

PAIN RELIEF AND PALLIATIVE CARE IN LEBANON ETHICAL ISSUES IN END-OF-LIFE CARE

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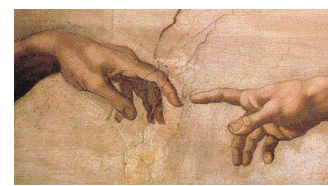
ABSTRACT : Technical advances in the care of advanced illness have created ethical challenges for physicians, patients, and families at the end of life. In the effort to survive longer, they are often confronted with difficult choices regarding medical advances that may inadvertently prolong suffering and the dying process rather than bring healing and recovery. Four major principles of medical ethics assist patients, families, and their physicians in making meaningful and morally acceptable choices with respect to care at the end of life : the Hippocratic principles of nonmaleficence and beneficence, as well as the more recently developed principles of autonomy and justice. The nature of these principles and their application in decision making and communication during the care of patients with advanced illnesses are reviewed.

INTRODUCTION

Ethics has been defined as “*that branch of philosophy dealing with values relating to human conduct, with respect to the rightness and wrongness of certain actions and to the goodness and badness of the motives and ends of such actions.*” In a more practical sense, it has also been defined as “*the rules of conduct recognized in respect to a particular class of human actions or a particular group, culture, etc.*” [1]. In this review of the ethical issues confronting physicians who care for patients with advanced life-limiting illnesses, both definitions will be relevant since considerable philosophical debate continues in the medical community regarding the rightness or wrongness of certain actions (e.g., physician-assisted death) while at the same time there is a strong desire to find a common ground for moral discourse that could guide medical decision-making in this difficult period in the lives of our patients. Because of technical advances in the care of critical illness, physicians, patients, and families are often confronted with ambiguous

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RÉSUMÉ : Les progrès techniques dans la prise en charge des patients à un stade avancé de leur maladie ont créé des problèmes éthiques en fin de vie, à la fois aux médecins, aux patients, et à leurs familles. Dans l'effort de prolonger la vie, ils sont souvent confrontés à des choix difficiles dans l'utilisation des progrès médicaux qui peuvent conduire à prolonger non intentionnellement la souffrance et le processus menant à la mort plutôt qu'à apporter guérison et rétablissement. Quatre principes majeurs d'éthique médicale aident les patients, leurs familles, et les médecins à faire des choix objectifs et moralement acceptables pour les soins en fin de vie : les principes d'Hippocrate de bienfaisance et de non malfaisance, ainsi que les principes plus récents d'autonomie et de justice. La nature de ces principes ainsi que leur application dans le processus de prise de décision et de communication au cours de la période de soins aux patients en stade de maladies avancées seront revues et commentées.

circumstances in which medical advances may inadvertently prolong suffering and the dying process rather than bring healing and recovery. Excellent resources are available that review these issues in greater depth [2-3]. The objectives of this article are to : 1) review major principles of medical ethics relevant to the care of terminally ill patients ; 2) explore further the principle of autonomy and its application to advanced directives, informed consent, and medical futility ; 3) characterize the ethical differences between withholding or withdrawing life-sustaining therapies and physician-assisted death ; 4) define a process for communicating bad news and negotiating decisions at the end of life ; and 5) examine ethical problems specific to terminal illness (in the form of case scenarios) in light of these principles.

ETHICAL PRINCIPLES RELEVANT TO END-OF-LIFE CARE

Suffering has been defined as “*...the state of severe distress associated with events that threaten the intactness of the person*” [4]. Suffering or perceived suffering may often be the underlying issue that enervates many of the ethical conflicts that arise during the care of patients with advanced life-threatening illnesses. Different perceptions of a patient's suffering within the medical team (e.g., between nurses and physicians), between the medical team and family members, or within families can

lead to conflict and are not infrequent reasons for ethics consultations in the acute care setting. The goal of palliative care is to relieve suffering. The World Health Organization has defined palliative care as *“the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families...”* [5]. Thus, the patient’s suffering and the physician’s mandate to address suffering provide the context for the application of four major principles of medical ethics : nonmaleficence, beneficence, autonomy, and justice. The so-called rule or principle of ‘double effect’ will be reviewed later in this article in conjunction with the discussion of physician-assisted death.

