings in all these studies, were that patients suffering chronic and terminal illnesses, such as cancer, never survived. Not only do these studies indicate a low survival rate, they also indicated that there is a 2 percent chance of developing a persistent vegetative state after the administration of CPR. Very often, families of patients choose CPR over death, thinking that it will improve their chances of survival. As noted above, however, this is not always the case. Sometimes CPR only prolongs life and increases costs. (*Id.*)

A study done shows that patients who under go cardiac arrests outside of the hospital and are resuscitated, have a weak prognosis. The study was conducted on patients with "asystole, idioventricular rhythms with pulselessness, or primary electromechanical dissociation" (Levin, 93). Many "out-of-hospital cardiac arrest patients were studied over a period of two years. Factors such as : "electrocardiogram, age, sex, presence and status of witnesses, performance of bystander cardiopulmonary resuscitation, and survival to successful hospital discharge" (Levin, 93) were considered. A total of 2,404 adults who repeatedly suffered out-of-hospital cardiac arrests were studied in this case.

The survival rates of patients with "asystole, idioventricular rhythms with pulselessness, and electromechanical dissociation were low (1.6%, 4.7% and 6.9%, respectively)" (Levin, 93) This study showed the poor outcome of adults who undergo out-of-hospital cardiac arrests. They do not have a high survival rate and furthermore their prognosis is not good. (Levin, 93)

Survival rates of adults in out-of-hospital cardiac arrests are already known to be poor, however the survival rates may not be the same for children. (Schindler, 96) A study was conducted on children who undergo out-of-hospital cardiac arrests. A total of 101 children were studied who had heart problems. Their median age was two. The result was such that only 64 of the 101 children actually returned vitals. (Schindler, 96) On top of that only 15 actually lived long enough to be discharged. (Schindler, 96) Of those 15, 13 children lived a year past their discharge. The outcome of this study was that children also have a "very poor prognosis" of out- of-hospital cardiac arrests. (Schindler, 96)

### 2.3 Quality of life of patients during and after support

A patient's quality of life is another important issue brought into consideration when deciding on a course of treatment. Many observers find it important to continue life support only for patients who have a chance of a having a good quality of life (Enc., 1360). This is due to the fact that many social needs such as health care and education are underfunded, making a patient who has a poor recovery a physical, financial, and emotional burden on their family. It is important to draw the distinction, however, between a judgement on quality of life and making a judgement on the value of that life. The two areas are distinct from each other. For example; a patient who is suffering from a terminal form of a disease is most likely to have a poor quality of life, this does not, however, mean that person's life is not valuable.

Different instruments of measurement must be instituted to make a decision on quality of life. One approach is the "willingness to pay" instrument. This allows individuals to place a monetary value on the prolongation of their lives through technology in a hypothetical situation. They are asked to examine exactly how inclined they would be to avoid mortality; that is, how much they are willing to go through as well as pay in order to avoid death. A drawback of this method is that it is somewhat biased towards people with wealth, as they do not have to fear placing a financial burden on their family. (Enc. Bioethics, 1359)

An alternative approach to this is the QALY. QALY stands for Quality-Adjusted Life-Years, and is an attempt to quantify the effect of interventions on the quality of life without putting a monetary value on the prolongment of that life. This method was used by the state of Oregon to correctly assess state dollars in the cases of medical need (Enc., 1359). Its aim was to see that state dollars were not wasted and were used in the most efficient way to produce the greater good. In accordance, Oregon's Medicaid program tried not to cover valuable expenditures and at the same time it expanded coverage to those who were uninsured. The state of Oregon created a priority list which took into account, among other things, the treatment cost of each condition. The problems faced by Oregon were the complexities of conditions, and the differing results of treatment on those conditions from condition to condition and patient to patient. It was also not clear whether or not quality of life considerations are a moral way of allotting health care resources. For example, those who believe in the equality of all life and believe that all life is valuable, would regard this method as immoral. (Enc. Bioethics, 1359)

The issue of quality of life can also been seen by a legal perspective. The legalities of quality-of-life issues are concerned with the withdrawal of life sustaining medical treatment. The moral and legal question of whether or not removal of life support is right arose from the problem of prolonged life through the use of modern medical technology. Today's technology is capable of keeping even the most debilitated persons alive. Another question that arises is whether or not it is lawful to make a decision on the removal of life support based on a patient's quality of life. Most often people opt to remove life support after debilitation of both the mind and body has occurred (Enc., 1362). This is in the case of both themselves and their loved ones. Elements influencing a decision are immobility, the loss of mental functions, and the helplessness of the patient. A concern that arises from the consideration of quality of life in medical intervention is that the life of the disabled will be rated as being of lower quality because quality of life is determined by both mental and physical function. We are at risk of devaluing the lives of those who do not function as fully as we do. (Enc. 1362)

Quality of life factors are also used in decision making by the competent patient. Under current law, competent patients have the freedom to decline life sustaining treatment or medical intervention. As is evident in many judicial cases, patients often make their decisions based on quality-of-life (Enc., 1362). Often times, quadriplegics who are not able to carry out normal functions without the use of aid, prefer to stop treatment (Enc., 1362). They find it difficult to go on and choose to die with dignity. Such were the circumstances in the *McKay v. Bergstedt* and *State v. McAfee* cases. The courts ruled that the patients could make their decisions based on quality of life, and this embraced an unacceptable quality of life. At the same time any notions of the decision's devalument of the life of the disabled were discarded. (Enc. 1362)

The act of surrogate decision making is a bit more complicated. Some oppose the use of quality of life considerations in the surrogate decision making. Economic factors and burden are also possible factors to be considered by the surrogate decision maker. This gives rise to the issue of whether or not it is moral to make decisions based on these considerations. (Enc. 1362)

Quality of life is often taken into consideration when making a decision and it is important to establish a fixed standard for determining quality of life. It is a very complicated issue when determining the value of someone's life, by judging the quality of it.

# 3 Issues of competence

## 3.1 What is competence (legalities/theory/cases)

The vast amount of ethical and legal literature that has been written on the subject of competence has been largely contradictory and resolved very little. In terms of actual law, very little has been firmly established as precedent regarding the determination of competence other than the fact that the law will presume sanity and competence, and requires proof to the contrary to establish incompetence. As has been suggested above with regards to a sliding standard of competence based on the decision at hand, the law does not provide a single standard which can be universally applied, but tends to render specific and narrow judgements in each individual instance. Additionally, instead of rendering broad findings of incompetence, in which the person judged incompetent was under essentially a "total legal disability" (Margolis, 921), there has been a trend to evaluate competence in terms of context, "incompetent to do what?" (Margolis, 921) This lack of clear standards can make determining competence risky and difficult for doctors, but the fact of burden of proof being on the patient and the difficulty of this proof as defined judicially mitigates this somewhat. The state's interests in preserving the autonomy of individuals conflicts with the state's interest in preserving life (as set forth in *Cruzan*), and the doctor is placed in the position of adjudicating between them.

Ideally, the question of competence would be a purely empirical one, asking if the patient under consideration has all the necessary faculties to make the decision at hand. Unfortunately, there are no clear definitions stated for what factors or faculties a person needs to be competent to make a given decision, and no simple tests that can be performed to evaluate these (although attempts have been made, such as in the MacArthur test battery, discussed below). And again, even these questions suppose "normative judgements as to … the relative abilities that comprise the continuum, and … the requisite level of performance for each of those abilities." (Margolis, 922) Under all but the most stringent and the most liberal standards of competence, the values and bias of the person who is attempting to make this determination perhaps inevitably will creep in due to the lack of clearly defined standards. Even the selection of which test is going to be used, made either consciously or unconsciously, can obviously influence the outcome. This can lead to both problems for the doctor or other person making the determination of competence, and the patient who's competence is being discussed.

The legal environment surrounding these tests has changed over the years, however. The "process" standard, based off of the doctrine of informed consent, has gained favor judicially as a recognition of the fact that treatment ideally must reflect the values of the patient and not the physician (Margolis, 926). Additionally, the "outcome" standard of competence has fallen into disfavor due to the intensely restrictive effect it has on patient autonomy and the fact that it essentially substitutes the value-system of the doctor or determiner of competence for that of the patient (*Id*, 927). Despite this, the "outcome" standard appears to be more often used that the "process" standard in practice, which most often leads to the performance of undesired operations (*Id*,927). This could represent "playing it safe" for doctors, as it is easier to reverse the course of most treatments than it is to reverse the course of whatever disease is left untreated, or it could quite simply represent the unjust imposition of the value system of the doctor on that of the patient. Unfortunately, not only is the doctor responsible for determining which test is going to be used, which standards are going to be employed in the test, and whether or not the patient meets those standards, doctors are more often than not responsible for determining when competence should be called into question. While the refusal of a standard or potentially life-saving treatment may be sufficient to call competence into question, it is certainly not a preponderance of evidence in favor of a finding of incompetence, and using this as a sole measure of whether or not competence should be questioned ignores those times when a patient may be incompetent to consent to treatment as well as refuse it. While completely eliminating bias is nearly impossible, establishing a standard institutional policy for the determination of competence can go a long way towards eliminating the bias of individual doctors (see the MacArthur Inventory, below).

