Chapter 27
Ethics in Palliative and End-of-Life Care

Jack M. Berger

Introduction

“Do the kind thing, and do it first,” said William Osler as advice to physicians (circa 1904) [1]. But in 1904 there were limited things that physicians could do for their patients with chronic pain or who were in need of care at the end of life. **William Osler in his Ingersoll Lecture 1904 entitled Science and Immortality (Houghton, Mifflin and Comp., Riverside Press, Cambridge 1904) stated**: “I have careful records of about five hundred death-beds, studied particularly with reference to the modes of death and the sensations of the dying…” “Ninety suffered bodily pain or distress of one sort or another…” (This is about 20%) [1].

Osler continued, “…eleven showed mental apprehension, two showed positive terror, while one expressed spiritual exaltation, and one expressed bitter remorse. The great majority gave no sign one way or the other; like their births, their deaths were as a sleep and a forgetting….” “As a rule, man dies as he has lived, uninfluenced practically by the thought of a future life…wondering but uncertain, generally unconscious and unconcerned” [1].

In Osler’s time, that’s how people died… a doctor could visit a patient and could tell the patient’s family that death was imminent. The doctor’s duty was then to provide comfort to the patient and the family, and to diminish suffering. The patient got plenty of Laudanum® and humane care.

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Extent of the Problem

Weiss et al. report that the number of seriously ill patients who experience "*substantial*" pain ranges from 36 to 75% [2]. And according to Jennings and his associates "***…too many Americans die unnecessarily bad deaths—deaths with inadequate palliative support, inadequate compassion, and inadequate human presence and witness. These deaths are preceded by a dying marked by fear, anxiety, loneliness, and isolation; deaths that efface dignity and deny individual self-control and choice***" [3]. So, we are not even doing as well as Osler over 100 years ago.

Defining Death

With advances in life support, the line between who is alive and who is dead has become blurred [4]. Thus, we need to define death in order to be able to declare a person physically and legally dead. In the first edition of *Encyclopaedia Britannica* "DEATH" was defined as the separation of the soul and body; in this sense death stood opposed to life, which consisted in the union of the soul and body [5].

The **Uniform Determination of Death Act (UDDA)**, written by the President's Commission on Bioethics in 1981, confronts the complexities concerning the declaration of death [6]. The UDDA wording specifically states: "An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all the functions of the entire brain, including the brain stem, is dead." In other words, the UDDA states that a person can be declared dead when ***either*** the heart and lungs ***or*** the brain and brain stem stop functioning permanently [7].

The problem today is not so much determining death but rather with our modern interventions, we can ***prolong the dying process*** (dialysis, ventilators, intravenous fluids, antibiotics, furosemide, etc.) and therefore, we are ***unable to recognize when death will occur***. It appears that we health care providers and physicians suffer from "Mural Dyslexia" defined as the inability to read the handwriting on the wall [8].

In their article, "Care of the dying: An ethical and historical perspective" published in Critical Care Medicine in 1992, Cowley, Young, and Raffin conclude that: "Despite the miraculous advances in medical theory and medical practice, ***the ethics*** surrounding medical care for the dying are more troubling today than they were in ancient Athens at the time of Plato [9]. In classical antiquity, the primary concerns were for health and living well. The 'Middle Ages' saw the emergence of the principle of sanctity of life. To these basic ideals, the 'Renaissance' and the 'Enlightenment' added the aspiration to prolong life. Finally, in the twentieth century, modern science has rendered this aspiration a reality of unclear merit" [9]. And we can expand that to include the twenty-first century now.

In making end-of-life decisions regarding symptom management and palliative care, one must have the ability to estimate accurately a patient's length of survival

(**LOS**) and improved quality of life. In 1994, Daas wrote that “we do not have the ability to accurately estimate LOS and that we have little knowledge or understanding of the end-stage illness experience” [10]. It is known that anorexia/cachexia in association with increased heart rate does correlate with the terminal cancer syndrome. Dysphagia, cognitive failure, and weight loss are highly correlated with shorter LOS, <4 weeks. The presence of ***pain***, although producing poor quality of life, does not contribute to decreased LOS in terminal illness [10].

