
Patients are talking - and we'd BETTER listen!

J Civetta

Citation

J Civetta. *Patients are talking - and we'd BETTER listen!*. The Internet Journal of Advanced Nursing Practice. 1998 Volume 3 Number 1.

Abstract

In an actual crisis, immediate treatment is necessary, even before the diagnosis is fully understood: a sudden hypotensive episode prompts a fluid bolus, "the patient desatted" and the inspired oxygen concentration is increased. Have we reached a similar crisis in end-of-life decision making? While we have been struggling with the moral and ethical issues involved, defining quality of life and patient's autonomy and making some progress, has our response with immediate treatment been enough? The medical literature is replete with articles that document our inability to deal with end-of-life decision making so that patients still die with pain. We still have difficulty making decisions in accordance with their wishes and with support from the family. In fact, one of the few improvements over the past few years has been the effectiveness of the hospice movement. The word "hospice" derives from the middle-ages at the time of the crusades. It was a place to rest before preceding on with the rest of one's journey. While hospice centers and home hospice care are perceived as valuable resources, perhaps the most valuable available to patients and families, oftentimes, the concept must be expressed in a separate building or setting as the acute care setting remains unable to respond to these needs of patients. I believe that we must listen now to some unpleasant and accurate expressions of the agony of patients and families.

Christina Campi (1) published a letter on The New York Times Web-Site, January 5, 1998, entitled "When Dying Is as Hard as Birth". The first sentence: "My sister, mother and husband died within nine months of each other last year. The cause of death: morphine." We will discuss the principle of double effect but her misinterpretation is striking and noteworthy: "This process of death by sedation, called "double effect" in the medical profession, is the physician-assisted death that occurs every day, but is largely ignored in the current debate on death and dying in America". What a tragedy that she not only did not understand the principle of

double effect but equated the ethically correct alleviation of suffering, with physician-assisted death, an act with a totally different moral implication. Further, she complains that she got little guidance, that she wasn't competent to make decisions but that she was "left to drive the engine of death." Among other quotations that cry out from agony, I find this to be the saddest of all: "Did I kill him? I don't know. Did I push the morphine pump to warp speed to relieve his suffering or mine? I don't know." We failed her. I surmise that her relatives at least received sufficient analgesia as they were dying but our task is to ensure that family members are assisted in understanding end-of-life decision making as well. For whatever reason, it is clear that in this instance, she never understood that intention determines the morality of actions and her relatives were not killed but died from the inexorable progression of disease. In fact, liberal use of analgesics, justified by the principle of double effect, is to be desired among caregivers and it would appear that their effects were praiseworthy; it is hard to know whether they failed to communicate well or she was just unable to understand what they said.

Maureen D'Honau published "On Machine: His Doctors avoided the Dying Patient's Agony" in the San Francisco Examiner. It was subsequently reprinted in Connecticut Medicine (2) in June 1998. She starts by recounting the episode: by specifying the number of words involved, should we infer that this was the extent of the discussion? "The doctor asked the question and waited. Words: I counted them. From the doctor there were six: "Do you want him on machine?" From my husband, Charlie, there had been three: "I can't breathe." From me there would be one: "Yes" or "no." "No" meant watching Charlie suffocate. How could I choose that? What fate had delivered the sentence to me? "Yes," however, must mean an ominous procedure. What kind of machine? Why had I not been prepared for this? Wasn't there another option – a medical way to relieve his

agony and terror?" Later on day 16 she stated "One doctor discussed the merits of doing an angiogram. Later, another doctor told me Charlie was dying. Later, a third doctor told me Charlie would have to be moved to a rehabilitation facility." Finally, two weeks after he died, "Our internist, the former primary doctor, called to ask me how Charlie was doing. I told him Charlie had been dead two weeks." "Oh," he replied. "The hospital listed him as discharged, so I had no way of knowing." One of the striking matters in this case was that, because of the generous medical insurance plan, she and her husband had decided to find the best medical care. The irony is all too evident.

One doesn't need to die or be the family member of a dying patient in order to realize that we are incredibly deficient in delivering end-of-life care. Jane Paulson (3) an internist and palliative care physician, wrote about "Bitter Pills to Swallow". Her story is especially poignant because until she became a patient, she felt that she was a particularly empathetic doctor who listened to and thought that she heard the stories of her patients. Some of the bitter pills included "Our new technologies are so much better", "Don't worry – your hair will grow back", and "You are not eligible for this study." This last point was particularly devastating to her as "not eligible" connoted being denied something desirable and had nothing to do with the criteria set for trial entry. She urges us to learn psychology of illness and concludes "encounter the suffering that accompanies human illness."

But we have more than patient and family anecdotes to document our inadequacies. Hanson (4) noted patients and families are uniquely qualified to define priorities to improve terminal care, yet they have rarely been asked to do so. Bereaved family members were polled: A quarter wanted treatment not recommended or refused other treatments. Nearly a third wanted more treatment for pain and more comfort measures. Over 60% of families had negative comments concerning the physicians, but only 30% negative comment about the facilities and 10% relative to hospice care. When asked for recommendations, 45% stressed increased communication and nearly 20% focused on the problem of access to physicians. The authors concluded that family members' priorities have little to do with being in control over specific treatment decisions. A clinical program designed to enhance physicians' communications skills and to give them more time with dying patients might better satisfy the needs of the patients and families. Again, the irony is evident to me that everyone is worrying about the costs of care and the solutions preferred by patients and

families cost nothing but time and attention. In fact, Bernard Lown in "The lost art of healing" quotes Anatole Broyard: "I wouldn't demand a lot of my doctor's time. I just wish he would brood upon my situation for perhaps 5 minutes, that he would give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh to get at my illness, for each man is ill in his own way. Just as he orders blood test and bone scans of my body, I'd like my doctor to scan me, to grope for my spirit as well as my prostate. Without some such recognition, I am nothing but my illness."