The basis for nullifying the authority of incompetent persons derives from the definition of personal autonomy as self-determination in such a manner that they receive treatment or lack thereof that reflects their personal value system, as opposed to simply voicing an opinion. In the case of an incompetent person, they are not making decisions that reflect their personal value system. Therefore, to grant them authority would be to *decrease* their personal autonomy and self-determination, as their decision in such a case would not be reflective of their personal value-system. Thus intervention of some surrogate decision-maker is not a violation of patient autonomy. (Margolis, 919)

Murphy and Wermuth (133) use the example of the *Lane v. Candura* case to illustrate the difficulty often attendant in proving someone to be incompetent. Mrs. Candura, who had suffered from painful gangrenous infections for most of her adult life and depression since the death of her husband two years earlier, developed operable but potentially fatal gangrene in her right foot. She initially granted consent, then withdrew it on the morning scheduled for the operation, continuing to vacillate for several days. Her daughter petitioned the court for custody insofar as the decision regarding amputation of the foot was concerned. Despite the circumstances, the court found that the daughter had not proven the incompetence of her mother and that her mother had the right to refuse treatment even though it meant her death.

Despite the broad construction that can be derived from this and similar cases, the right to refuse treatment is not always a given, even if the person refusing it in proved competent. In *Norwood Hospital v. Munoz*, in which Norwood Hospital sought the right to perform a blood transfusion on a competent Jehovah's Witness who was refusing treatment for religious reasons, the court found that the countervailing state interest was the prevention of the child's abandonment, and had Mr. Munoz not been fully capable and obviously willing to continue taking care of the child in the event of the mother's death, Mrs. Munoz's wish would most likely have been "overridden by the state's interest in protecting children." (Murphy and Wermouth, 135)

The most basic standard of competence that has been legally defined is similar to the process standard of competence described in the introduction. In *Wilson v. Lehman*, it was found that the mental instability of a woman who consented to electroshock treatment for that instability did not invalidate her consent as she was able to "understand… and make intelligent decisions" about the treatment itself (Wilson v., 1964). Should a patient be shown to be incompetent, any consent that they may give is legally ineffective (Margolis, 919).

This capability to reason and make decisions came up again in *Grannum v. Berard* (1967, 70 Wash 2d 304). Grannum was to undergo surgery for a nasal defect stemming from a childhood injury that was resulting in minor breathing difficulty. While being prepared for the operation, a doctor and a nurse on two separate occasions discussed the surgery with him and obtained oral consent, and then subsequently obtained written, signed consent. Grannum underwent the surgery, which was successful, and then brought suit against the doctor (Berard) for assault, arguing that the drugs had incapacitated him and hence his consent was invalid.

The court returned a decision in favor of the defendant stating that "…it is well settled that the law presumes sanity and competence in the absence of clear, cogent, and convincing evidence to the contrary." (*Grannum v. Berard)* and that since both the nurse and the doctor, having spoken to the patient and discussed the surgery, had no doubts at the time regarding his competence, the burden of proof was on Grannum. As he could not supply clear, cogent, and convincing evidence that he had been incompetent the judgement was found in favor of Berard. In a further ruling, the court stated that the mental capacity required for decision-making had to be determined on a case-by-case basis. Unfortunately, this case brought up and failed to adequately solve the very problem mentioned above; that competence is far more likely to be questioned in cases of refusing treatment that in cases of accepting treatment.

The Hastings Center made a similar recommendation in their 1987 report, stating that:

> "A patient has the capacity to make the treatment decision when he or she can *understand* the relevant information, *reflect on it in accordance with*

> *his or her values,* and communicate with the caregivers."[Hastings Center, 1987, emphasis added]

While at first glance, this seems to recap and nicely state the attitude towards decision in the current legal and medical environment, it continues to beg the question of how one can objectively determine the ability of a patient to understand and think about the information. While the Hastings Center recommends that "the assessment of an individual's decision-making capacity [must be] properly conducted."[*Id*] it offers little in the way of suggestion of methodology.

### 3.2 How can competence be determined? (practice)

In order to help fill in the gap between a patients capacity to make a decision and a doctors ability to evaluate that capacity, the MacArthur treatment competence study was designed "to address clinical and policy questions regarding the ability of persons with mental and medical illnesses to make decisions about treatment."(Berg et. al., 362) Six general criteria to develop the test were used:

> "1) The functions being measured needed to have close conceptual relationships with the appropriate legal standards of competence.
>
> 2) The content of the instruments needed to be relevant to the decision being studied. Since the specific concern was whether or not to proceed with a treatment, the instruments needed to reflect this goal.

3) The content of the instruments needed to be meaningful to the persons being studied.
4) The content of the instruments needed to be sufficiently standardized so that comparisons within and across subject groups were possible.
5) Measurements had to have objective criteria for scoring that could be applied in a reliable fashion.
6) The instruments had to be practical for use in a research setting and potentially adaptable for clinical use. Most importantly, the instruments had to be able to be administered in one sitting and by interviewers without extensive clinical training." (Berg et. al. 363-365)

By designing a test that fit these requirements, it was hoped that doctor bias could be removed from the determination process of competence, and some reasonable level of security could thus be obtained for both doctors and patients.

The functions in part one from above were determined to be the ability to express a choice, the understanding of their condition and potential treatments, an appreciation of the consequences of their choice, and an ability to rationally make decisions. These criteria were operationally and objectively defined, and are presented in Berg et. al 365-368. They were then tested against people of known incompetence suffering from specific categories of medical disorders and a random sampling of people known not to be ill. The final analysis of the data showed that the measures did produce reliable, accurate data, although the majority of the negative results could be attributed to schizophrenic patients that were studied. This is consistent, however, with the known effects of schizophrenia in impairing cognitive function.

## 3.3 Standards of competence/incompetence, and applying them

Various attempts have been made to define clear and applicable standards of competence in order to circumvent these problems. Buchanan [p 48-50] defines three major standards that are in use today. At the most permissive end of the scale is the "minimal" standard of competence. According to the minimal standard of competence, if a patient is physically capable of somehow expressing a preference and does so, then that patient is competent to make that decision. This standard has obvious problems in that it makes no allowance for mental defects of a patient, and in many cases can bind a patient to a decision that, in a more rational state of mind, they would not have made. On the least permissive end of the spectrum is the "outcome" standard of competence. In this case, the patient is considered competent if and only if their decision will lead to what is "best" for the patient, otherwise they are considered incompetent. This obviously begs the question of what is "best" for the patient and who makes that determination. The third standard is a "process" standard of competence. Under this standard, the outcome is irrelevant to the determination of competence, the patient must demonstrate a rational and acceptable process used to arrive at the decision that is being made. If this process is acceptable, then the patient is competent to make the decision at hand. A related standard similar to the "process" standard but not mentioned by Buchanan is derived from the principle of informed consent. To be determined competent by this standard, the patient must be capable of being fully informed of all factors regarding the decision, as well as likely outcomes for different choices. If the patient is capable of demonstrating an understanding of these factors, then they are competent to make the decision.

The ideal standard of competence maximizes patient autonomy while minimizing outside influence (Ryan, 1996). If by outside influence we also mean the debilitating effects of disease, we can immediately see how the “minimal” standard fails. If it is in effect the debility, rather than the patient, making the decision, then the patients autonomy is not maximized at all by such a standard. At the other extreme, the “outcome” standard places the patients autonomy at the mercy of whoever is deciding what their “best” interests are. Even should the patient – fully conscious and aware of the possible consequences – decide to withdraw from a course of treatment, if it is determined by another party that this is not in their best interests, then their wishes count for nothing, essentially eliminating their authority. Both the “process” and “informed consent” standards take this problem directly under consideration by attempting to answer the question of whether the decision is being made essentially by the patient or essentially by their infirmity. While these standards are not without their problems when it comes to putting them into practice, they most directly address the real issue at hand when discussing competence.

# 4 Dealing with incompetence

## 4.1 Advance directives and their uses/applicability

Decisions have to be made on a regular basis by patients and their families on whether or not to continue life support. Since the burden of making surrogate decisions is a serious and difficult one, an advance directive is helpful in alleviating this burden. Advance directives are a statement of a patient's wishes expressed in either an oral or written agreement prior to being incompetent. This agreement gives specific instructions on how to deal with the patient on medical terms.

Advance directives came about as a response to the public's disapproval of the use of medical technology to prolong the inevitable process of death. Luis Kutner pioneered the proposal of the living will. A living will is a document that executes the cessation of medical treatment in the event that a person succumbs to a vegetative state. This also takes into account the possibility that the patient is unable to recover mental and physical ability. Living wills allow an individual the opportunity to die a "natural death". (Enc., 573)

"The plight of the Quinlan family in trying to remove a ventilator from their daughter Karen Ann, who was in a persistent vegetative state, inspired the first U.S. state law granting legal status to living wills"(Enc., 573).

### 4.1.1 Types of advance directives

Advance directives can be divided into two types, the proxy directive and the instruction directive. A proxy directive allows the patient to grant permission of making the decision to someone else. An example of a proxy directive is durable power of attorney. An instruction directive on the other hand, supplies instructions regarding medical concerns and end of life care. These two types of directives can also be combined to form a combined directive. Another type of directive is the medical directive. This allows the patient to give directions about more than one possibility. The patient must look at other possible outcomes and give directions on each of them. (Enc., 573-574)

Advance directives can either be formal or informal. Formal advance directives are in a written documented form. They detail the patients wishes and commands for their medical treatment. Informal advance directives can be oral agreements made by the patient on their medical outcome. Oral advance directives are informal and can account for any verbal agreement or comment made by the user. This also takes into account, letters and notes. The advantage of formal advance directives is that they are likely to be more detailed and concrete as far as direction is concerned, as well as being a more reliable source of the patient's values and decision than informal communications. Most importantly, formal advance directives are legally binding in most states.

Durable power of attorney awards a surrogate decision maker authority. This allows the decision to be made over a greater range as opposed to just flat out rejecting treatment. The decision maker uses his or her knowledge regarding the whishes of the patient and applies them to the situation, attempting to make the best decision possible given the circumstances.