Nonmaleficence and beneficence are Hippocratic principles, in which nonmaleficence specifically enjoins physicians to not harm patients (exacerbate their suffering) and beneficence goes further in insisting that physicians accomplish a positive good for their patients (relieve their suffering). For many centuries these two principles, in balance, have sustained a medical paternalism in which physicians have held the primary decision-making authority for their patients. More recently, a third principle, i.e., autonomy, has become prominent, especially in Western Europe and North America. Autonomy recognizes the right of self-determination, or in the medical context, the right to establish one’s own goals of care. With progression of an advanced illness there is increasing debility and loss of independent function that erodes a patient’s autonomy. This progressive loss of autonomy, inasmuch as it further threatens the integrity of the person, adds to the suffering of those with advanced illnesses. Consumer autonomy, an extreme application of the principle of autonomy, views healthcare as a commodity to be purchased and received on demand. It has almost completely replaced the old medical paternalism with the concept that “the customer (i.e., patient) is always right,” potentially leading to requests for inappropriate or futile medical treatments. In direct opposition to consumer autonomy, is the fourth major ethical principle, justice. The principle of justice emphasizes the need for the equitable distribution of resources, including the often limited access to healthcare. An individual’s desire or demand to have any and all potential treatments for an advanced incurable illness (consumer autonomy) may be in direct conflict with the just distribution of care for others who are also suffering, because of the limited resources available. Thus, the ethical responsibility of a physician to an individual patient is limited to the extent that utilization of resources for the individual unfairly compromises the ability to provide similar resources to others.

In the United States, the transition from medical paternalism toward patient autonomy has been supported by certain legal decisions. In *Schloendorff versus New York Hospital* (1914), the right of patient self-

determination was established : *“Every human being of adult years and sound mind has a right to determine what will be done with his own body”* [6]. In the more recent case of *Karen Ann Quinlan* (1976), an individual who was in a persistent vegetative state on a ventilator, the New Jersey Supreme Court recognized the principle of a surrogate decision-maker speaking for an incompetent patient [7].

ADVANCED DIRECTIVES, INFORMED CONSENT AND MEDICAL FUTILITY

A practical extension of patient autonomy has been the development and use of advanced directives. Typically, advanced directives can be in the form of a living will in which treatment preferences usually related to care at or near the end of life (especially regarding attempts at resuscitation) are documented or a durable power of attorney for healthcare in which a surrogate decision maker is identified (often one’s spouse or other close relative). In actual practice, advanced directives have not been as useful as hoped. It is almost impossible to anticipate every possible situation that might arise, especially during intensive care of a critically ill individual, in which specific decisions can be made in advance. Also, even when advanced directives have been prepared they are often ignored, either because of the urgent nature of a given situation and lack of ready access to the advanced directives or because of differences in interpretation of the specific wording of a living will. In one study, patients at risk for hospitalization for serious life-threatening illness were interviewed prospectively about their preferences regarding aggressive measures to sustain life and then were followed for six months. During careful follow-up, there was no significant association between actual patient willingness to receive aggressive therapy (as documented in an advanced directive) and whether the patients actually received aggressive therapy when they were critically ill [8]. There is more support for designation of a durable power of attorney (DPOA) for healthcare [9]. In the United States, a surrogate decision-maker (DPOA) would be approached by the patient’s physician(s) for assistance with healthcare decisions only when the patient has lost capacity for decision-making. In determining a patient’s capacity for decision-making the following criteria should be met : 1) the patient should be able to clearly identify a preference with regard to a specific intervention ; and 2) the patient should demonstrate a clear understanding of the consequences of his/her choice and be able to clearly articulate this to his/her physician. Capacity for decision-making can be determined by any physician. However, competence for decision-making, a legal designation, requires court action and psychiatric consultation in the United States. Once capacity for decision-making has been lost by the patient (e.g., secondary to delirium), then the surrogate decision-maker/DPOA for healthcare assumes the role of making a choice for the patient based

on his/her understanding of *the patient's preferences* not those of the DPOA. If the patient regains capacity for decision-making (e.g., delirium resolves), the role of the surrogate decision-maker is superseded by the patient's restored autonomy. Designation of a surrogate decision-maker in the form of a DPOA for healthcare creates flexibility in that the DPOA can address whatever situation may arise based on his/her understanding of what the patient's values and preferences are. Although less than a third of Americans have prepared either a living will or identified a DPOA for healthcare [10], there is real value in having the discussion with family and loved ones regarding care preferences at the end of life, since this discussion will likely inform discussions in the future when the patient has lost capacity for decision-making.