We must remember that here in the United States, patient autonomy and family wishes are still drivers of care – or at least they should be. This is in contradistinction, at least in some part, to government systems of care such as exist in Australia. The Royal North Shore Hospital of Sydney Policy of Withdrawing and Withholding Treatment (5) has as its first policy point "to render to each patient an appropriate level of treatment consistent with good medical practice and available resources." We have not linked good medical practice and available resources as yet so explicitly in this country.

Finally, Malacrida (6) surveyed relatives of ICU patients who died. Again, they found that needs of the family were to be reassured, concerned comfort measures, to be relieved of anxiety and to be notified of deterioration of their loved one's status. Now, for the most part, families were satisfied and some of the practices might not be relevant to the United States but the principal reasons for dissatisfaction were: being notified of the patient's death by phone, insufficient information concerning the cause of death, insufficient information concerning diagnosis and consequences of the illness. Again, the solution to the problems expressed in this study are not costly. This background information can be placed in perspective to what we have been doing as a profession over the past few years as we try to deal with these issues from medical and socioeconomic perspective as well as ethical bases.

Although it seemed for a time that the bioethical and legal issues had become clarified, this may have only been true for those who devoted time and study to bioethics and to the courts and legislators who passed the laws. There has, in fact, been a series of studies published in the past few years that casts serious doubts on whether practitioners, both physicians and nurses, are comfortable with these areas or even practicing correctly. In fact in some situations it appears that individuals are practicing correctly yet believe

they are performing acts which are at least illegal or still unsettled from a bioethical standpoint. Before proceeding with resolution, I believe we should review the severity of the problem in terms of recent surveys and experimental studies. Further, unfortunately, issues that previously were deemed to be in the bioethical sphere now have financial implications that are unsettling or, at the worst dangerous. Finally, the US Supreme Court continues to encourage further attempts to clarify issues such as assisted suicides.

In 1992 (7) the ethics committee of the Society of Critical Care Medicine published the results of a survey. Disturbingly only 46 percent equated withholding and withdrawing life support of treatment. That means that more than half of the professionals in a society devoted to critical care did not understand that these two practices were indistinguishable ethically and legally. With respect to misinformation, the study by Caralis and Hammond (8) revealed the tremendous gap in understanding. In this study approximately a quarter of the polled residents, students and faculty believe there was a difference between withholding and withdrawing treatment. However one third believed that withdrawing treatment was active euthanasia and approximately the same percentage believed that active euthanasia was equivalent to murder. Thus the ethically and legally appropriate withdrawal of treatment (in prescribed situations) was considered to be murder by nearly one third of the individuals involved at the bedside. In 1995, Cook et al.(9) polled Canadian health care workers using different scenarios that modified various factors that had been considered important determinants. The first phase rated 17 factors as determinants of treatment decisions. They then created 12 different scenarios and allowed respondents to pick one of five levels of support. The levels of care included:

Given 12 scenarios and 5 levels of care, there are 60 separate choices; in only one of these did more than 50% of respondents agree. In 8 of the 12 scenarios 10% or more chose the opposite extremes. They concluded "we believe that most patients would find this situation in which the care they received is highly dependent on the attitudes of the healthcare provider unsatisfactory". In 1995 a very controversial study was published (10). This 30 million dollar study was divided into two phases: the first to understand current practices and the second to devise methods to improve care of patients. Based on physician suggestions, "reliable prompt information concerning prognosis" was made available through a scoring system

similar to APACHE. Efficient communication between physicians, families and patients was established through liaison nurses who are highly trained, highly motivated and available. These nurses helped to elicit and document patient preferences and communicated the prognosis and desires among the team members. In Phase One it was ascertained that these patients were seriously ill as there was a hospital mortality rate of 27% and 48% had died by six months. The prognostic estimate was that 52% of the patients would die within six months. Discussions were uncommon between physicians and patients/families. Nearly half the DNR orders were written just two days before death. Half the patients spent more than 8 days in undesirable states before death. Half of the patients were in moderate to severe pain. In Phase Two there were no statistically significant differences in the odd ratios for the number of days before death after a DNR order was written, agreement between physician and a patient concerning DNR, undesirable days to die, pain or cost. In fact physicians misunderstood patient's preferences about DNR 80% of the time. They did not honor refusal of interventions and a DNR order was actually only written in half of the patients who wanted such an order to be written. An editorial by Lowe (11) commented why the SUPPORT intervention was ineffective. He felt that physicians did not use the statistical probability as an estimate of prognosis. One of the major issues was that physicians did not hear of patient preferences nor pain despite the fact that the nurse liaisons were established to improve communications. He also pointed out since 1/2 survived six months and 3/4 survived hospitalizations, the situation was not hopeless. It is also clear from many other studies that patients with the "50/50 chance" are the hardest to deal with because their clinical appearances are nearly identical for weeks to even months.