According to Spiegel, Stroud, and Fyfe, here at the end of the twentieth century, the old adage, to “***cure rarely, relieve suffering often, and comfort always***,” **(Hippocrates) has been rewritten**: The doctor’s job has become ***to “cure always, relieve suffering if one has the time, and leave the comforting to someone else”*** [11]. They further state that the acute disease model, which emphasizes diagnosis, definitive treatment, and cure, works in many situations, but the leading killers of Americans—heart disease, stroke, and cancer—are by and large chronic and progressive rather than acute and curable [11]. Western Medicine’s success is also its weakness. The application of a curative model when disease management is all that can be given leaves doctors and patients dissatisfied [11].

Ethical Principles

In providing palliative and end-of-life care, one must consider Medical Ethics and Ethical Conduct, Moral Obligations, and Legal Responsibilities.

In end-of-life care, there are four guiding ethical principles which govern our decision making and care of patients. These are the same principles that guide us in the conduct of medicine in general.

- **Nonmaleficence** [11] (minimize harm) (Hippocratic oath)
- **Beneficence** [12] (do good if you can) (St. Thomas Aquinas thirteenth century)
- **Patient autonomy** [13] (respect for the patient as a person, informed consent) (Nuremberg trial of Nazis physicians who performed experiments on humans without consent)
- **Justice** [14] (fair distribution of available resources) (not everyone is entitled to everything that medicine has to offer when resources are limited)

In implementing the above principles the physician has to balance “Three Dichotomies.”

- The potential benefits of treatment must be balanced against the potential burdens.
- Striving to preserve life but, when biologically futile, providing comfort in dying.
- Individual needs are balanced against those of society.

Eric J. Casssel, in his article the “Nature of suffering and the goals of medicine,” stated “…The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to care of the sick. Physicians’ failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering, but becomes a source of suffering itself" [15].

Rule of Double Effect

At the end of life, providing pain relief can present a dilemma for physicians who operate under misconceptions of both the law and ethics. The "Rule of Double Effect" which is the moral doctrine taken from the teachings of St. Thomas Aquinas of the thirteenth century gives physicians the ethical duty and moral obligation to relieve pain and suffering [12]. Yet these philosophical arguments do not provide insight into the ambivalence that practitioners feel when they legitimately engage in these practices. Why should a physician feel ambivalence about doing the "***right thing?***"

With regard to palliation and comfort care, many clinicians are unaware of the current ethical and legal consensus regarding palliative care at the end of life. This consensus is built around ***the principle of the double effect***. The thrust of the principle is to ***focus on the intention*** of the caregiver in seeking to provide comfort to terminally ill patients, even if the clinician realizes that a side effect of the therapy could be an earlier death [14].

The principle of double effect continues to be an area of lively debate in bioethics, in part because of the ambiguous intentions of caregivers in treating patients at the end of life. For example, even when a physician has no desire to hasten the patient's death, the death of the patient may nevertheless be seen as a good or desirable outcome. Despite these ambiguities, however, the principle remains an ethical and legal touchstone around treatment of the terminally ill [14].

The US Supreme Court in ***Vacco v. Quill***, validated the rule of double effect when Justice Rehnquist stated that "It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient's death if the medication is intended to alleviate pain and severe discomfort, and not to cause death" [16].

In the ***Vacco v. Quill*** case, a landmark decision was reached by the Supreme Court of the United States regarding the right to die [16]. It ruled that a New York ban on physician-assisted suicide was constitutional and preventing doctors from assisting their patients in bringing about death, even those terminally ill and/or in great pain, was a legitimate State interest that was well within the authority of the State to regulate [16]. In brief, this decision established that, as a matter of law, there was no constitutional guarantee of a "right to die" [16]. But it also affirmed that a patient retains the ***Right*** to choose not to continue treatment, even life sustaining treatment, and that choosing to discontinue treatment or declining treatment is not equivalent in the eyes of the law to requesting a treatment to end life [16].