For patients and their surrogate decision-makers to make truly autonomous decisions, they must be informed. Too often in American medicine this has been translated in practice into giving patients a long list of potential interventions that are components of a resuscitative effort (e.g., electric shocks, external cardiac massage, ventilatory support, intravenous pressors, etc.) without putting such interventions in a larger context. Because physicians are pledged to preserve life, we are often very uncomfortable addressing the issue of death, especially when it is the large, silent but palpably oppressive presence during a discussion about goals of care. Instead of asking: "if your heart stops, would you want us to start it again..." try: "when (if) you die from this illness an attempt to resuscitate your body will happen (by default). Would you want this to occur? It will not change anything but potentially be disturbing for those caring for you and your loved ones who might witness it." It can also be very helpful to frame such discussions in the larger context of prognosis. If, for example, a patient with advanced cancer on the basis of functional status has a projected survival of weeks to months at best, any attempts at resuscitation will usually be futile and essentially prolong the dying process and the patient's suffering. On the other hand, an individual with advanced cancer with a projected survival based on functional status of months and who is still receiving active disease-modifying therapy (e.g., chemotherapy) may be an appropriate candidate for more aggressive resuscitative measures. All of this presupposes an informed discussion of prognosis and the mention of death itself in such a discussion. Otherwise, how can patients (or their surrogates) have a realistic context in which to make meaningful choices relating to their care that are consistent with their own personal values and goals?

Where prognosis is less certain (e.g., in a patient who is critically ill from complications following a major operation), physicians are under no ethical obligation to provide futile treatment(s); however, futility is in the eye of the beholder. Medical futility has been defined as "... performing treatments that have no reasonable chance of achieving a therapeutic benefit for the patient" [11]. How does one define *reasonable*?

A number of attempts have been made to define medical futility in more specific terms or for populations of critically ill patients including: 1) a treatment that has been ineffective in the last 100 cases; 2) for bone marrow transplant patients – respiratory failure requiring ventilatory support plus four or more hours of intravenous pressor support or sustained hepatic and renal failure; 3) cardiopulmonary resuscitation (CPR) that has been initiated for victims of major blunt trauma in the pre-hospital setting; and 4) possibly CPR for unwitnessed cardiopulmonary arrests in the elderly (70+ years of age) hospitalized patient may be futile. There has been limited to no success to date using objective scoring systems (e.g., APACHE II) to proactively identify and limit futile ICU care (e.g., SUPPORT study) [11]. Ultimately, shouldn't the patient play a role in defining futile care? Wouldn't the patient's goals of care have some impact on the definition? Fundamentally, physicians should not wait for a determination of futility to introduce palliative care. Waiting for futility implicitly says to the patient: "If we think you will live, we will tolerate your suffering, but if we think you will die, we will treat your suffering!" Emphasizing palliation in the face of uncertainties regarding futility is not only the right thing to do; it may ultimately help to clarify what is futile care. Ultimately, futility cannot be only a medical determination. The patient's and family's values must also play a major role in defining futility in tension with the complexities of the given medical condition.

At this point, a digression is necessary to comment on the 'best interests standard' for incompetent or incapacitated patients. In some countries (e.g., England) there is no provision for creating a DPOA to empower a surrogate decision-maker in the event that a patient loses decisional capacity. In England, when the capacity for autonomous decision-making by the patient is lost, informed consent cannot be obtained (in contrast to the United States where a surrogate decision-maker would act) [12]. Under such circumstances, the physician must make the decision guided by the 'best interests standard'. When this standard is used to address practical problems, asking the question: "What is in the best interests of this patient at this time?" should help guide the medical decision-maker(s) to pick from various options "*that reasonable persons of good will would consider acceptable in similar circumstances...*" [13]. Ideally, such an approach in addressing decision-making for incapacitated individuals would attempt to identify and act on behalf of the best short- and long-term interests of the patient while minimizing the associated burdens. Choices made for incapacitated patients using the 'best interests standard' should meet a minimum acceptable level of care (e.g., what reasonable and informed persons would regard as acceptable for themselves under similar circumstances). Choices made for incapacitated individuals should be consistent with accepted moral and legal duties to vulnerable individuals [13]. One can readily see that the 'best interests standard' represents an approach more

consistent with a medical paternalism model of care. In most instances, it should be an effective guide for good ethical care. However, historical precedents have already occurred in which vulnerable individuals lacking capacity for decision-making fell victim to a new moral standard imposed by the state and implemented by physicians (e.g., the destruction of the mentally ill in Nazi Germany). Thus, the principle of autonomy as applied to medical decision-making in the context of patient incapacitation is in a process of evolution depending on the country and culture.

WITHHOLDING/WITHDRAWING LIFE-SUSTAINING THERAPIES vs. PHYSICIAN-ASSISTED DEATH [14-15]

There is no fundamental difference ethically between withdrawing or stopping a treatment that is no longer beneficial and not starting or withholding such a treatment [16].