### 4.1.2 Applicability and ambiguity

Given the complexities of advance directives and living wills, it is necessary to address the possible ignorance of people who use advance directives that might lead them into making the wrong decisions. User's ignorance refers to the patient's lack of detailed medical knowledge. While he may have full of awareness of a certain condition, he does not have the medical expertise of a physician. This lack of knowledge can lead the patient to make the wrong decision. (572, Enc. Bioethics)

Advance directives are typically used to increase patient autonomy. Cruzan in 1990, ruled that artificial nutrition sustaining a young adult with extreme amounts of brain damage could be stopped if the patient had chosen to do so. Cruzan herself had given no formal advance directives although she had verbally expressed her wishes. In her case, as she lacked a formal advance directive, the court held that a preponderance of evidence that she wished treatment to be withdrawn did not exist and so she could not be removed from life-support. The wording of the ruling, however, gave way to the principles and guidelines behind applying advance directives.

In general, the population displays a positive attitude about advance directives. The general public is aware of advance directives (Enc., 574). This being the case, it seems odd that advance directives are not actually used as much as one would think. They are not in frequent use. Evidence suggests that advance directives do not play a large role in the decision process of medical treatment (Enc., 574). This was the case with patients who remained competent throughout their treatment. The use of advance directives is so minimal that, in a study of 52 patients who were counseled and presented with printed materials, only eight actually went on to draw up a living will. (Enc., 574) In a similar study done, only forty eight out of seventy four patients completed a durable power of attorney. (Enc., 574) In one study, it was found that many patients were not willing to complete advance directives because they were relying on their families to make the right decisions for them. (Enc., 574)

All advance directives have a common goal. That is to mould the future medical care to the patients preferences and desires. They allow people to live and die according to their wishes, granted they are within the social, moral and legal boundaries of society. They give the patient a sense of independence and control, and are aimed at improving their outcome.

### 4.1.3 Are they a good idea?

The question of decision making for the incompetent, has to take into account normative and empirical inquiry. Normative theory clarifies, and systemizes our moral intuitions. Empirical research can help us to identify our moral intuitions, and in fact, describe our behavior. Normative theory is based on assumptions about people and empirical research can either support or contradict these assumptions. This relates to advance directives since, in theory they seem like a good idea. Empirical research questions their effectiveness. Studies have shown that only one intervention by a physician has actually been successful, reportedly. In this case, intervention by a physician refers to the act of counseling the patient on advance directives. (New, Journ)According to this study, about two in every three patients actually wrote a directive. Related studies have found that most forms of intervention, such as brochures, and counseling, have not convinced the greater majority of patients to complete a written directive. Those patients who do complete some form of an advance directive often do not discuss it with their families and those involved in care. This suggests that advance directives do not play a major role in decision making. This is the empirical research that questions the use of advance directives.

Advance directives put their users in a position in which they have to make a decision in a hypothetical situation, about whether or not they should receive full treatment. Advance directives are a large part of medical treatment. In fact, there is a mandatory federal law that constitutes every person admitted to a hospital's right to be offered the opportunity to make an advance directive. The *U.S. Patient Self-Determination Act* requires that all patients be made aware of there "rights to make decisions and to write advance directives" (Enc., 575) upon their admittance to a hospital.

Advance directives have their pros and cons. Many cases have been studied, displaying the cons of advance directives. These cases examine only those in which the patient received only conservative care. In these cases, the patients were currently in an incompetent state, but also had the chance of gaining some competence. Their degree of damage was somewhat reversible.

A major argument against advance directives is the idea that most people are highly likely to minimize their desire for medical intervention. This is because when faced with a hypothetical situation, a person tends to downplay the situation. He does not realize what facing possible death is actually like and sees it as a way of escaping pain. A large reason for this downplay of death in the human psyche is denial. People are often in denial about these situations: when they actually occur, they desire intervention. This was evident in the studies done in which terminally ill patients who had filled out advance directives, were less eager to follow them (Ryan, 97). Denial plays a large part in the decision of a terminally ill patient. The patient cannot accept that they will suffer in the way that is expected with their illness. Another form of denial is denying the possibility of becoming terminally ill, and a possible early death. A person would rather die early than realize that they could become so ill, since it is just a hypothetical situation. Once faced with an actual illness, the situation changes. Early death is not out of the question anymore; it is no longer a hypothetical situation. This changes the way a person views death. In such a situation, one might want to live longer. Most people would rather suffer and hold their battle than face death. Healthy people who do not have to face death in the near future, believe it is better to die quietly without all the medical intervention. In the studies done, terminally ill patients, however, preferred medical intervention over slipping away quietly. It was rare for a terminally ill patient to want to die (Ryan, 97). Many healthy people who chose to refuse treatment in their advance directives, ended up changing their minds when becoming terminally ill. This suggests that people who have had some form of illness prefer intervention. (Ryan, 97)

While having their downside, advance directives also have some positive aspects. Advance directives seem to be viewed as a positive thing by the American population. About 75 percent of the American population approves of some form of a living will (http://www.echonyc.com/~choice/issues.htm#Facts). According to the same studies mentioned earlier on terminally ill patients, those who had accepted some form of advance directives spent less time in the ICU before death. This lead to lower medical costs. This evidence suggests that advance directives can alleviate economic burden. Although there is some evidence to support that advance directives offer economic gains, it is difficult to prove since there is also evidence to the contrary; that overall advance directives don't offer much economic gain. Other than possible economic gains, advance directives also have personal gains. By issuing an advance directive, a patient is exercising autonomy by taking some control over her medical future. By doing so, it is argued that advance directives are ethical and beneficial. In addition to giving the patient autonomy, they also give them a choice. Those who feel they are better off without treatment, benefit from this. It allows them to end their suffering and die a dignified death. By providing an advance directive, the user is relieving the burden of decision making from the family and physicians. Although the sheer thought of autonomy might seem like a good idea, it does have its consequences. It is true that no one knows what is better for an individual than the individual, but oftentimes the individual can be wrong. Autonomy can be misused if there is not complete knowledge of the situation and if the information is incomplete. The bottom line is that a person can not make an accurate decision based on just a hypothetical situation.

### 4.1.4 Overriding advance directives

Advance directives may not always be legally binding in all cases. In some cases they can be overridden by a physician. For example, the state of California has a Natural Death Act, overrides the legality of advance directives. Under this act, a physician is not legally bound to follow the advance directive if the person who ordered it is healthy. (California, 103) Under this legislation, adults are given the right to be in charge of decisions regarding their medical care and have the right to withhold or withdraw treatment in the event that they may be terminally ill or in a state of permanent unconsciousness. (California, 103) The patient's wishes may be expressed in an advance directive. However, if the patient is determined healthy with a good prognosis by the physician, he is not legally bound to carry out the advance directive.

### 4.1.5 What Constitutes Making Your Wishes Known?

In the case of Cruzan, Nancy Cruzan was left incompetent after obtaining severe injuries in an automobile accident. She was left in a PVS and showed no signs of improvement. Her parents plead with the hospital to have her removed from her life sustaining technology knowing it would result in death. Prior to her death, Nancy Cruzan had expressed her desire to discontinue life if she were not able to live it "at least half normally" (U.S. Reports, 261). Thus she had left an informal advance directive. A state trial court had recognized her desire to end life and had authorized the termination. The State Supreme Court later reversed this decision. The court had recognized her right to refuse treatment based on informed consent, but did not think it applied to her case.

"The court then decided that the State Living Will statute embodied a state policy strongly favoring the preservation of life, and that Cruzan's statements to her housemate were unreliable for the purpose of determining her intent" (U.S. Reports, 261)

Furthermore, her parents were not granted the right to terminate her medical treatment based on the fact that there was no living will statute that had given them the right to do so. Along with a lack of a living will, there was also no clear evidence of the patient's wishes.

Similar to this is the Quinlan case. Karen Ann Quinlan, brought herself into a debilitated and incompetant condition. Since her medical treatment did not seem like it would lead to recovery, Joseph Quinlan her father, petitioned to get guardianship in order to stop her treatment. Since she had not left a living will or durable power of attorney, he fought a long and hard battle to try and obtain the legal right to terminate her treatment. (Atlantic Reporter, 651)

# 5 Factors in a decision, and how much they should be considered

## 5.1 Family

### 5.1.1 Religion of the family

Frequently, one of the major factors affecting a family's decision regarding life support, is religion. On deciding whether or not to continue life support, in a religious context, one must first examine what the scriptures say about life in general. The issue of life support withdrawal and prolongment is an ongoing debate in Islam, Judaism, and

Christianity, since all three were started at a time where people did not have the technology to prolong life. Death was a clear thing. It is not a hundred percent clear what any of these three religions say on this matter.

### 5.1.1.1 Contemporary religious viewpoints on death and dying

#### 5.1.1.1.1 Christianity

Christianity can not be generalized into having one specific view on the matters of treatment withdrawal since different sects have different views. Roman Catholicism for instance has a totally different opinion of this than Protestantism; these are the two major branches of Christianity worth focusing on.

##### 5.1.1.1.1.1 Catholicism

Roman Catholicism in general "encourages care for the sick" (Curran, 78, 1522). God is seen as the ultimate healer in the Catholic tradition. Under this tradition, people are expected to find treatment for their conditions. They should not just let their condition worsen and wait to die if they have a chance to live. "...human beings can and should try to heal and overcome sickness if possible, but ultimately all will die" (Curran, 78, 1522). This makes it clear that in the event that one becomes ill, treatment should be sought. This is a must since Catholicism encourages humans to overcome their ailments (Curran, 78, 1522).