Not only is the rule of Double Effect well ensconced in the law, but also all of the major religions have doctrines that support this approach. The principle of double effect was initially developed in the Catholic tradition, from the teachings of St. Thomas

Aquinas in the thirteenth century [12]. Clinicians should, therefore, never withhold needed pain medications from terminally ill patients for fear of hastening their death through respiratory depression or other complications [12, 15].

The "Rule of Double Effect" states that an action having two effects, one good and one bad is permissible if five conditions are fulfilled:

1. The act itself is good or at least morally neutral, e.g., giving morphine to relieve pain.
2. Only the good effect is ***intended*** (relieving pain) and not the bad effect (ending the patient's life).
3. The good effect is not achieved through the bad effect (pain relief does not depend on hastening death).
4. There is no alternative way to attain the good effect (pain relief).
5. There is a proportionately grave reason for running the risk, e.g., relief of intolerable pain and suffering.

Clearly, to justify use of this rule, the patient or surrogate decision maker would need to be informed of the risks and give valid consent (***Principle of Autonomy***). It is clear that any patient coming for surgery is expecting that his/her physician will attend to the pain which results from the surgery including the use of opioids. If other forms of pain relief are to be used, such as epidural analgesia or peripheral nerve blockade, then additional consent discussions should be undertaken so that patients can make informed decisions about their pain management care.

According to the Rule of Double Effect, it is clear in end-of-life care that there are ethical and legal sanctions for the use of whatever doses of opioids that are necessary so long as death is not directly intended. If the doses of the opioids necessary to relieve pain are large enough to produce deep sedation, this too would be permissible, if suffering can be relieved in no other way.

Thorn and Sykes studied 238 consecutive dying patients [17]. In a retrospective study they found that there was no difference in survival between those patients requiring escalating doses of opioids versus those patients that were on stable doses of opioids [17]. Because of this finding, they concluded that the rule of double effect was not even needed to justify the use of opioids for the control of pain at the end of life, and this could be that the first two principles of ethical conduct, nonmaleficence and beneficence, are maintained [17].

Ethics and the Use of Opioids

Much of inadequate pain management, particularly in end-of-life care can be traced to lack of knowledge on the part of physicians. In a typical example, a physician was managing an end-stage AIDS patient who had a DNR status and a documented pain scores of 6/10 (10/10 on the verbal analogue scale is the worst possible pain imaginable). The patient was receiving 3 mg/h IV morphine infusion from which the physician stated, "***We must wean off the morphine. We're killing him***." The physician wanted to give naloxone to reverse the effects of the morphine and then remedicate the patient with 25 mg Meperidine IV q4 h PRN for pain control. What's wrong with this scenario?

- **3 mg/h of IV Morphine = 72 mg/day**
- **1 mg Morphine IV = 10 mg Meperidine IV**
- **72 mg Morphine = 720 mg Meperidine**
- **25 mg Meperidine q4 h = 150 mg/day**
- **The patient was already in moderate to severe pain at the current dosage which was already inadequate, and the Physician was reducing the dose by 80%. Further, by writing a PRN order, the physician was insuring that the patient would not even receive the 25 mg of Meperidine q4 h**

This is a classic case of "***Opiophobia***"—"*the unreasonable fear of opioid use, based on an inaccurate assessment of its dangers*." It affects patients as well as physicians and may be one of the greatest barriers to the provision of effective pain medication [18]. The 1993 California Medical Board Statement on the Prescribing of Controlled Substances stated that…Concerns about regulatory scrutiny should not make ***physicians who follow appropriate guidelines*** reluctant to prescribe or administer controlled substances, including Schedule II drugs, for patients with a legitimate medical need for them [19].