Once a decision is made to withhold a “life-sustaining” treatment, other ongoing treatment should be reviewed as to the appropriateness of its continuation, as well.

Another legal precedent in the United States, the case of Nancy Cruzan in 1990 has informed the ethical and legal discourse regarding withdrawal of any form of therapy in an incapacitated individual. Specifically, this case involved the proposed withdrawal of artificial nutrition (tube feedings) in a patient who was in a persistent vegetative state. In the legal opinion, it was concluded that the surrogate decision-maker must demonstrate “clear and convincing evidence” that the incapacitated patient would have rejected such treatment [17]. The effective outcome and interpretation of this decision in practice has been to determine that there is no essential difference between ordinary and extraordinary therapy [18]. It’s possible to reject any treatment, although it may still be more difficult for a surrogate decision-maker to reject artificial nutrition/hydration on behalf of an incompetent or incapacitated patient.

The decision to withdraw life-sustaining therapy is rarely an emergency. It is essential to take all the time necessary to resolve any conflicts that may exist between the medical staff and family members or that may exist within the medical team. Clinicians should be aware that personal biases and values often play a dominant role in their clinical decisions (as opposed to objective data). All team members (attending physician, physicians-in-training, nurses, social workers, etc.) who have a direct role in the patient’s care should have input in the process. As much as is possible, build consensus. Some important principles to consider when considering withdrawal of life-sustaining therapy include :

- 1) All treatments can be withdrawn. If circumstances justify withdrawal of one therapy (e.g., intravenous pressors, antibiotics), they may also justify withdrawal of others.
- 2) Be aware of the symbolic value of continuing some therapies (e.g., nutrition, hydration) even though

their palliative value is questionable.

- 3) Prior to withdrawing life-sustaining therapy ask the patient and family if a spiritual advisor (e.g., pastor, imam, or priest) should be called.

The rule or doctrine of ‘double effect’ is important to consider in any discussion of the role of palliative care in relieving the suffering of patients with advanced illnesses whether or not withdrawal of life-sustaining therapy is also under consideration. A treatment (e.g., opioid administration in the terminally ill) that is intended to do good and not harm the patient (i.e., relieve pain) is ethically acceptable even if a potential consequence (side effect) of its administration is to shorten the life of the patient (e.g., by respiratory depression). The use of opioids for pain relief in advanced illness has been cited frequently as the classic example for the rule of double effect. However, it has been shown from a careful review of the literature, that in the vast majority of instances of opioid administration for symptom relief in advanced illness, the rule need not be invoked, since opioids can safely be used without significant risk, if administered appropriately [19]. Thus, in managing the distress of the dying, titrate medications (e.g., opioids, benzodiazepines) to relieve all signs of distress (tachypnea, agitation, grimacing, etc.) prior to removing life support. There is a fundamental ethical difference between titrating medications rapidly to achieve relief of distress and administering a very large bolus which causes apnea. Some have used what they perceive as ambiguities in the rule of “double effect” in arguments supporting euthanasia and physician-assisted suicide [20]. However, this principle ultimately rests on the intent of the individual acting under its guidance. For the majority of physicians who would not willingly perform euthanasia, the rule of “double effect” underscores the reality that sometimes treatments with potentially dangerous side effects must be used to relieve the distress of our patients ; but not with the *intent* of killing them in order to relieve their distress [21]. To further clarify these issues, in physician-assisted suicide, a physician intentionally provides the means, while the patient is the direct, proximate cause of his/her own death. In euthanasia, the physician is the direct cause of the *intended* death of the patient. With regard to medical ethics, there is no fundamental moral difference between physician-assisted suicide and euthanasia. Intent is everything, but *document* your intent. Thus, withholding or withdrawing treatments which are no longer beneficial or administering opioids for pain relief that may indirectly hasten death are not euthanasia.

In the ongoing debate regarding physician-assisted death (physician-assisted suicide or euthanasia), the most compelling argument in favor of the practice relates to suffering. If suffering is the greatest evil (which many advocates of physician-assisted death would endorse), then all means should be available to address it, including intentionally causing the premature death of one’s patients. There are a number of reasons to resist embracing such a “solution” to the suffering of our patients.