These studies confirm that we have made little or no progress in facilitating understanding of patients preferences by the physicians and having physicians insure that patients' wishes are carried out concerning withdrawing care. We must also insure that the process is done appropriately and does not abandon the patient and family. One would think that advance directives would facilitate this communication and that a salutary resource related side effect might accrue because unwanted treatments would not be given; thus the patients' final hospitalization would not be excessively long if there were nothing to be gained. This was examined by Chambers et al (12). Patients were studied on their last admission. Nearly 3/4 of the 474 patients had no advance directive or discussion documented in the chart; the hospital

bill was \$95,000.00. Of the 28% who had an advance directive, the hospital bill was \$30,000.00. If this represents limitation of treatment because of the patient's preferences then the advance directive could be considered to represent expression of enhanced physician -patient communication. On the other hand, forcing people to sign advance directives so that treatment might be limited is a spectre that is clearly worrisome. More recently Kollef (13) reviewed 159 patients deaths in an academic tertiary care MICU. Withdrawal of treatment was 2.5 times more likely if there were no attending. Patients with attendings had higher costs and charges. While it was not clear, there were some ominous possibilities considered: private attendings extend dying for profit, private attendings do not know when to stop treating patients, death of a private patient is seen as a defeat. On the other hand, I would hope that uncertainty, personal involvement and a desire to succeed are more likely to be motivating forces for continuing care than profit.

It appears that the general public and the judicial process have responded to our lack of ability to fulfill our responsibility to alleviate suffering and insure that patients die without extension of unwanted treatment and without suffering. Because we have failed to carry out the patient - physician relationship and provide that last measure of caring, two new alternatives have arisen and are attaining legal status. The first is physician-assisted suicide reviewed by Annas (14) states that "the debate over physician-assisted suicide has dramatically shifted into a discussion of constitutional issues. In 1997, within a month of each other, US Circuit Courts of Appeals on both coasts ruled that state prohibitions of assisted suicide are unconstitutional when applied to physicians who prescribe lethal medication for terminally ill, competent patients who wish to end their lives." The Ninth Circuit on the West Coast opinion created a new constitutional right: the right to determine "the time and manner of one's own death" based on the due process clause of the 14th Amendment. The 2nd Circuit covering New York, Connecticut and Vermont, opinion found a new constitutional right underlying a doctor's lethal prescription based on the equal protection clause of the 14th Amendment. This clause requires states to treat people who are similarly situated in a similar manner. The court did this by making two related assertions: the right to refuse treatment is the same as the right to hasten death and there is no distinction between a person who is dependent on life support equipment and one who is not. Orentlicher (15) argues that assisted suicide has been prohibited not because it is meaningful different from withdrawing life sustaining

treatment but because it served as a means of distinguishing between morally acceptable and morally unacceptable decisions by patients to end their lives. In this view, assistance with suicide is not only compatible with a physician's role but quite possibly an obligation. He does feel that the changes in law have brought society's legal rules more in line with society's moral reasoning.

The issues thus have changed from the Quinlan case in which physicians were afraid that they might be prosecuted for murder in withdrawing treatment through establishment of legal and ethical guidelines to enhance patient autonomy so that dying need not be extended. Now because we have failed to recognize the fear of prolonged dying and suffering, the people are pushing into new ground wherein physician-assisted suicide would not only be available to terminate unbearable suffering but would be available on demand. I would like to examine the implicit contract between society and the medical profession in the past, and try to pinpoint why recent technological changes have resulted in the conflict between these frames of reference which previously, at least on the surface, seemed free of major confrontation or incompatibility.

The Edwin Smith Surgical Papyrus is, perhaps, the oldest existing medical document (16). It was scribe-copied about 1600 B.C.E. from a much older document, possibly dating as early as 3000 B.C.E. It is a collection of 48 case descriptions but, of greatest importance for our consideration, each case is classified by one of three different "verdicts", the term used to describe the diagnosis: a) "an ailment which I will treat;" b) "an ailment with which I will contend;" or c) "an ailment not to be treated." Thus, in the earliest medical documents physicians were cautioned to recognize those ailments which were beyond their curative powers. One of the problems in the ICU today is that we have lost the ability to distinguish and separate these ailments. The definitions of treatment and therapy both contain the expectation that cure is possible. If we could recognize an ailment that "ought not be treated," we would realize that the term "life support" is misapplied; our intentions are futile as true therapy and can only prolong the patient's dying. However, this distinction is not clear and certainly is not fully accepted by either the medical profession or society in general.

We must direct our efforts to understand the relationship between society's values and the goals of medicine; this has been well described by Ernie Young (17). The goals of medicine, the preservation of life, and the alleviation of suffering, are respectively derived from societal values of

both the sanctity and quality of life. Today these two societal values are often in conflict. Because the passage from dying to death may almost be suspended through the application of technology, resolution of the conflict is now necessary. Prior to life support, death rapidly followed the onset of dying and there was “no real problem”. Of course, the conflict existed; however, it was so rare or short-lived that nothing needed to be done about it. However, resolution did not occur; the conflict simply disappeared with the death of the patient. Now, the prolongation of dying and suspension of death, at least for potentially long periods of time, force recognition and resolution. We must make a choice. There seems to be an increasing awareness that sanctity and quality of life may not be attainable at the same time; there is a conflict between the preservation of life and the alleviation of suffering.

Furthermore, the right of a competent patient to determine treatment, autonomy, has become increasingly well recognized both ethically and legally, leading to an increased awareness of the elements necessary to have truly informed consent. The three vital elements are: disclosure by the physician, understanding by the patient, and a free choice (18). All three elements often lack a comfortable degree of certainty in the ICU. When we speak of a distinction between critical illness (a reasonable prospect of recovery) and dying (a patient whose disease process is irreversible), we have no way to do so conclusively. Most often, we act on consensus among treating physicians, gained from observation over time, about the trajectory of the patient’s clinical course. This lack of certainty may make it even more difficult to explain the situation to the patient or the family.