Likewise, the Federal Controlled Substances Act (**CSA**) does ***NOT*** address medical treatment issues such as the selection or quantity of prescribed drugs [20]. The US Supreme Court addressed these issues in the 1990s [21]. While the Court did not support either using drugs to terminate life or the legalization of drugs and controlled substances, it fully encouraged and supported adequate pain and symptom management, as reported in the New England Journal of Medicine in 1997: *A [United States Supreme] Court majority effectively required all states to ensure that their laws do not obstruct the provision of adequate palliative care, especially for the alleviation of pain and other physical symptoms of people facing death* [21].

The CSA regulates drugs, not the practice of medicine. **The practitioner's judgment, based upon training, medical specialty, and practice guidelines determines what may be considered *legitimate medical purpose, (DEA Policy Statement)*** [22]. According to the federal CSA, in order for a prescription to be valid, it must be issued for a legitimate medical purpose by an individual practitioner acting in the usual course of professional practice. A dentist, for example, cannot prescribe opioids for gynecological pain even though he/she has a DEA number.

Model guidelines for the use of controlled substances for the treatment of pain were developed jointly by the DEA and Federation of State Medical Boards of the United States and adopted May 2, 1998 [23, 24]. The purpose was: ***(to) protect legitimate medical uses of controlled substances while preventing drug diversion and eliminating inappropriate prescribing practices. Simply put, you have a license to drive your car but you have to recognize stop signs and traffic lights***.

Good faith prescribing requires an equally good faith history, physical examination and documentation {of benefit}. One can always be sued by a patient or the family claiming injury or the patient becoming addicted to opioids. One can always be manipulated or deceived by individual patients seeking to abuse opioid medications. But careful monitoring and particularly ***documentation of benefit*** will reduce these risks to both the physician and patient to a minimum.

Ethics in Decision Making

In providing symptom management and palliative care at the end of life, difficult decisions have to be made with respect to initiating therapeutic interventions or discontinuing interventions. There appears to be a great deal of discrepancy between what physicians state as to their biases for withdrawing life support measures and what they actually practice in real life. Asthenia, malnutrition, and cachexia are common in dying patients with advanced cancer. They may in fact be adaptive mechanisms which do not require intervention [25].

Enteral feedings can lead to pneumonia from aspiration or diarrhea from poor absorption. Parenteral feeding requires intravenous access, and there is no evidence for improved survival, no evidence for improved tumor response to chemotherapy, and no evidence of decreased chemotherapy toxicity. Decreased surgical complications with the use of total parenteral nutrition are debatable. In animal studies, there is evidence of actual enhanced tumor growth, and there is no evidence for enhanced quality of life or satisfaction of hunger [26].

Withdrawing Supportive Measures

In their study on “Biases in how physicians choose to withdraw life support,” Christakis et al. reported that in order of preference, physicians find it easier to withdraw or withhold treatments in the following order: blood products, hemodialysis, intravenous vasopressors, total parenteral nutrition, antibiotics, mechanical ventilation, tube feedings, and finally intravenous fluids [27].

These therapies correlate with the preferences to withdraw forms of therapy supporting organs that failed for natural rather than iatrogenic reasons, to withdraw recently instituted rather than long-standing interventions, to withdraw forms of therapy resulting in immediate death rather than delayed death, and to withdraw forms of therapy resulting in delayed death when confronted with diagnostic uncertainty [27].

In their report entitled Outcome of Cancer Patients Receiving Home Parenteral Nutrition, Cozzaglio et al. retrospectively studied patients with metastatic cancer who were treated with home parenteral nutrition [28]. They note that the use of parenteral nutrition in end-stage cancer patients varies from country to country [28]. In the USA, Japan, and Italy, 40–60% of all patients getting home parenteral nutrition have cancer while only 18% in France and 5% in the UK [8]. Cozzaglio et al. state that “the variance reflects a difference in cultural, ethical, social, and economic approaches to the problem, with a lack of a scientific basis resulting from the scarcity of specific literature" [28]. Cozzaglio et al. conclude that home parenteral nutrition does not benefit cancer patients with a Karnofsky score of <50 [28]. In those patients who were treated less than 3 months (Karnofsky <50) there was no benefit in quality of life improvement [28].