Treatment can be seen as anything that helps to keep the person alive. Under this context the use of artificial means to prolong life would not be outlawed, in fact it would be considered good to try and fight for life. (Curran, 78, 1523) "The Christian tradition in general and the Catholic tradition in particular have emphasized that God usually works mediately through secondary causes and not immediately without the help of human causes...in the area of healing, human means of curing illness have been encouraged, for in that way the doctor is cooperating in God's work, although ultimately sickness and death will triumph. To relieve suffering and strive for healing are viewed as working with God and in no way an offense to divine providence, since the creature is called to responsibly take care of one's life and health" (Curran, 78, 1523). Life support measures and the technology associated with prolonging a life can be considered "human means of curing illness" (Curran, 78, 1523). Taking all this into account, it is very clear that prolonging life through the use of artificial life support and such technology is definitely allowed in the Catholic branch of Christianity. Ending treatment even with the possibility of recovery would be unfavorable under this context (Curran, 78, 1523).

"Human beings are made by God, who is the author of life and has dominion over all life. A right enables the person who possesses it to achieve one's end...The human being as creature does not have absolute power or full dominion over one's own life or body, for the individual is a steward or administrator over one's life" (Curran, 78, 1528). This makes it clear that a human being does not have total control over his body. He may not end it needlessly as Christianity strongly opposes both suicide and euthanasia (Curran, 78, 1528). An interesting point is that the use of pain killers is allowed in Catholicism even if they cause the dying patient to die more quickly. (Curran, 78, 1528)

While it has been made clear that treatment should be sought by the dying individual, it has not been made clear how far this treatment should go. To which extent should a life be saved. Under Roman Catholic teachings, it is clear that a person "does not have to use extraordinary means to preserve human life" (Curran, 78, 1528). If there seems to be no chance of recovery, it is okay to withdraw life support. There is no need to prolong life excessively. (Curran, 78, 1529)

"The principle is long established that, generally speaking an individual has no obligation to use extraordinary means to preserve life. A well-accepted contemporary description views extraordinary means as all medicines, treatments, and operations that cannot be obtained or used without excessive expense, pain, or other inconvenience, or if used would not offer a reasonable hope of benefit. From such an ethical perspective there is no difference between not using an artificial respirator to sustain life for a few hours or even days or shutting off the respirator already in use" (Curran, 78, 1528-29 et. al). Resuscitation can also be denied if it is evident that doing so would not cause the patient to live. (Curran, 270)

The use of artificial life support to keep an individual alive is not wrong as long as there is a possibility of recovery. In the case where there is absolutely no chance of recovery and continuing life support would only increase expenses and pain, it is okay to withdraw life support. (Curran, 78, 1528-29).

### 5.1.1.1.1.2 Protestantism

Protestantism unlike Roman Catholicism, has different approaches to the whole area of medicine and technology in general. These approaches range from "laissez faire" to "pro- medical science" (Johnson, 78, 1364). In light of the recent technological advances of this century, many Protestants have begun a "pro-medical science" approach (Johnson, 78, 1364). Protestantism allows individuals the freedom of thought, this leaves little room for an actual "Protestant position". "...it is impossible to say - as one can say for the Roman Catholic Church – that this or that is "the Protestant position" at any place and time" (Johnson, 78, p1365, ).

Two crucial elements in Protestant healing are "the free grace of God" and "to show the healing love of God" (Johnson, 78, 1365). This does not mean that Protestantism relies on miracles for recovery, but it does emphasize the role and importance of God in any illness or matters of life and death.

Protestantism holds a "respect for life" (Johnson, 78, 1368). While it is important under Protestant tradition that treatment be sought for the ailing it is not mandatory. "Health and even survival are indeed to be sought after , but they are not ultimates" (Johnson, 78, 1368).

> "Barth first rules out any possibility of declaring some persons unfit to live longer. Killing such persons is murder, he unequivocally declares. Distinctions between direct killing and allowing to die, between a death wished by the patient and one decided upon by others, are no more than "sophistry". No one, even the patient has the right to look upon ending life as a blessing" (Johnson, 78, 1368).

Under this type of teaching, it could possibly be wrong to even make a judgement on quality of life. Not all of Protestantism however, approaches the issue of life in this manner. As mentioned earlier, there is no one Protestant approach to a situation.

Protestantism tends to be lenient in that it allows for freedom of thought. (Johnson, 78, 1367) For example, the same author who wrote the quote above also wrote: "if it is murder to end life too soon, it is an equally bad "human arrogance in the opposite direction" to prolong life beyond that point at which the patient's human dignity is expressed in a claim on the living to respect a life which is now truly dying" (Johnson, 78, 1368 et. al.). What this author is trying to express is that, our lives belong to God and when God allows us to live we should accept that as well as when God wants us to leave this life. "...life is God's to dispose of: So long as God is giving life, we are to support it; but when he is taking it away, we must support that as well" (Johnson, 78, 1368)

Other authors view life as precious, but do not oppose the idea of judging the quality of it. "...Thielicke is willing to engage in trying to determine the meaning of "human" life as opposed to life which is only "biological" (Johnson, 78, 1368). Under this it would be okay to judge the quality of life and therefore it would be okay to remove someone from life support if they were deemed to be living only a "biological" (Johnson, 78, 1368) life.

This author believes in the preservation of human life, however he does not believe in going through extreme measures to ensure that life. He bases his judgement on the consciousness of the individual. (Johnson, 78, 1369)

Another way of looking at treatment withdrawal is through love. Some believe that the main concern is love, and if treatment withdrawal is done out of love then it is okay. (Johnson,'78, 1369). "The Christian is to seek to act in love toward the other in order to enable him to grow in his God-given personhood" (Johnson, '78, 1369).

Protestants can range from conservative to liberal in their views. Conservative Protestants rely mainly on forms of healing that come from religion as opposed to science and technology. (Johnson,'78, 1374) They seldom rely on modern technology and medicine to cure their ailments. For them it would be wrong to even be put on any form of life support since they aren't strong supporters of medical science. (Johnson, 78, 1374)

Most Protestants are moderate to liberal on their views regarding life and death and since Protestantism allows individuals to make their own judgements and interpretations, they could best decide what they would want. Some Protestants like Barth believe it is wrong to even consider judging the quality of life of an individual. At the same time he does not believe in taking extreme measures to prolong life. (Johnson, 78, 1368) This leads one to believe that, Protestantism, unlike Roman Catholicism, tends to be more lenient on the subject. Both branches of Christianity hold that life is precious, and both believe in preserving it. Both branches also contend that it is unnecessary to take ultimate measures to continue life. Roman Catholicism sees the physician as the mediator and God works through him, so it is not against the use of technology to prolong life.

Protestantism unlike Roman Catholicism has different ways of approaching the situation of prolonging life. Under one sect of Protestantism, it is wrong to even be put on any form of artificial life, while in more liberal sects, it is mainly up to the individual who is deciding. Basically, there is no one answer that is right or wrong for either religion since this is an ongoing debate.

Roman Catholicism relies mainly on the bible and the papacy for its answers while Protestantism allows individuals to base their decisions on life experience and their interpretations of the bible.

#### 5.1.1.1.2 Islam

To see the Islamic point of view on life support, one must analyze the passages of the Quaran dealing with the notion of death. The Quaran repeatedly emphasizes the point that no person can die without God's permission. Appearance to the contrary, death only comes to a person when God wills it. The Quaran also states that every human being, every living, breathing creation will at some point have to face death. The Quaran even goes so far as to say that death will find you wherever you are. There is no place we can hide, death will seek us all out. (Quaran, SIV: 78)

Death is considered to be the physical separation of the body from the soul. This occurs when the body perishes. Comatose patients are not dead in the sense that their souls have not left their bodies, and their bodies have not perished. Taking this into account, they should still be looked at as living individuals.

The Islamic Shariah has defined certain guidelines for the attainment of medical treatment. The Islamic Shariah, is a group of scholars who make up the Muslim Law Council. They have come to an agreement on certain principles. For instance, in Islam, a person has the complete legal authority over his or her body (Ryan, 99). This supports the notion of autonomy. This means that a person can engage in activities which may expose the person to the possibility of death, or exhaustion. This may be used to justify advance directives since when dictating an advance directive, a person can choose to refuse treatment knowing that it may result in death. (Ryan, 99)At the same time there is a counterpart to this. In Islam, it is mandatory for the ill to seek treatment. They must do everything in their power to continue life. So under this context, ending treatment, even with a chance of recovery, would be wrong. This is because Islam places a lot of emphasis on life and the necessity to continue it. Suicide and murder are both major sins in Islam. Maintaining life is so important that certain sins can be void if the person's life is at stake. An example of this is someone who is starving. Now normally Islam prohibits any meat that comes from a pig, but in the case of a starving individual, it is better for that person to eat the pig rather than starve to death. In extreme circumstances, prohibitions are waived. Just the fact that under conditions in which one's life is at stake, certain prohibitions are waived, shows how necessary it is for a practicing Muslim to seek treatment and try to preserve life. (Ryan, 99)

The Islamic Shariah has concluded that the appropriate authority in determining the signs of death should be given to the medical profession. The Islamic council also acknowledges the fact that brain stem death is the proper definition of death. Brain stem death is determined by physicians attending the patient. While brain death is determined by the physician, the majority of the choices may be made by the patient, as long as sufficient medical knowledge is supplied. In the event that a person is unable to express their wishes, the next of kin makes the decision for them.(Ryan, 99)

There are exceptions to these regulations. For instance, a case in which the prolonging of treatment would lead to nowhere, it would be okay to end treatment (Enc., 1291). This is only if the use of life support would not increase the chances of survival.