The second element is equally difficult. Note that disclosure alone is not enough but that we must assure ourselves that the information is understood by the patient or in the case of an incompetent patient, by the family. This, too, is problematic. If the illness is unexpected or unexpectedly acute, as may occur in trauma or a devastating complication suffered during the course of elective surgery, the patient, of course, may be incompetent and the family may be incapable of understanding even the most lucid and careful explanation. One of the most primitive but temporarily effective defense mechanisms is that of denial (19). Oftentimes, we could have obtained information directly from the patient concerning his or her values so when a choice would become necessary, it could be based upon information directly supplied by the patient. In addition to living wills and durable powers of attorney, oral declarations are considered valid in some jurisdictions. It is of more

importance to remember that many patients with chronic illness could be questioned about their thoughts and values regarding prolonged ICU care and the inevitability of death - when they are still competent, that is, prior to hospitalization, upon admission to the hospital or even at the beginning of their ICU stay. The element of choice, too, is problematic in the ICU, especially for incompetent patients, but we can often obtain information from the patient or family concerning the patient’s previously identified values and expressed wishes concerning quality of life decisions.

Current HCFA regulations state that patients must be informed of their rights concerning Advance Directives and the hospital’s policy concerning honoring Advance Directives on admission. While this has had a minor influence upon the percentage of patients who have actually filled out Advance Directives, we should encourage such discussions with patients and families, including our own families. I developed a format which contains different scenarios in order to explore the patients’ wishes in some detail. It has been prepared to allow for expression of each person’s preferences and uses the US Supreme Court standard of “clear and convincing evidence” as justification of quality of life choices. It is appended for your own perusal.

Interestingly, recent studies of geriatric populations have shown that only about a third of elderly patients, in the absence of any knowledge about the effectiveness of CPR, indicate that they would want CPR if their heart or breathing should stop. Furthermore when told that the prognosis for in-hospital cardiac arrest was approximately 15%, half of those who had chosen CPR then declined. Placed in a scenario of chronic illness with superimposed acute illness in which the likelihood of successful CPR was reduced to 5%, almost all patients opted for a DNR order. We must be aware that the presentation of accurate information concerning likely outcomes of CPR may enable patients to make more appropriate choices.

Now we can align our goals of care with societal values for this patient both prior to and after our recognition that further medical care will be fruitless, that is to say, the patient’s condition is irreversible(17). Up to this point of recognition of irreversibility, care is appropriately directed toward cure. Our therapeutic efforts can be successful and we should strive for the preservation of life in concert with the societal value of sanctity of life. When the disease process is considered irreversible, when our care cannot achieve cure, it is all too easy to sense failure and frustration,

but we actually have new and important goals for our caring efforts. Armed with conclusive knowledge of the irreversibility of the patient's disease and specific information relating to this patient's perceived quality of life, our continued care aligns the alleviation of suffering with the societal value of the quality of life. Pain and anxiety should be relieved, of course, but we must extend the concept of the alleviation of suffering to include efforts (20) to aid the patient and family in adjusting to the nearness of death. However it is frequently impossible to decide whether continued care may be successful or whether the patient is beyond the point of response to medical intervention and thus further care might be considered futile. In these situations we must simultaneously proceed with both aspects of care. Medical intervention should be continued and discussions with the patient (if competent) and family should proceed exploring the possibility that death may be inevitable. I have found it useful to say that we are on a road leading off into the distance. It is foggy and no signposts are visible to tell us which road we are on. However as we proceed, signposts will become visible and we will know where the road will lead us. I then list signposts that can be easily understood as leading to recovery and also those which lead to death. For instance, resolution of respiratory failure and extubation clearly are positive whereas worsening renal failure, particularly oliguric renal failure in association with cardiovascular dysfunction and sepsis has essentially 100% mortality rate. As care continues, and the signposts do become visible, families will already be prepared and even have expressed to me that the point of futility has arrived. When cure cannot be achieved, dying itself should not be prolonged with technology. If life cannot be extended with dignity and purpose, meaningless prolongation of dying is the inevitable outcome. This costly and ineffective utilization of resources during a patient's dying is neither necessary nor desirable for medicine, the patient, or society.

When the point of futility has been reached, we should also examine all the medications, interventions, testing and treatment which may be continued and actually prevent a peaceful death. For instance, arrhythmias, hypotension, hyperglycemia or other forms of hyperosmolar coma including renal failure have little suffering associated with them. However dyspnea, nausea and vomiting, pain and other symptoms may cause great distress and suffering. Accordingly medications such as anti-arrhythmics, digoxin, anti-coagulants and insulin might be discontinued because patients do not develop distressing symptoms. Positioning

the patient for X-rays and blood drawing are never comfortable and should be stopped. Endotracheal suctioning always is at the top of lists of patients' bad memories of the ICU experience. It is up to the physician to examine all of the so-called treatment modalities including medications, diagnostic testing and "routine patient care procedures" in order to minimize suffering in all of its aspects and allow fewer distressing events to occur while a patient is dying.