Since dyspnea is a subjective experience like pain, it has a complicated pathophysiology that is affected by physical, psychological, social, and spiritual factors. The involvement of the entire interdisciplinary team is essential for treating dyspnea effectively, particularly in the terminal stages of disease.

Hydration is another area that presents ethical problems for physicians in the dying patient. Too much hydration in a patient who is unable to eliminate the fluid can lead to pulmonary congestion and dyspnea, edema around encapsulated tumors leading to pain. Yet withholding fluids may make the family members uncomfortable or suspicious. One must explain to the family about the harmful effects of excess fluid and that if the patient is thirsty, he/she will tell the doctor or nurse. In dealing with pain or end-of-life care, we must make every effort to control pain, being mindful of the risks of our interventions, but at the same time not be afraid to take action.

Futility

Luce [29] discussed in detail the Consensus report on the "Ethics of Foregoing Life-Sustaining Treatments in the Critically Ill" prepared by the Task Force on Ethics of the Society of Critical Care Medicine and published in 1990 [30]. Much of Luce's discussion centers on the definition of futility of care. This term generally conveys the idea that a patient cannot benefit from treatment, that the patient's acute disorder is not reversible, that the patient will not survive the current hospital stay, or that the quality of the patient's life following discharge will be poor [31].

Many barriers to decision making center on misunderstandings of the legal aspects of withholding and withdrawing life support measures. As a result (according to Luce) the courts in recent years have underscored the right of patients to refuse treatment, affirmed the concept that human life is more than a biologic process that must be continued in all circumstances, defined how therapeutics may or may not benefit patients, argued against a distinction between the withholding and withdrawing of life support, established guidelines for limiting life-sustaining treatments, and approached the resolution of disagreements among physicians and patients or their surrogates [16, 31].

Generally the courts have ruled that most patients would accept or refuse medical therapy based on the ability of the therapy to support sentient life over mere biologic existence. Of course, it is always best if the patient is able to participate directly in informed decision making, but baring this the concept of "substituted judgement" is employed where family or surrogate decision makers speak for the patient, based on their intimate knowledge of what the patient would have wanted.

In Barber V Superior Court of California, 1983, the court did not distinguish between removing mechanical ventilation or removing fluids or nutrition because all were interventions that could either benefit or burden [32]. ***But the issue of futility of care was entered into court proceedings***. In a case in Boston at Massachusetts General Hospital, the Suffolk Superior Court decided that physicians and the hospital could discontinue life-sustaining therapy despite the objections of a patient or surrogate if further care was deemed futile [33]. This decision has not been tested in the appellate courts. But among ethicists and intensivists a consensus is evolving for physicians to have the medical responsibility and privilege to decide to limit care, even against the wishes of the patient or the patient's legal representative [34, 35].

An illness may well be incurable, but not necessarily terminal. *Terminal* is used herein to mean a condition that will directly and inexorably result in death within the foreseeable future. If the condition is also *incurable*, then death will result regardless of whether medical treatment is undertaken or not [36]. And thus would be considered ***futile***.

Surveys from ICU's in 1994–1995 involving 71,513 admissions indicate that 75% of the deaths involved patients in whom some form of limitation of treatment took place [37]. Therapies commonly withheld or withdrawn were cardiopulmonary resuscitation (CPR), mechanical ventilation, vasoactive drugs, antibiotics, renal dialysis, blood and blood products. Decisions to recommend withholding or withdrawal of therapies deemed futile depend often on the presence or absence of the "persistent vegetative state," as discussed by Waisel and Truog [37].

A presumptively terminally ill patient may request a therapy the clinician does not believe will be successful. Some hospitals have incorporated policies that permit physicians to unilaterally withhold treatments with a low likelihood of success [12]. Others recognize the inherent problems in determining qualitative and quantitative thresholds for futility judgments. For example, how low does the probability of success have to be for a therapy to be considered futile? How great a benefit must a patient receive from a therapy for that therapy not to be considered futile? How certain must physicians be of their predictions? [38]. How do the patient's values play into these determinations? [38]. Because these questions are difficult to answer, a growing trend is to step away from defining a specific policy to limit futile care and instead focus on individual benefits and burdens in the particular situations [39].