It would also seem that prolonging life through the use of artificial means would not be wrong under Islamic law. The same could be said about ending treatment as long as it seems that there is no chance of recovery. If there seems to be the slightest chance of recovery, then it is important to sustain life support. Basically, there is no clear cut answer to the question of treatment withdrawal. The main thing that is important is that treatment is sought and everything is done to continue life. The one established fact is that there is no harm in prolonging life (Ryan, 99 ). Withdrawal of treatment is allowed only if the outcome does not look good, for life is of utmost importance in Islam (Enc., 1291).

There is however a conflicting view to this as the Islamic Shariah is divided on this issue.

The Islamic Shariah also rule that there is no difference between "causing someone's death" and "letting someone die" (Chaim, 95). "Since in Islamic theology the body is not considered to be owned by anyone, no one is free to do with it as he/she wishes, still less to kill it. This is why suicide is forbidden in Islamic law, and it is even forbidden to pray for death to come. God alone may decide on the duration of a life or when it will be ended" (Chaim, 95). This leads one to believe that removal of treatment in any case is definitely outlawed. In fact, it is also considered wrong not to further medical treatment if doing so will result in death.

Patients who are suffering are not allowed to end their lives either. They are expected to tough it out, and do *sabre* which is "perseverance against pain and agony, self-restraint" (Chaim, 96). Under Islamic law, the desire to die is not justified when it is due to physical pain. "The mercy killing of a terminally sick patient is forbidden in

Islamic law because it ignores Allah's ability to perform miracles, and because it interferes with Allah's exclusive control over life and death" (Chaim, 97).

Under Islamic law, doctors and nurses and all health care professionals involved have the duty to maintain life, they are not to start the process of dying. "When a doctor terminates life, it is as if medicine is utilized for the opposite purpose for which it was created by God. It is an offense against the Lord" (Chaim, 97).

Islam is strongly condemns treatment withdrawal of patients : "Because of the perceptions of Islamic law (a) that Allah alone decides on life and death, and (b) that the world is a continuous testing ground for mankind, the killing of a terminally ill person is equivalent to murder, on which Islamic law is very clear...all the more the doctor who disconnected the life-sustaining machine and the relative who signed the authorizing papers, are guilty of the same crime-murder" (Chaim, 98).

People are expected to live with perseverance, going through a painful ordeal or an illness should be seen as a purification of the soul, for *sabre* leads to Paradise in Islamic tradition.

"These questions are whether the high costs of maintaining the dying should not be substituted by better health services for those who have a chance of recovering; and whether non-terminal patients whose quality of life has no prospect of improving, such as severely deformed newborn babies and patients in a vegetative state, should also be included in the "terminally ill" category" (Chaim, 99). This clearly indicates that even patients in a vegetative state, who have even the slightest chance of recovery, do not have the Islamic right to be removed from treatment. Quality of life should also not be an issue when determining whether or not to keep the patient on treatment. Muslims are expected to be strong and are aware that everything they go through here will be rewarded in the hereafter. Therefore Muslims are not to remove treatment only for the purposes of relieving one's pain.

#### 5.1.1.1.3 Judaism

The area of bioethics is as new to Judaism as is to all three major western religions. Conclusions can be drawn based on ethical norms and rules of Judaism. Judaism norms derive from the Scriptures and Oral traditions, the written Torah and the Oral Torah. (Enc., 1301)

The first and foremost principle of Judaism is the notion that God is the creator and lord of the universe. An important part of the Jewish tradition is the fact that God is considered to be the only owner of exclusive property rights. "Indeed all lives are mine" (*Id.*) This takes into account the ownership of our bodies and our souls. The sanctity of life must be upheld, for it is also an important part of the Jewish tradition.

According to Jewish tradition, our "right" to end life does not exist in these terms. In addition, Advance directives contradict the fact that divine creatorship is a major principle of Judaism. Therefore a case of euthanasia would definitely be considered wrong according to Jewish tradition. Removing life support however, is a more complex issue. (Enc., 1361)

In all cases, the moral value of the sanctity of life, which is used in Jewish religious practice, always remains a steadfast factor. The autonomy of the individual however, is not out of the question, and may be considered.

Autonomy is a big issue with bioethicists these days. Autonomy is a big part of advance directives as well. Jewish law is not a strong supporter of autonomy. The thought that humans are their own masters and have the complete right to make their own decisions on the matters of life and death is not agreeable with Jewish tradition and norm. Patients do however, have the right to play an active role in the decision process. Autonomy does not only give a person an opportunity to play an active role, but gives them complete power over what is done to them. Since advance directives are drawn up before a situation arises, they would seem to go against Jewish tradition. (Enc., 1302)

An interesting contradiction to this is the fact that Judaism concerns itself with the cause of human pain and suffering. Pain is to be relieved immediately.

"Unbearable pain is considered worse than death, and to escape it, anything short of direct killing is exonerated"(Ketubot 33a, bioethics). This would make it seem as though removing life support in order to stop pain would be okay. However, it is wrong to relieve one from pain at the cost of life, therefore it would not be okay to remove treatment to end suffering if it would result in death.

"Any person who has the power to save life and does not exercise it, but stands idly by, violates the Biblical command: thou shalt not stand upon thy neighbor's blood. The religious and moral obligations of the physician necessitate that he perform his duties without regard for the financial, social, or religious status of his patient" (Enc. 2, 1430).

The interpretation of this quote is such that it is one's duty to save another's life. In other words, if one has the means to save one's life and chooses not to, then he has violated Jewish law.

So it is evident that physicians have the obligation to do everything in their power to preserve life. With the issue of withholding or withdrawing treatment, it would seem that the only time it would be permissible to withhold or withdraw would be if survival does not seem possible. (Enc. 2, 1431)

This does not necessarily outlaw the possibility of treatment withdrawal. This is because of the medical advancements that have been made over the years. Death does not necessarily come as quickly and easily as it did in the early times. Now it is possible to extend life aimlessly for years. There are no actual teachings or texts that can solve this problem. It is an ongoing struggle for the contemporary Jewish bioethicists. However, certain writings by Rabbi Jacob Reishcher, do shed some light on the subject. He permitted surgery that could result in death. If a person has a chance to live but an equal chance to die from a surgery, he is permitted to undergo it. (Enc., 1302)

However the surgery is only permitted with medical consensus that gives a good chance of success. This indicates the permission given to risk one's life in the context of Judaism.

Judaism, like Islam, gives utmost precedence to the sanctity of life. In Israel, doctors have no legal obligation to discuss DNR's with their patients. Living wills do not have any legal standing. This shows how much importance is given to the preservation of life in the Jewish tradition. In cases where the patient is incompetent, any decision regarding treatment may be made by either the next of kin or the physician. (Gray, 1991)

In all cases, the moral value of the sanctity of life, which is used in Jewish religious practice, always remains a steadfast factor.

Defining death is an important issue. According to the liberally inclined Jewish bioethicists, "brain death" is considered death. This is important because once the patient has shown signs of brain death that have been determined by physicians, it is imperative that the patient be removed from life support. In fact if the patient is breathing through a machine and only through a machine, it is required that he be taken off immediately since this is in violation of Jewish law.

"...the prohibition against leaving the dead unburied"(Novak, bioethics). Since the patient is considered dead, he should be buried rather than kept "alive".

Some conservative Jews view death as the "cessation of spontaneous reflexes, heartbeat, and breath"(Novak, bioethics). According to this school of thought, it would seem wrong to prolong life through the use of machines once the patient has arrested. So in this case the removal of life support is not only ethical, but in a way, mandatory.

There are however, contradictions to all this. Under Judaism, it its essential to maintain life at all costs. Judaism like Islam, suspends religious laws if there is even the slightest danger to one's life. For example, an infant would not have to undergo circumcision if his life were at stake. This despite the fact that it is Jewish law that the male child be circumcised. (Enc., 793)

"A physically or mentally handicapped life, in whatever state of debility, is worth no less than a full and healthy life...one person has exactly the same value as a million people" (Enc., 794).

Under this context, considerations of quality of life in deciding treatment, would not be allowed. The person's life would still be valuable and worth saving even if he were in a PVS or an economic burden to both the hospital and family. It would seem that termination of treatment of a patient in a PVS would be wrong on the basis that their life is still considered valuable.

"He who kills, whether [the victim to be] a healthy person or a sick person approaching death, or even a patient already in his death throes, is treated as a capital criminal"(Enc., 794 et. al.).

According to this law, it would be wrong to terminate or hold back treatment, even if the prognosis was not good. It would be seen as a punishable crime. Therefore it is safe to conclude that treatment may not be withdrawn or held back for patients even when the prognosis does not look good under Jewish law.

On the issue of treatment withdrawal for patients who have no chance of recovery, and for whom treatment would only prolong life, rabbinical views differ. One view sees it as being okay to remove "medications or machines that serve only to draw out the dying patient's agony, provided no natural means of subsistence (e.g. food) are withdrawn" (Enc., 801). Therefore under this view, it would be okay to end treatment or not start treatment where doing so would only prolong life. A contradicting view makes it completely wrong to stop treatment even if it only prolongs life. Under this view, treatment should not be held back nor should it be withdrawn.

#### 5.1.1.1.4 Buddhism

Discerning a specific ethic in Buddhism concerning death and dying is a more problematic issue than finding one in any of the other world religions. Gotama (also known as "the Buddha"), a figure roughly analogous to either Jesus or Mohammed, traditionally refused to discuss any issues that he did not consider relevant to the enlightenment of mankind, as is reflected in several teaching fables about him, choosing instead to remain either silent or challenge the premise of the question. Furthermore, the teaching stories of the Pali Canon (the collected teachings of the Buddha, along with commentary by some later authors) do not claim absolute inerrancy or divine inspiration, as do the Old Testament, New Testament, and Koran. Despite this, different lineages of Buddhism have definite opinions regarding "self-willed death".