Many individuals, including physicians, nurses and families are unsure of when to stop; exactly what to do and how to withdraw treatment. We have tried to create explanations and specific orders to be sure that all involved feel secure and that the patient's dying is without any signs of suffering. Remember first, that most state laws have restrictive definitions of the conditions in which withdrawal or withholding life support are permissible. For instance in both Florida and Connecticut (the two venues in which I have practiced), the laws state that withdrawal and withholding can be applied to patients in "terminal condition" and patients who are "permanently unconscious". A terminal condition means the final stage of an incurable or irreversible medical condition which, without the administration of a life support system, will result in death within a relatively short time, in the opinion of the attending physician. Permanently unconscious is defined in Connecticut law as permanent coma and persistent vegetative state and means an irreversible condition in which the individual is at no time aware of himself or the environment and shows no behavioral response to the environment. (21) The Law is then explicit with regard to Liability; "Any Physician... or any licensed medical facility who or which withholds, removes or causes removal of a life support system of an incapacitated patient shall not be liable for damages in any civil action or subject to prosecution in any criminal proceeding for which withholding or removal, provided: (1) The decision to withhold or remove such life support system is based on the best medical judgment of the attending physician, in accordance with the usual and customary standards of medical practice; (2) The attending physician deems the patient to be in a terminal condition or a consultation with a physician qualified to make a neurologic diagnosis who has examined the patient, deems the patient to be permanently unconscious; and (3) The attending physician has considered the patient's wishes concerning the withholding or withdrawal of life-support systems. Section 19a-573 titled Comfort Care and Pain Alleviation to be provided, also states "... comfort care and pain alleviation shall be provided in all cases".

Subsequent to the development of new recommendations for withdrawing life-sustaining treatment by the Bio-ethics committee and Directors of ICUs at the University of Miami Jackson Memorial Medical Center, a similar approach was published in February 1997 in the *New England Journal of Medicine*.(22) One of the issues that has been most problematic concerns artificial nutrition and hydration. Not only has it been difficult to convince healthcare professionals that it is appropriate to withdraw tube feedings and intravenous nutrition and even fluids, but it has been problematic for legislators. In fact 10 years ago, tube feedings and intravenous fluids were excluded from the list of treatments that could be withdrawn. An ethical and finally legal resolution occurred when consensus developed that artificial nutrition and hydration were medical treatments no different from ventilatory support or vasoactive agent infusions. They should not be considered part of society's obligation to feed and nourish the aged and infirmed, as is done for infants. Brody et al state "emerging consensus suggests that seriously ill or dying patients experience little if any discomfort upon the withdrawal of tube feedings, parental nutrition or intravenous hydration - perhaps because of the release of endogenous opioids or the analgesic effects of ketosis. Indeed, some terminally ill patients who prefer to refuse nutrition but felt obligated to eat to please their families, suffered abdominal discomfort and nausea." Compelling case reports illustrate the high level of comfort and satisfaction among patients that may accompany dying after refusing nutrition and hydration, even in rare cases in which survival is prolonged. They then list disorders symptoms in management in two excellent tables that are summarized here.

MANAGEMENT OF SYMPTOMS ASSOCIATED WITH WITHDRAWAL OF THERAPY

Figure 1

Underlying Disorder	Resulting Symptom	Management
Hypervolemia	Dyspnea	Permit oral fluids; if dyspnea occurs, administer oxygen, morphine, or topical or oral vasodilators.
Uremia	Gastritis Pruritus	Antacids, histamine-receptor antagonists. Oxygen, morphine, sedation.
Dehydration	Thirst (rare)	Sips of fluids.
Dehydration	Dry mouth (common)	Glycerine swabs, ice chips, sips of fluid. Artificial saliva, petroleum-jelly lip balm.
Oral inflammation	Pain, irritation	Diphenhydramine liquid, viscous lidocaine; antimicrobial therapy.

Perhaps more recent data concerning actual practice can help clinicians choose withdrawal of life support in appropriate situations. Luce (23) reported the results of the prospective survey conducted in 1994 and 1995 of 167 ICUs associated with training programs in critical care medicine. Data from 6,110 deaths in the 107 sites, revealed that 25 % occurred following full ICU care and failed CPR, 23% of patients received full ICU care but had CPR excluded, 13% had some form of life support group withheld, 33% of deaths followed withdrawal of life support and 6% were brain dead. Thus only 25% of patients died in the "classic" ICU manner: full support including CPR. Further, there was significant variability among units with regard to failed resuscitation (from 4% to 79% of deaths) and willingness to withdraw life support (from 6% to 71%). Although significant heterogeneity existed, 3/4 of the patients had some form of therapy withdrawn or withheld and more than 1/2 died because therapy was withdrawn or withheld.

RECOMMENDATIONS FOR WITHDRAWING LIFE-SUSTAINING TREATMENTS

INTRODUCTION

In order to provide terminal care which is competent and compassionate the following recommendations are offered as a guide to withdrawing life sustaining treatments:

- I. Discussions with the patient/family/proxy about the process of withdrawing life-support.

Enlist Pastoral Care or Social Services as desired. Emphasis should be given to the patient and their family/proxy that the health care providers will not abandon the patient and will continue to provide all measures to enhance the patient's comfort and respect their dignity. These discussions should

include information about the use of analgesics and anxiolytics for the purposes of relieving pain and suffering and the recognition that these may have as side effects reduction in mentation, blood pressure, and respirations. The patient/family/proxy should be informed about the variable time that may elapse before death occurs. They should be offered alternative ways for saying their "good-byes" (e.g. going home, staying in the waiting room, remaining at the bedside).

II. Certification of terminal illness (Florida Law requirement)

Once these discussions have occurred and the process agreed upon, certification of terminal illness should be written in the progress note by two licensed physicians (one of which is actively involved in the care of the patient).