Principle of Double Effect

With regards to palliation and comfort care, many clinicians are unaware of the current ethical and legal consensus regarding palliative care at the end of life. As stated earlier, this consensus is built around the ***Principle of the Double Effect***. The thrust of the principle is to focus on the intention of the caregiver in seeking to provide comfort to terminally ill patients, even if the clinician realizes that a side effect of the medications or treatments could be respiratory depression and earlier death.

Comatose patients on ventilatory support look the same to family members as other patients, even though they may be in a persistent vegetative state or even brain dead. These patients may even be theoretically capable of reproduction which biologists sometimes cite as the ***sine qua non* of life**. Using a phrase such as “withdrawing life support” is not only incorrect but is also misleading, and potentially harmful to family members struggling with the diagnosis of brain death or persistent vegetative state. Life support cannot be withdrawn from a patient who is already dead, and such linguistic imprecision can confuse an already shaken family as to the meaning of the diagnosis. At this point, the only purpose of “life” support is to maintain homeostasis. (This section was taken out of context from Waisel and Truog but it fits with the concept of futility of care) [37].

Although individual convictions and religious beliefs should be respected and supported, maintenance of prolonged intensive care is expensive and State Laws differ in the degree to which they require clinical diagnosis to defer to religious conviction.

Palliative

As stated earlier, the goals of end-of-life care encompass symptom management for comfort. Palliative interventions may be necessary for improved comfort. Palliative care is defined as care that recognizes the inevitability of the patient’s death and therefore whose goal is to lessen, ease, and make less severe the patient’s suffering, without curing the disease. Symptom control of such things as pain, nausea/vomiting, constipation, dyspnea, etc., should be the goal [38].

A multidisciplinary or interdisciplinary team approach to end-of-life care is the most successful. Medical decision making such as withdrawal of treatments, total parental nutrition, ventilator support, and DNR discussions should be part of the duties of this palliative care team. In providing palliative care one must maintain a respect for life, while at the same time be able to accept the ultimate inevitability of death. The potential benefits of treatment must be balanced against the potential burdens of such treatment. The physician must strive to preserve life but, when biologically futile, provide comfort in dying. At the same time the physician must recognize that individual needs must be balanced against those of society [39].

Luce and Rubenfeld considered the question of whether costs could be reduced by limiting futile care [40]. The public must define futility if they are to accept limits on such care! But it is unrealistic to expect the lay public to accept this responsibility. Therefore, the healthcare profession must take the lead. Borrowing from the nursing profession “***Compassionate Stewardship***” is also part of physician behavior [41]. During 1993, an estimated 118 attempts at CPR were reported for 172 facilities with a total of 19,596 licensed beds, for a frequency of one CPR attempt per 166 beds per year in one survey [42].

Reductio ad Absurdum, having a 108-year-old man make a decision about CPR suggests the unreal and macabre. The level of competence to which patients should be held varies with the expected harms or benefits of acting in accordance with the patient's choice. A minimal level of decision making competence should be applied to a patient who consents to a lumbar-puncture for presumed meningitis. A maximum standard should be applied for a patient who refuses surgery for a simple appendectomy. CPR discussions held at the time of acute illness may lead patients and their families to believe erroneously that any last hope is being withheld.

Decisions About Cardiopulmonary Resuscitation and Do Not Resuscitate Orders

When patients were educated about CPR, 87% chose to forego CPR or allow the physician to decide if it was appropriate. When surveyed, patients consistently overestimated their chances of surviving CPR and survival to discharge. The physician must initiate discussion of CPR since no patients reported initiating the discussion themselves although most desired to have this type of conversation [43]. The general public has an inflated perception of CPR success. While most people believe that CPR works 60–85% of the time, in fact the actual survival to hospital discharge is more like 10–15% for all patients and less than 5% for the elderly and those with serious illnesses [44].