The Hiyanist (or "Therevada") school of Buddhist thought typically focuses in on the Parajika Sutra, from the Pali Canon, in which one monk encouraged many others (either 60 or 600 depending on the translation) to commit suicide in order to transcend the earthly realm of appearances (lit. "reach beyond samsara"). Upon hearing of this, the Buddha declared that the enlightened one would not choose to end their life, for to do so would mean that they would be incapable of helping others become enlightened, and anyone who died before becoming enlightened would remain trapped in the wheel of rebirth. Therefore, he mandated that anyone within the monastery who helped or encouraged someone to end their life should be expelled from the order immediately. The Mahayanist lineage typically considers that particular Sutra to apply specifically to monastic orders, and points to various other secular stories within the Canon which seem to indicate that those experiencing unbearable pain and are assured of death have nothing left to gain by suffering, and that therefore there is no reason to prolong it. This implicitly allows for suicide as well as withdrawing life support (Young, Encyclopedia of Bioethics, "Death - Eastern Thought", 1995).

Differences in these interpretations are generally thought to derive from doctrinal differences that arose due to the cultures that the lineage developed in. Hiyanist Buddhism developed primarily in northern India and Tibet. The predominant cultural influence remained Hinduism, with the focus on the inevitability of rebirth following death, and the primary concern was personal escape from this cycle. Thus Hiyanist thought tends to emphasize becoming an "ahrat" (lit. "wise one"), rather than a Buddha ("awakened one"). Becoming an ahrat allows personal escape from the wheel of life, but does not allow one to save others from it as well. This change in emphasis also derives from the Hindu idea that only karma ("fate" or "judgement") follows a person from one life to the next, that any degree of personality or "self-ness" is lost. Therefore, since it is nearly impossible to become a Buddha in one lifetime, but becoming an ahrat is possible, that is where the emphasis should lie. Mahayanist Buddhism developed in China, and was influenced there by both the pagan animist religions and the naturalist Taoist religions. The conception developed there was that of being capable of purifying one's karma through successive lives and eventually attaining Buddhahood, allowing not only the salvation of oneself but of all others as well. This was seen as a superior path, hence the name "Mahayanist" ("Great Vehicle") as opposed to "Hiyanist" ("Lesser Vehicle"). Borrowing from it's roots the Hindu concept of infinite time, the time frame mentioned for this process is absolutely astronomical, in some cases as high as 62 x $10^{52}$ x 37 *years*, more than the age of the universe by many orders of magnitude.

In the light of these two traditions, the one seeing all permanent changes taking place within one lifetime, the other seeing change occurring over an incredibly immense period of time, we can see more clearly where the stand on end-of-life develops from. When one has only the frame of one's own life to work in before being essentially sent back to the beginning, suicide or any voluntary ending of life is undesirable, as it reduces the time available to break free from death and rebirth. On the other hand, when a concept of continual development is introduced and the span of one lifetime is compared to the time scale mentioned above, the emphasis on one lifetime is considerably reduced, and hence the voluntary cessation of life by any means is less of a negative thing.

#### 5.1.1.2 Comparisons

The one thing that is clearly common among the three major western religions is that there is no clear answer to the question of whether or not treatment should be withdrawn for a patient in a PVS. Islam and Judaism are alike in the sense that they both believe in the sanctity of life. Both religions contend that it is important to find treatment and fight for life rather than just wait to die. Considering this, it is not surprising that both these religions allow individuals to use modern day technology to help preserve life. Another thing that is common to both religions is that in the event that a person's life is endangered, both allow the suspension of other laws that may interfere with trying to live, i.e. a Muslim who is normally prohibited from eating pork, may do so if he or she is starving to death and likewise for a person of Jewish faith.

The one belief shared by all three western religions, is that God is omnipotent and has complete rights to our bodies and souls. Christianity unlike Judaism and Islam is more or less divided on this issue between its different branches. Roman Catholicism like Islam and Judaism places a lot of emphasis on the preservation of life. It does not however, insist that extreme measures be taken to continue life. One branch of Protestantism does not even allow the use of any medical technology whatsoever in the process of finding treatment. Cures are mainly sought through faith healing and religious medical practices. On the other hand, the moderate branch of Protestantism allows individuals the freedom of thought. Protestantism unlike Roman Catholicism and even to an extent Islam and Judaism, allows the individual to decipher between the bible and personal experience. It leaves the bible open to a wide range of interpretation. Another thing that is common to all three religions but distinct from Buddhism, is the belief that suicide is definitely wrong and life is a gift from God which should not be taken for granted. Although Buddhism does not out and out support suicide and the cessation of life, it does not actually oppose it either. Buddhism allows an individual to commit suicide and cease any life or suffering that may seem prolonged.

When deciding for a patient who is deemed incompetent, religion may be an influential factor. A competent person may also base his or her decision on their belief system. A person should be and is allowed to base their decision on their faith and what it says about the matter as long as it is in accordance with federal laws and hospital policies.

## 5.2 The role of doctors

The doctor's control over the treatment of a disabled patient as well as their medical knowledge puts them into an awkward situation when it comes to withdrawing treatment from incompetent patients. When combined with the fact that they are in fact the ones administering that treatment and will have to be the ones to withdraw it should that decision be reached, their position becomes even more untenable. Their large degree of power over the situation leaves them with a large burden of not only responsibility, but accountability which in all fairness they may not deserve. Even with the consent or direct request of the patient that they are withdrawing treatment from, doing so is still a somewhat risky proposition. Take, for example, *Barber/Nedjl v.*, in which those two doctors were initially charged with murder when they removed Mrs. Bouvia from life support at her direct request. It was not until the appeal finally reached the California Supreme Court that they were found innocent. Withdrawing patients from life support without the consent of the patient themselves and in the absence of any surrogate decision makers is much more dangerous for the doctor.

### 5.2.1 Doctor's attitudes

Most medical directors (approximately 94%), when surveyed, felt that patients in PVS were in fact "better off dead", and better than half thought that the patients should be considered legally dead (Payne, Taylor, et. al, 1996). This attitude was more clearly displayed when in the same survey, there was little concern for providing long-term preventative care (i.e. mammograms or prostate examinations), and less than half (40%) were in favor of even such routine care as blood pressure readings. The only conditions that the directors were to any degree in favor of aggressively treating were such pre-existing conditions as diabetes (45%), hypertension (31%), or general infections (34%).

Long-term treatments were generally seen as unnecessary for PVS patients by doctors. Fewer than 3% were in favor of "generally providing" CPR, ventilation, or dialysis. 10% were in favor of transfusion. Surprisingly, antibiotic therapy was more popular as a long-term care measure for PVS patients than hydration and nutrition. 34% were in favor of antibiotics, while 29% were in favor of hydration/nutrition. Their desires regarding their own care, should they become PVS patients, were mostly consistent with their beliefs about the treatment of PVS patients in their hospitals. Very few desired CPR, ventilation, or dialysis (fewer than 2%), while 8% desired antibiotics, 5% desire transfusions, and 10% desired hydration/nutrition.

When the situation given in the survey question was changed to include the action of living wills or legally endowed surrogate decision makers, medical directors were nearly universal in their agreement that it was ethical to withhold or withdraw such treatments as CPR (97%), ventilation (96%), dialysis (97%), antibiotics (93%), and transfusions (95%). There was slightly less universal agreement regarding withholding artificial hydration and nutrition, with only 89% agreeing that it was ethical.

The apparently inconsistent responses with regard to withdrawing nutrition and hydration become more clear when physician biases with regards to what treatments are withdrawn when the decision has been made to withdraw treatment are examined. In a study by Christakis and Asch (1993), a bias in favor of withdrawing recently instituted treatments and treatments whose absence would lead to relatively swift death was observed. Approximately 67% of doctors surveyed preferred to withdraw treatment that had been instituted a matter of days before, as opposed to a matter of months. Additionally 81% of doctors surveyed were inclined to withdraw treatment that would result in death within a matter of minutes or hours, as opposed to days in cases where the diagnosis of the cases was certain. In cases where the diagnosis was uncertain, the percentage dropped to 60%. Nutrition and hydration typically have been administered for quite some time when the decision to remove life support from patients in PVS is made, and such an action will typically result in a longer time to death.

### 5.2.2 Roles currently assumed by health-care professionals

As such a favorable position regarding withdrawal of treatment might indicate, physicians nearly always initiated the discussions regarding such matters (Reckling), with the majority advocating the withdrawal of treatment. Despite the fact that the power of the decision has generally been held to lie primarily with the family (see *Wanglie*), the presumed medical authority of the doctor combined with their inclination to recommend withdrawal of treatment could quite possibly skew the decision in favor of ending life. When combined with the fact that situational factors and “organizational culture” influenced the decision-making process, this raises cause for serious concern.

The most commonly cited factors for doctors to consider for and against withdrawal of treatment were the allocation of scarce resources and fear of a lawsuit, respectively (Reckling). Despite reporting that they feared lawsuits, it was commonly felt among physicians that it was "their responsibility" to bring up the topic of ending treatment. Apparently their expectations stopped there, however, as Reckling reports that "…decision makers consider other factors than their own personal attitudes…" While this is good in the sense that doctors do not apparently, as a rule, ignore the wishes of the family, there are (as discussed in earlier sections) some wishes that should *not* be acceded to and in fact should be actively resisted.