III. Considerations in choosing drugs and dosages necessary

Experience in this hospital in providing analgesia and freedom from suffering during the process of withdrawing life sustaining treatments has shown that the doses that are necessary to eliminate signs of distress or suffering are often many fold higher than the doses used just to relieve pain. When prescribing the initial doses, take into account what drugs and doses have been used to this point as many patients have been treated with high levels already and may have developed tolerance. For patients who have not been receiving high doses previously, 5 - 10 mg of morphine sulfate intravenously and 2 mg of ativan may be given as pre-medication. Do not hesitate to use 2 or 3 times these doses if pre-medication fails to produce sedation even before treatment has been discontinued.

Additional doses of morphine as high as 300 mg within 30 minutes have failed to relieve distress and suffering. Be prepared to change agents as well as to increase doses.

Propofol, a fast acting sedative which can actually be used as an anesthetic agent, may be a helpful adjunct in attaining control of respiratory distress and signs of suffering. Initial doses range from 25 - 50 mcg/kg/min. As a point of reference, when propofol is used to produce general anesthesia, dosages are typically in the range of 120 - 140 mcg/kg/min.

Physicians and nurses must be prepared to increase doses and add agents quickly. The higher ranges are mentioned to facilitate escalation of doses rapidly enough that neither the patient nor the family sense distress.

IV. See Attached List of Physician's Orders

V. Pronouncement of patient's death

Pronouncement of death, time and documentation in the chart.

**PHYSICIAN'S ORDER SHEET
WITHDRAWING LIFE SUSTAINING
TREATMENTS**

The Supreme Court delivered its ruling on June 26th, 1997. From the decision in *Washington v. Glucksberg*, Chief Justice Rehnquist's opinion stated, "The question presented in this case is whether Washington's prohibition against causing or aiding a suicide offends the 14th Amendment to the United States Constitution. We hold that it does not." Further, his decision, from the decision in *Vacco v. Quill* stated "the question presented by this case is whether New York's prohibition on assisting suicide therefore violates the equal protection clause of the 14th Amendment. We hold that it does not." The decision emphasized that the opposition to and condemnation of suicide are consistent and enduring themes of our philosophical, legal and cultural heritages. They further state that the history of the law's treatment of assisted suicide in this country has been and continues to be one of the rejection of nearly all efforts to be permitted. "That being the case, our decisions lead us to conclude that the asserted 'right' to assistance in committing suicide is not a fundamental liberty interest protected by the due process clause. Rehnquist's opinion stated, "Throughout the nation, Americans are engaged in earnest and profound debate about the morality, legality and practicality of physician assisted suicide. Our holding permits this debate to continue, as it should, in a democratic society."

Thus, once again, a constitutional right to assisted suicide has been denied. The tragic implication is that, although many patients can receive adequate pain relief if only physicians and other healthcare providers will prescribe and administer sufficient quantities of these medications, many patients will continue to suffer. They will suffer because physicians and nurses are unable to utilize medically appropriate doses and the frustration of the patients and families translates into efforts to obtain relief, particularly in end-of-life situations when unbearable suffering has no value or meaning to patient, family or society. The appeal to the courts is recognition of the failure of the healing professions to exercise the strong ethical and moral positions that enable us to relieve suffering in most instances. This is possible today.

As we have seen, the legal issues in the United States have been clarified by the recent Supreme Court decision that upheld the states' right to forbid physician-assisted suicide on a constitutional basis. As we all know, Jack Kevorkian continues to go unpunished for his activities and the emotional debate in the United States truly typifies the cliché that there is more heat than light concerning the issue. Some claim that the healing profession should never be involved in death and even a single step taken towards the legalization of physician-assisted suicide would force us on a slippery slope leading to abuses that horrified the world in Nazi Germany. Yet throughout much of this debate, euthanasia and physician-assisted suicide have been practiced in the Netherlands and there have been dispassionate reviews of the results of the standards that have allowed these practices, although technically they remain illegal.(24) The number of reported cases increased from 486 in 1990 to 1466 in 1995. 43,000 total deaths occurred in a five month period. During the five year period, there was a 37 percent increase in the number of requests for euthanasia; there were 34,500 requests in 1995 for both euthanasia or assisted suicide later in the disease and 9,700 explicit requests at a particular time. However, as a percent of total deaths, euthanasia was 2.3 percent; physician-assisted suicides 0.4 percent; ending of life without an explicit request 0.7 percent; opioids in large doses 14 percent. It appears that 3.5 percent of requests led to euthanasia or assisted suicide. Euthanasia and assisted suicide predominantly involved patients with cancer (80%).

A companion article (25) evaluated a notification procedure in the Netherlands. The Assembly of Prosecutors General decides whether to prosecute. Of 6,324 cases, only 13 involved prosecution of the physician. 9 physicians were acquitted, mostly because their actions were deemed medically necessary; 2 were discharged from further prosecution, 3 were found guilty but not punished, and 6 were given suspended sentences of one to six months.

Continuing investigations in the Netherlands, psychiatric practice in physician-assisted death was investigated more recently. (26) In 1994 the Dutch Supreme Court ruled that in exceptional circumstances, physician-assisted suicide might be justifiable for patients with unbearable mental suffering but no physical illness. The authors calculated there are approximately 320 requests a year in psychiatric practice and 2 to 5 assisted suicides. The study concluded that in Dutch psychiatry there is a rather liberal attitude toward physician-assisted suicide in psychiatric patients but a very reluctant practice.