DNR Discussion

Although the techniques of CPR were originally intended only for use after acute, reversible cardiac arrests, the current practice is to use CPR in all situations unless there is a direct order to the contrary [45]. Since cardiac arrest is the final event in all terminal illness, everyone is eventually a candidate for this medical procedure [45]. DNR orders were developed to spare patients from aggressive attempts at revival when imminent death is anticipated and inevitable [45]. Nevertheless, patients or families sometimes request CPR even when care givers believe such attempts would be futile [45]. Some have argued that in these circumstances a physician should be able to enact a DNR order without consent of the patient or family [45, 46].

Many physicians feel "uncomfortable" about discussing DNR status with their patients. Regardless of this when a physician initiates such a discussion, the manner in which the discussion takes place could lead to a medical dilemma if not done appropriately. A proper discussion consists of two questions.

Question 1

"Would you want to be resuscitated in the event of cardiopulmonary arrest?"

This question needs to be asked in lay terms that the patient can understand. This question needs to be presented in the manner of informed consent with a presentation of the true risks and realistic chances of successful outcome. If the patient chooses to have full resuscitation, then a second question must be asked.

Question 2

"Let us assume you were resuscitated. If the critical care team, despite doing everything they can to save your life, determine after 72 h that you have no chance to regain a reasonable quality of life, would you agree to let them withdraw support and allow natural death to occur with peace and dignity?" It is believed that most patients who choose to be resuscitated will choose to not have their death prolonged if there is no reasonable chance to recapture a meaningful life. The earlier these questions are discussed in the course of a terminal illness, the more likely that a prolonged course of suffering in dying can be avoided.

If one only asks a patient with a terminal disease "if your heart stops, would you want us to start it again," the implication is that the resuscitation will be successful and all will be well. This of course is untrue. By simply changing a few words, "if your heart stops beating, would you want us to **try** to start it again," immediately places doubt that the resuscitation will be successful and can then lead to further inquire by the patient about "odds" "consequences," etc. If the patient still wants an attempt at resuscitation, the second question must be asked. There is of course the possibility that a patient with capacity to make his/her own decisions about care will still want everything done. Then an ethics consult should be obtained if the physician feels that the act of CPR would be futile and potentially lead to more harm and suffering for the patient.

DNR Status and Palliative Surgical Procedure

A final issue that must be addressed is whether do-not-resuscitate (DNR) orders should be routinely rescinded when terminally ill patients undergo palliative surgery? If so, patients will be forced to balance the benefits of palliative surgery against the risks of unwanted resuscitation. On the other hand, if physicians are required to honor intraoperative DNR orders, they may feel unacceptably restrained from correcting adverse effects for which they feel responsible [47]. Walker argued for the permissibility of honoring intraoperative DNR orders [47]. Walker maintains that the patient's right to refuse treatment outweighs physicians' concerns about professional scrutiny over intraoperative deaths [47]. Physicians' moral concerns about hastening patient death are important but may be assuaged by (1) emphasizing patients' acceptance of operative mortality risk; (2) viewing matters as analogous to surgery on Jehovah's Witnesses who refuse lifesaving transfusion; (3)

viewing the patient's intraoperative death as a double effect, that is, an unintended negative effect that is linked to the performance of a good act (palliation); and (4) distinguishing this from assisted suicide [47].

In 1992, Franklin and Rothenberg reported on a survey of 156 accredited hospitals in the USA as to their policies for suspending do not resuscitate (DNR) orders when patients went to surgery even for palliative procedures [48]. One hundred twelve hospitals responded. The majority (81%) noted that they suspended the DNR order when patients went to surgery [48].

Today it is customary to engage in an informed discussion with all concerned parties about the consequences of performing CPR, a chemical code only, or withholding resuscitative efforts should a code occur during palliative surgery and anesthesia. More recently it has been recommended by the American Society of Anesthesiology, multiple Surgical Societies, as well as the AMA that the DNR order could be maintained in force even during surgery [49].