Closer examination of two treatments at opposite ends of the spectrum, artificial nutrition/hydration and artificial ventilation, indicates quite a bit about what the tacit and explicit role expectations medical professionals have about themselves, as well as what factors drive their decisions. Artificial feeding and hydration, which was the least disliked, was viewed as relatively noninvasive and simple way to maintain life. Also cited was uncertainty about whether or not the patient was conscious of hunger pangs and the associated discomfort of dehydration and starvation (Wurzbach). For those in favor of withdrawing tube feeding and hydration, it was typically felt that continuing such practices prolonged the suffering of the patient without increasing their chances for survival. The end of both groups was the same; "…to decrease the suffering of the resident." (Wurzbach) It is important to note that in both cases, the patient is *not* expected to recover, and the emphasis is on increasing their comfort. Alluded to by Wurzbach, but never explicitly stated and supported by data, is a tendency for more experienced nurses to be in favor of withholding feeding, perhaps as a result of having more experience with both the discomfort of the patients and the futility of such intervention. Whether or not this trend is substantiated, in a study concerning severely demented patients (Norberg et. al. 1987) there was a surprising tendency for nurses to be in favor of withdrawing food or hydration. Over 50% were in favor of different degrees of withdrawing treatment. No age range was given in the study.

Artificial ventilation, as noted above, is viewed less favorably than tube feeding/hydration, despite the fact that withdrawal of ventilation is more immediately fatal than withdrawal of artificial nutrition. In the case of bone-marrow transplant patients, less than six percent of those who required artificial ventilation survived the thirty days until discharge. Only half those survived two years or more. When further intervention was required, such a vasopressors or treatment for hepatic or renal failure, the survival rate dropped to zero (there was no data included regarding patients who did not receive artificial ventilation). When the trauma that results in respiratory failure is to a degree predictable and can be prepared for, such a low survival rate is worth taking note of. (above data from Rubenfeld et. al.)

### 5.2.3 The power of doctors and availability of resources (greatest good)

Given the above, what role should medical professionals play in making a decision about withdrawing treatment? Their large bias in favor of withdrawing treatment is quite evident, and while this bias does have a fair amount of reasoning behind it, it is perhaps this reasoning that should be brought up rather than the simple recommendation that life support be terminated. Numerous cases involving living wills or powers of attorney have left a clear precedent indicating that the wishes expressed in such a manner are not subject to the approval of a physician or other medical professional. In this case, the interest of patient autonomy has been held to be more important than the countervailing state interest in preserving life. When such documents are lacking, but the patient has a family, most major precedent-setting cases have emphasized that the final decision about continuing life support, when it is not a simple case of medical futility, rests with the family of the patient, and the doctor is required to accede to their wishes or step aside in favor of one who will.

When a patient has no immediate family, no living will, and no specified power of attorney, the issue becomes more clouded. Assuming a case of clear incompetence (i.e. a PVS patient) or a case where incompetence has been established by some means, what should they have to say about the future of the patient? Given their clear bias in favor of withdrawing life support, should they be allowed to make such a decision?

It is obvious that they should not have *carte blanche* to do what they want with patients in such a situation, but in the absence of any clear knowledge regarding the patients wishes or any relatives it would be difficult to find someone more familiar with the case (and therefore more qualified) than the physician of such a patient to make such a decision in the absence of anyone else. Presumably he or she has an understanding of the case, the specific medical problems the patient has, and a good idea of a prognosis as well as how certain that prognosis is. In the absence of any mechanism to ensure the patient's autonomy, there remains no basis for the decision other than medical concerns.

In such a case as the one described, the doctor is obviously the one who should make the decision.

The question in these situations is how best to ensure that the best interests of the patient are looked after, and specifically what criteria should be used to ensure this. Such guidelines should take into account not only the individual patient's situation, but also the overall situation of the hospital in terms of resources. Balancing these two factors is the critical point, for while it is foolish to tie up resources that could potentially save several lives to prolong the life of one person who has a good chance of never recovering, it can be argued that it is equally wrong to essentially condemn one person to death in order to *possibly* save a few other lives. An added complication is that the equipment cannot simply be switched from patient to patient. Some of the more complicated life-support equipment requires maintenance between patients, and the time it takes to disengage a patient from them without causing further injury is prohibitive in an emergency situation. The decision to render the equipment available must unfortunately be made *before* the equipment is needed. The patient's access to health care must be weighed against the availability of those resources to others. Ethically, "justice tempers patient autonomy in those cases where complying with the patients directive would unfairly deprive others of equitable access to an adequate level of scarce medical resources."[Hastings Center, 1987]

### 5.2.4 Medical futility

A diagnosis of medical futility (i.e. spinal decapitation or severe and extensive brain damage) is sufficient to justify disconnecting life support. Even in cases where there is no obvious medical futility, a condition with no chance of survival as determined by research (e.g. Rubenfeld et. al.) should also be sufficient to justify disconnecting life support. In any case, "a physician has no ethical obligation to provide a life-sustaining intervention that is judged futile" (American Thoracic Society, 1991). In other words, even if the patient's life can be prolonged for a matter of days with a given measure, if it is merely prolonging the inevitable then one cannot justify the expenditure of resources on the patient. This begs the question of what sort of time limit should be imposed, however, since it could be argued that *any* medical intervention is merely postponing the inevitable. Given the following quote, however, it seems reasonable to assume that futile treatment in this case refers to treatment which stands no chance of restoring conscious function to a patient. In their 1991 statement, the American Thoracic Society takes the issue one step farther, stating that

> "survival in a state with permanent loss of consciousness, i.e. completely lacking cognitive and sentient capacity, may be generally regarded as having no value for such a patient."

While such a criteria is apparently reasonable, there exists little data that predicts the outcome of a coma, whether it leads to some degree of recovery or PVS. Physicians in day-to-day cases have little basis for judging whether or not a procedure will be futile in the sense above, and hence this criteria is better reserved for decisions about long-term care.

### 5.2.5 Responsibilities in surrogate decision-making

Legally, there are precedents set for doctors to disconnect life support machinery with the consent of the patient or the immediate family of the patient if the patient is incompetent. Despite the outcome of *Cruzan*, several other cases such as *Barber* and *Nejdl v. The Superior Court of Los Angeles County* found that the desire of the patient's family was alone sufficient to provide doctors with the right to withhold life-sustaining treatment in the absence of clear previous direction from the patient. Advance directives as defined by such acts as the California Natural Death Act are often limited in scope and power. Additionally, such advance directives are often incompletely or ambiguously filled out. In *Barber and Nejdl*, the court found that "under the circumstances, the wife was the proper person to act as a surrogate for the patient." This is a significant difference from *Cruzan*, which found that in order to withdraw life support "clear, cogent, and convincing evidence" of the patient's desires was necessary to effect the removal of life support measures. As noted above, the varying precedents from state to state make a decision to withdraw life support difficult and risky for the physician involved, as well as making a universal statement difficult to create or apply.

# 6 Recommendations for decision making

This section contains our recommendations for the decision-making process based upon the considerations shown above. As above, masculine pronouns are used in the inclusive sense, and no bias should be assumed from the exclusive use of such forms as he/him/his.

## 6.1 Doctors

As doctors are the most familiar with the medical and technical aspect of the patient's situation, the process of deciding whether to continue or withdraw life support will most likely start with them. Implicit in the doctrine of informed consent has always been the notion that a patient should be kept as fully informed as possible about his situation, prognosis, and treatment options. In the case of patients that have been judged to lack capacity to decide on certain courses of medical treatment for themselves, this information is instead passed on to whomever is making a surrogate decision. Regardless of the source of the decision, the doctor's expertise lends significant weight to his recommendation, which should be considered by the decision-maker. Ultimately, however, the choice lies with that decision-maker, who will rarely be the doctor.

Especially in cases of long-term care, where the physician's contact with the patient's case is at a minimum, the medical knowledge of the doctor should be used in conjunction with that of any medical professionals who have provided daily care to the patient (such as nurses). Such caretakers typically have a more immediate understanding of the personal issues involved, and can lend an extra dimension to the clinical knowledge of the physician.

Regardless of the doctor's personal beliefs, his duty to the patient is to keep him fully informed. Thus, even if the religious or personal beliefs of the doctor are against withdrawal of life support, the doctor may not for that reason neglect to mention that option or leave out any pertinent data that may influence the decision of the family. See section 6.3.2 for more information on dealing with religious conflicts.

### 6.1.1 Consideration of futility

As has been shown above, a doctor is typically under no obligation to provide a treatment that has been judged futile, and to do so is usually considered ethically wrong as it not only needlessly prolongs the suffering of the patient, but denies other patients who may have a chance of successful treatment access to resources that may potentially save their lives. Since in most cases of futility the same trauma that has rendered the patient moribund typically removes their decision-making capacity, the decision to withdraw treatment must be made by others. In the event of a diagnosis of futility, the doctor must have clear and convincing evidence (of the sort that would stand up in court) of the futility of the treatment. While in most cases, this is not difficult to provide (i.e. partial decapitation), in such cases as ventilation of bone-marrow transplant recipients where the cases is much less obvious, much statistically validated data must be supplied. Religious and ethical thought in this area tends to be less divided, a common theme being that there is not an obligation placed on the physician to perform a treatment which has essentially no chance of success, but only the potential to prolong the suffering of the patient.