The tentative steps to establish a legal process for euthanasia and physician-assisted suicide in the United States has usually included a requirement for psychiatric consultation to eliminate treatable causes of depression. Another recent article has examined this association in the United States. (27) In the Netherlands, only 3 percent of physicians ask for psychiatric consultation. In the Oregon Death with Dignity Act, approved by voters in 1994, before honoring a patient's request for a lethal prescription, the primary physician must refer the patient to a psychiatrist or psychologist if the physician believes a psychiatric disorder may be present. Only 6 percent of psychiatrists are very confident they can determine, in the context of a single consultation, whether a mental disorder is influencing a person's decision to request physician-assisted suicide. Furthermore, they felt that presence of depression does not always invalidate a voluntary choice and successful treatment of a major depressive disorder increases the desire for life-sustaining therapy in only a minority of patients.

CONCLUSION

It is a common axiom that to learn about the future we must often return to a study of the past. We must re-emphasize the marvelous therapeutic quality of the physician/patient relationship, the principal tool possessed by our predecessors - to recognize when we should not treat. For the patients who survive, we can make the experience less fearful. A sympathetic approach will help, but we should strive to diminish their dependency when possible by giving them some control. For the dying patient, we will supply the only needs which matter and can be met, an easing of the lonely, frightening, and often painful transition to death. For society, we will preserve scarce resources. For ourselves, as professionals, we must learn the fundamentals of the art of medicine. Effective decisions for clinical care, at this point in time, still depend primarily on the processor, a knowledgeable and caring physician.

LIVING WILL

YOU MAY ADD, CHANGE OR CROSS OUT ANY WORDS ON THIS FORM

I, _____, have a right to life-prolonging procedures including food and water (nutrition and hydration) and I also have a right to have life-prolonging procedures stopped or no new ones started. I can choose someone to do this for me if I am unconscious, in a coma, incompetent, or otherwise mentally or physically incapable of making my wishes known.

Patients are talking - and we'd BETTER listen!

I understand that treatments or medications which take away pain, suffering, anxiety or other forms of distress will not be withheld or withdrawn (even if they hasten my death).

By signing below, I hereby choose _____, whose telephone numbers are _____ (work) and _____ (home), and whose address is _____ as my health care agent.

By signing below, I hereby choose _____, whose telephone numbers are _____ (work) and _____ (home), and whose address is _____ as my alternate health care agent.

I would like my designee, (if I have named one), my health care or residential facility, physician, or other health care provider, to read my answers to the following questions and use my answers to help them carry out my wishes if I am unable to do that myself.

1. If I have a terminal condition, from which I will probably not recover or survive and my death will likely occur within weeks,

1. I would want life-prolonging procedures to be:
_____ withheld/withdrawn _____ continued

2. I would want artificially administered food and water such as tube or intravenous feedings to be:
_____ withheld/withdrawn _____ continued

3. If my heart or breathing stopped, I would want my doctor to try to restart it through CPR or other means:
_____ YES _____ NO

4.

1. If I have a medical condition that is steadily getting worse and my doctor has told me that there is no reasonable possibility of recovery, but I could survive in this condition for weeks or even months,

1. I would want life-prolonging procedures to be:
_____ withheld/withdrawn _____ continued

2. I would want artificially administered food and water such

as tube or intravenous feedings to be:

_____ withheld/withdrawn _____ continued

3. If my heart or breathing stopped, I would want my doctor to try to restart it through CPR or other means:
_____ YES _____ NO

1. If I am in an irreversible coma, persistent vegetative state or other condition where my doctor has determined that there is no reasonable medical likelihood I will ever be awake or to make medical decisions for myself again,

1. I would want life-prolonging procedures to be:
_____ withheld/withdrawn _____ continued

2. I would want artificially administered food and water such as tube or intravenous feedings to be:
_____ withheld/withdrawn _____ continued

3. If my heart or breathing stopped, I would want my doctor to try to restart it through CPR or other means:
_____ YES _____ NO

1. If I must live in a hospital or nursing home for the rest of my life because I am unable to feed or groom myself or take care of my other bodily functions such as responding to my toilet needs,

1. I would want life-prolonging procedures to be:
_____ withheld/withdrawn _____ continued

2. I would want artificially administered food and water such as tube or intravenous feedings to be:
_____ withheld/withdrawn _____ continued

3. If my heart or breathing stopped, I would want my doctor to try to restart it through CPR or other means:
_____ YES _____ NO

1. If I have progressive or permanent memory loss such that I am no longer able to recognize my family and friends or communicate my thoughts to others,

1. I would want life-prolonging procedures to be:
_____ withheld/withdrawn _____ continued

2. I would want artificially administered food and water such as tube or intravenous feedings to be:
_____ withheld/withdrawn _____ continued

Patients are talking - and we'd BETTER listen!

3. If my heart or breathing stopped, I would want my doctor to try to restart it through CPR or other means:

_____ YES _____ NO

1. If I am in the hospital with a serious condition and my doctor and I have decided to continue treatment because we believe it may be effective and treatment seems to be going well, if my heart or breathing unexpectedly stopped, I would want my doctor to try to restart it through CPR or other means:

_____ YES _____ NO

1. In my current state of health, if my heart or breathing unexpectedly stopped, I would want my doctor to try to restart it through CPR or other means:

_____ YES _____ NO

2. If I am pregnant I want the instructions I have given above to be followed, prior to the time that my fetus is determined to be viable:

_____ YES _____ NO

If not, please give any alternative instructions here:

I understand that I can make quality of life choices. I am not asking anyone else to make quality of life choices for me. This document merely serves to provide clear and convincing evidence of the quality of life choices I have made. If, in the course of making decisions for me, my health care agent is dissatisfied with any determination of my attending physician, my health care agent may substitute another attending physician.