Now it is obvious that the induction of general anesthesia including endotracheal intubation incorporate life sustaining measures and it may not be possible to immediately extubated patients at the end of surgery. These acts alone do not constitute cardiopulmonary resuscitation. It therefore requires full discussion with the patient, family, or surrogate decision makers and the surgeon about informed consent.

Next, resuscitative efforts can be expressly limited to chemical resuscitation without chest compressions if full CPR would result in more harm to the patient than good. Again this is a joint decision made by the patient and the entire care team.

Concluding Remarks

Neville Goodman stated that "Words are all we have to describe what we do, the way we do it, and what we infer from clinical research [50]. We must use them carefully and properly" [50].

The late Primo Levi, an Italian journalist said "If we know that pain and suffering can be alleviated, and we do nothing about it, then we ourselves become the tormentors" [51]. ***But "when men lack goals, they tend to engage in activity," (unknown author)*** [52]. It is our job as compassionate and professional physicians to "Do the right thing, and do it first" as William Osler told us so many years ago [1].

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52. But "when men lack goals, they tend to engage in activity" (unknown author).

Review Questions

1. The number of seriously ill patients who experience "*substantial*" pain ranges from…
   (a) 36–75%
   (b) 5–10%
   (c) 75–90%
   (d) 25–30%
2. The Uniform Determination of Death Act (UDDA) defined death as a state of…
   (a) Irreversible cessation of circulatory and respiratory functions
   (b) Irreversible cessation of all the functions of the entire brain including the brain stem
   (c) Irreversible cessation of both cardio-respiratory function and brain functions
   (d) Either irreversible cessation of circulatory and respiratory functions or irreversible cessation of all levels of brain function including the brain stem
   (e) Any of the above
3. Symptoms that correlate with the terminal cancer syndrome are except…
   (a) Anorexia/cachexia in association with increased heart rate
   (b) Dysphasia
   (c) Cognitive failure
   (d) Weight loss
   (e) The presence of pain
4. Which of the following acts is not protected by the rule of double effect?
   (a) Do good if you can
   (b) Do no harm
   (c) Rationing of health care
   (d) Physician-assisted suicide
5. Appropriate prescribing of opioids requires all of the following except…
   (a) Complete medical history
   (b) Diagnosis of pain generator
   (c) Documentation of physical examination
   (d) Documentation of benefit
   (e) Treatment of side effects
   (f) Increasing dosing of opioids for terminal sedation is not sanctioned by the rule of double effect

6. Which of the following is not true with respect to do not resuscitate (DNR) orders?
   (a) DNR orders must be suspended when patients go to have palliative surgery
   (b) DNR orders are written by physicians after obtaining consent from the patient or assigned patient decision maker
   (c) DNR orders obtained in the appropriate manner may not be over turned by physicians or family members
   (d) DNR does not mean "do not treat" or "do nothing"

7. Which of the following is a true statement about CPR?
   (a) CPR is meant to be used in all circumstances of cardio-pulmonary arrest
   (b) CPR is successful in more than 70% of cases
   (c) Patients with end-stage disease who undergo CPR after cardiac arrest have virtually no chance of leaving the hospital and returning home
   (d) Most patients in long-term nursing care facilities do receive CPR when they have a cardio-pulmonary arrest

8. Which statement is not true relative to the rule of double effect?
   (a) Providing opioids for pain relief or terminal sedation is permissible as long as the intent is not to hasten death
   (b) Providing opioids and other sedatives for relief of suffering is permissible even if there is a risk of hastening death as long as death is not the intent of the treatment
   (c) Providing treatments that can have a bad outcome are permissible as long as the intent of the treatment is to provide the good effect and the patient or authorized designee has consented to undergo the treatment and is aware of the risks
   (d) Physician-assisted suicide is protected by the rule of double effect

Answers

1. (a)
2. (e)
3. (e)
4. (d)
5. (f)
6. (a)
7. (d)
8. (d)