### 6.1.2 Evaluation of legalities

While what is right to do in a specific situation should, in principle at least, be universal, different states have wildly differing laws and set precedents regarding what life support measures may be withdrawn under what circumstances. In the case of a conflict between a state law and the ethical beliefs of a doctor, the doctor should typically consider the laws regarding life support to be definite boundaries on his range of possible actions (see section 6.4.1, "Need for up to date legal knowledge"). The difficulties of a legal battle to change the laws regarding a course of treatment should not, in normal circumstances, be added to the grief and stress of having a severe illness or a family member with a severe illness. However, if the decision-makers and the doctor both feel willing to undertake the process of challenging a relevant law, then due legal process should be observed (see section 6.3.1, "Ethical v. legal conflicts").

### 6.1.3 Evaluation of competence

In cases such as PVS, competence is fairly clearly absent, but in less clear-cut cases a more detailed examination is necessary. As noted above, simply determining overall competence is not only difficult but unnecessary, what is needed is a determination of "competence-to". The relative hazards, complexity, and unusualness of the treatment should be considered and weighed against the mental function of the patient in order to determine whether or not a surrogate decision-maker is needed. If the patient is judged competent, then they are the primary decision-maker and all recommendations of the doctor should be directed to him, and the issues of advance directives, powers of attorney, or informal statement of wishes may obviously be ignored. If it is determined that the patient lacks the capacity to make that decision, it should be noted that that evaluation pertains only to the particular decision under consideration. The doctor should in that case refer to the advance directive, the designated power of attorney, the family, or any close friends to obtain the primary decision-maker. If none of the above exist or can be found, then the doctor must assume the role of primary decision-maker in consultation with his colleagues.

### 6.1.4 Consideration of other patients

While a single patient or family is typically concerned only with themselves, doctors have the responsibility of maximizing the welfare of the several patients that may be under their care at any one time. With this in mind, doctors must carefully assess which resources may be best used where to maximize patient welfare. While in situations such as futile treatment it is easy to determine where to allocate the resources that the patient is using, in other cases it becomes more difficult. As noted above, the difficulties attendant in placing patients on and removing patients from life support machinery, as well as the maintenance that must typically be performed between each use of these machines, makes it extremely difficult to simply move patients between machines as needed. This necessitates making firm decisions regarding what machines will be used for which patient as soon as is possible considering the diagnoses. The availability of life support equipment must be taken into account when the capacity of a facility to handle patients is being considered. Recommendations regarding the treatment of a patient must take the availability of resources into account, but it must be made clear in the recommendation that that is partial basis for the recommendation.

### 6.1.5 Recommendation to family

Taking the above factors into consideration, the doctor must make a recommendation to the decision-maker explaining not only the doctor's recommendation *and the reasoning behind it*, but also alternatives to the recommendation. All recommendations or alternatives mentioned, except as noted in section 6.3.1, must fall within the laws of the state. The doctor's ethical or religious beliefs may properly influence his recommendation as long as they are mentioned as influencing factors. The doctor may not, however, *neglect* to mention alternative treatments as a result of his ethical or religious beliefs. In such cases as futility, or where the law limits the ability to choose, the doctor is still responsible for informing the decision-maker of the single decision that is available as well as why the decision is limited to one option. Again, in the case of legal limitations, the treatment or withdrawal thereof may not need to be carried out immediately, as per section 6.3.1.

## 6.2 Family

As the ones presumably closest to the patient, the family is most aware of the values and beliefs and therefore most qualified to ensure that advance directives are properly interpreted in accordance with the patient's beliefs and values, and the surrogate decision-makers decide in line with such beliefs and values as well. Furthermore, in the absence of an advance directive or power of attorney, this knowledge of a person's values makes the family the most qualified to make a decision that would reflect such beliefs and values. Such a decision will typically be selected from a complete list of options presented by the doctor.

### 6.2.1 Patient's wishes/advance directives/power of attorney

A legally filled out advance directive, implemented in accordance with state law, is typically legally binding on all concerned. In such cases the responsibility of the family is limited to seeing that it is interpreted correctly and to provide decision-making support in the event of a circumstance that is not covered in the advance directive. Powers of attorney are similarly binding, and the responsibility of the family, assuming that the family is not given the power of attorney, is limited to preventing abuse of that power. Presumably the power of attorney directive would be thoughtfully filled out and granted to one who would decide as best as possible within the values and beliefs of the patient, but in the case of abuse it is the responsibility of the family to intercede on the behalf of the patient.

#### 6.2.1.1 If not available, consideration of patient's values

In the absence of any formal statement of wishes or designated authority, the decisions regarding treatment must be based off of any informal statements regarding treatment that had been made. Lacking any information of that sort, the decision must be made as fully as possible in accord with what is known about the values and beliefs of the patient. Again, as the family is closest to the patient, they will be most qualified to judge which of the outlined treatment options falls most in line with their values and beliefs. The elucidation of the reasoning behind the recommendation by the doctor will assist in this determination. Furthermore, apart from direct judgement regarding values and beliefs, any hearsay regarding the patient's views on the quality of life that they would consider worth preserving must be very carefully weighed against the prognoses provided by the doctor to assist in making a decision.

### 6.2.2 Consideration of doctor's recommendation

The doctor, as the medical professional in the case, must be assumed to have accurate and complete medical knowledge regarding the case. As such, his recommendation and the reasoning behind it must be carefully considered. Furthermore, his relative detachment from the situation may give him a somewhat better perspective on what would be best for the patient. All this considered, the family must carefully weigh the recommendation, the reasoning behind it, the alternatives and probable outcomes outlined by the doctor, and the known values and beliefs of the patient in order to select a course of action that is best for the patient. The doctor must be fully prepared to discuss "what-if" scenarios with the family, including chances of survival, chances of regaining a decent quality of life, and all possible outcomes as frankly and in as unbiased a manner as possible. Additionally, he must inform them of outside extenuating circumstances that may influence their decision, such as the allocation of scarce resources, the possibility of organ harvesting, etc. The doctor's role is to provide information that is as complete as possible to the decision-makers in a manner which is appropriate to their level of medical knowledge and to make them aware of options which due to their less extensive knowledge they may not have been aware of. His recommendation, while important, is merely that; a recommendation.

### 6.2.3 Determine which measures (if any) to continue and which (if any) to withdraw

When all relevant factors have been considered, the decision-makers must choose a course of action, determining which life support measures to continue or withdraw. It is important that the patient's autonomy is maximized during this process, ideally by means of advance directives or designated power of attorney, but at least by consideration of what is known about their beliefs and values. It is important that the law must be considered in this process, but in cases where the law is strongly felt to be unjust it is *not totally binding* (see 6.3.1). The decision should be discussed with the doctor, who has the responsibility of rejecting absurd requests or the addition of futile treatments that would deprive other patients of resources. Typically it should be assumed that the doctor has outlined the most reasonable course of action, and the decision should be drawn largely from there.

## 6.3 Dealing with specific problems

Such a decision-making process as outlined above can lead to some serious problems. There are cases where the law is ambiguous or unjust and the need is felt to pursue a treatment outside the boundaries of the law. There are also cases where the religious values of the patient, family, or doctor conflict with the selected course of action.

### 6.3.1 Ethical v. legal conflicts

Challenging a law is rarely a “time-critical” process, as the administration of a potentially life-saving treatment is rarely illegal, whereas the removal of a treatment that is currently sustaining life is more often to be considered so. Furthermore, in time-critical cases (such as in an emergency room), administering treatment in a technically illegal fashion, such as administering CPR to a person with a DNR order, is typically not considered breaking the law (or at least not prosecuted) if the action was performed in ignorance of the DNR. While the cumulative cost of providing life-sustaining treatment may lend a certain element of urgency to the matter, the cost is rarely so prohibitive as to require outright action clearly against the law. In cases where the law is felt to be unjust, collection of relevant data should be undertaken and with the aid of the legal department of the hospital, a request for judicial approval to perform the procedure or remove the treatment should be made, and if denied the appeals process followed through. An effective preparatory step in such cases would be consultation with the ethics committee of the hospital, should one exist, and gathering of information such as related cases. Such a procedure should never be taken solely on the initiative of the doctor against the wishes of the family however, and before beginning such proceedings, everyone involved should be made aware of the costs and time involved. Alternatives to such procedures should also be examined, such as transferring patients to a different hospital, and used in preference to challenging an existing law.

### 6.3.2 Religious conflicts

While the religious beliefs of the patient must be respected, the beliefs of the doctor must as well. A doctor can not be compelled to perform a procedure that is against his religious beliefs. In such a case, one option that must always be made easily available is transferring the patient to another doctor. Furthermore, it must be made clear by the doctor that he is refusing to perform this treatment for reasons of religion or personal values, and that the family has the option of transferring the patient to another doctor. A writ of *habeas corpus* can be obtained in extreme circumstances. On the other hand, the religious beliefs of the patient must be weighed against countervailing state interests, as has been shown above. Such a situation must be carefully handled in order to avoid infringements on anyone's freedom of religion.

## 6.4 Other recommendations

### 6.4.1 Need for up to date legal knowledge

Doctors must be fully informed regarding the legalities of various treatments in various situations, but should not be expected to either spend less time on patients (their primary responsibility), or take extra time to research the relevant laws or cases. Due to the rapidity at which the science of modern medicine advances, the relative inertia of the legal system, and the varying laws from state to state, this can be a very difficult task. For this reason, in the absence of such a capacity, there should be a concerted effort in the legal department of the hospital to keep fully abreast of current cases. Ideally, they should be able to supply up-to-the-minute guidelines regarding what treatments are and are not legal, and assist doctors in judging the legalities of various questionable treatments. Such a department, for the sake of both the hospitals, to avoid costly malpractice suits, and the family, to avoid long court cases prolonging their suffering, is instrumental in the decision-making process. Both state and local laws, including reviews of precedents set in previous cases must be considered.

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