If I cannot make medical decisions for myself, I want the directions in this Declaration to be accepted and fulfilled as the final expression of my legal right to accept or refuse medical or surgical treatment and to accept the consequences of my decisions.

I understand the full import of this Declaration, and I am emotionally and mentally competent to make this Declaration.

By executing this Declaration, I am revoking all prior Declarations.

Date Patient

In signing this Declaration on the date noted above, I state that the declarant is known to me and I believe him/her to be of sound mind. I certify that I am not the declarant's health care agent as named in this document.

Witness

In signing this Declaration on the date noted above, I state that the declarant is known to me and I believe him/her to be of sound mind. I certify that I am not the declarant's spouse, blood relative or health care agent as named in this document.

Witness

ORGAN DONATION

In the hope that I may help others, and if I am medically acceptable, after my death, I wish to give the following to those suffering organ failure:

1. _____ any needed organs or parts.

1. _____ only the following organs or parts: _____

For the purposes of transplantation, therapy, medical research, or education. I authorize that physiologic interventions directed at preserving organs for transplantation be maintained until death has been declared. I further authorize that any and all tests be performed to determine the viability and safety of the organs. I understand that there are no costs to me, my family, estate or insurance companies for the tests and procedures.

_____ Agree

_____ Disagree

_____ Undecided

Date Patient

Witness Witness

References

1. Campi CW: When Dying Is as Hard as Death. The New York Times on the Web January 5, 1998.
2. D'Honau MM: "On Machine": His Doctors Avoided the Dying Patient's Agony. CT MED 1998; 62:349-351.
3. Paulson J: Bitter Pills to Swallow. NEJM 1998; 338:1844-1846.
4. Hanson LC, et al. What is Wrong with End-of-Life Care? Opinions of Bereaved Family Members. JAGS 1997; 45:1339-1344.
5. Royal North Shore Hospital. Withdrawing and Withholding Treatment Policy and Guidelines. 1998.
6. Malacrida R, et al. Reasons for dissatisfaction: A survey of relatives of intensive care patients who died. Crit Care Med 1998; 26:1187-1192.
7. SCCM Ethics Committee Attitudes of Critical Care Medicine Professionals Concerning Foregoing Life Sustaining Treatments. Crit Care Med 1992; 20:320.
8. Caralis P, Hammond J: Attitudes of medical students, housestaff and faculty physicians towards euthanasia and termination of life support. Crit Care Med 1992; 20:683.
9. Cook D et al: Determinants in Canadian healthcare workers of the decisions to withdraw life support from the critically ill. JAMA 1995; 273: 703.
10. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). A controlled trial to improve care for seriously ill hospitalized patients. JAMA 1995; 274:1591.
11. Lowe B: Improving care near the end of life, why is it so hard? JAMA 1995; 274:1634.
12. Chambers et al: Relationship of advance directives to hospital charges in the medicare populations. ARC Intern Med 1994; 154:541.
13. Kollef M: Private attending physician status and withdrawal of life sustaining interventions in the medical intensive care population. Crit Care Med 1996; 24:968.
14. Annas G J: The promised end - constitutional aspects of physician-assisted suicide. NEJM 1996; 335:683.
15. Orentlicher D: The legalization of physician-assisted suicide. NEJM 1996; 335:663.
16. Hook D: The Edwin Smith surgical papyrus. In: Bulletin of the Cleveland Medical Library Association. Partington MM (Ed.) Cleveland, 1973; 22.
17. Young EWD: Life and death in the intensive care unit: Ethical considerations. In: Critical Care, 3rd Edition. Civetta JM, Taylor RW, Kirby RR (Eds.. Philadelphia, Lippincott-Raven Publishing, 1997; 5:63.
18. McCollough LB: Informed consent and refusal. In: Critical Care, 3rd Edition. Civetta JM, Taylor RW, Kirby RR (Eds... Philadelphia, Lippincott-Raven Publishing, 1997; 6:81.
19. Barnhill GW: Understanding Reactions of Patient and Family. In: Critical Care, 3rd Edition. Civetta JM, Taylor RW, Kirby RR (Eds... Philadelphia, Lippincott-Raven Publishing, 1997; 7:89.
20. Wanzer, Federman, Adelstein et al: The Physician's Responsibility Toward Hopelessly Ill Patients. New Engl J Med 1989; 320(13.:844
21. Connecticut Public Health and Well-Being: Title 19a, Chapter 368w, Removal of Life Support Systems: 888.
22. Brody H, Campbell ML, Faber-langendoen K, Ogles K. Withdrawing Intensive Life-Sustaining Treatment -- Recommendations for Compassionate Clinical Management. NEJM 1997; 336:652-657.
23. Luce JM, Withholding and Withdrawing of Life Support: Ethical, Legal and Clinical Aspects. New Horizons 1997; 5:30-37.
24. Van der Maas PJ et al, Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995. NEJM 1996; 335:1699-1705.
25. Van der Wal G et al, Evaluation of the Notification Procedure for Physician-Assisted Death in the Netherlands. NEJM 1996; 335: 1706-1711.
26. Groenewoud JH et al, Physician-Assisted Death in Psychiatric Practice in the Netherlands. NEJM 1997; 336:1795-1801.
27. Ganzini L, Lee MA, Psychiatry and Assisted Suicide in the United States. NEJM 1997; 336:1824-1826.

Author Information

Joseph M Civetta, M.D.

Professor and Chairman, Department of Surgery, University of Connecticut Health Center