1. Requests for physician-assisted death are often a sign of un-addressed issues including : inadequately treated physical symptoms (e.g., pain), untreated clinical depression, fear of a loss of control (autonomy), fear of being a burden, and potential existential or spiritual distress.
2. Physical suffering can be relieved without writing a lethal prescription. Distressing symptoms can be controlled in > 95% of cases with medications and supportive care. Terminal or palliative sedation can be used to control very difficult symptoms without taking a life.
3. The end of life is a critical time for personal growth which would be shortened by premature physician-assisted death. During the last days and weeks of life a number of very important activities can occur including reconciliation and healing of relationships, life review, and spiritual growth as one searches for meaning in one's suffering.
4. Legalization of physician-assisted death would be inherently unsafe. Patients with limited or unequal access to healthcare (e.g., the poor) would be particularly vulnerable, since physician-assisted death would inherently be quite "cost effective." There have been well documented failures or "problems with completion" of physician-assisted suicide (complications in 21 of 114 cases reported recently from the Netherlands) that could exacerbate rather than relieve the suffering of the dying [22].
5. Physician-assisted death poses an inherent conflict of interest for physicians. Physicians can't remain as trusted advocates for the life and health of their patients, if they also may be the means of terminating that same life. With rising health care costs (particularly at the end of life), the pressure for more "cost effective" solutions (e.g., physician-assisted death) will mount. Physician-assisted death is in direct conflict with the Hippocratic Oath and tradition.
6. Finally, physician-assisted death represents the very thing the terminally ill fear the most – abandonment. Although physicians may be able to address the physical distress of the dying, they may not have the skills or resources to address deeper, existential issues troubling their patients. This lack of knowledge does not justify taking a patient's life when others who may have the skills and patience are available to help.

COMMUNICATING BAD NEWS AND NEGOTIATING DECISIONS AT THE END OF LIFE [23]

In keeping with the Hippocratic principles of non-maleficence and beneficence, if done well, communication and negotiation with patients and families about advanced life-threatening illnesses can potentially avoid great psychological harm and help make a very difficult transition easier. To communicate and negotiate effectively and compassionately, it is helpful to pursue an organized and thoughtful process, keeping the needs of

the patient and family in mind. Find a quiet, private place. Be sure to minimize potential interruptions (e.g., turn off pagers and cell phones ; have someone else respond to calls or pages). Make sure the timing is right for the patient and that there is enough time. Give the news in person. Avoid giving bad news over the telephone, if at all possible. Sit close to the patient. Give the impression by your body language that you have unlimited time to spend with the patient and family and that they have your full attention. Standing at the door, implies that you might leave (escape) at any time and thus implicitly abandon the patient. Avoid using bad body language – don't look too relaxed. Don't cross your legs, but lean forward toward the patient making good eye contact, while being sensitive to important cultural and gender differences that may impact communication. Whenever possible and if desired by the patient, it is important to have a family member or friend present to provide comfort and support to the patient. At the beginning of the conference, clarify the patient's understanding of the situation. *Listen* to the patient's reported understanding of his/her disease and condition. Not infrequently patients may have already guessed the bad news and may volunteer their worse fears which can make the physician's task easier. Remember that giving bad news is like any other medical procedure in that it can cause potential harm or suffering and thus requires the patient's informed consent. This can be done by giving a "warning shot." For example, "I am afraid I have bad news for you." The patient could then indicate that s/he is not ready to hear it yet or could identify a family member who should be the conduit of the information. Denial is such a strong reaction and defense mechanism for humans facing their death that it should be addressed in a gentle manner. When confronted with this response, it may be appropriate to indicate to the patient that the conversation still needs to occur but that it will be deferred awhile until s/he is ready. Always tell the truth, but don't force it on someone who is not yet ready to hear it. After communicating the bad news, pause. Silence is a good thing but often is very difficult to maintain while the patient absorbs the full shock of the bad news. Allow the patient to react appropriately (e.g., tears, anger) to what may be very devastating news indeed. Convey hope that is realistic to the circumstances, if no longer for cure, then for good symptom control and quality of the life remaining. Most importantly, reassure the patient that s/he will not be abandoned. Encourage the patient to identify realistic goals that are consistent with the likely prognosis that will help the medical team prioritize and individualize his/her care in order to honor the stated goals. For example, if a relatively high risk operative procedure to relieve a malignant bowel obstruction is the only option a patient may have to survive long enough to see a beloved child graduate from university, taking such an informed risk may be the best means of honoring the informed patient's autonomy. As implied above, during the course of an advanced illness,

more than one meeting may be necessary to address “bad news” as the patient’s disease progresses and options diminish.

CASE SCENARIOS

First case scenario

A 55-year-old female has an elective sigmoid colectomy for recurrent diverticular disease. She returns to the hospital on the tenth postoperative day with diarrhea and signs of sepsis. A computed tomographic (CT) scan of her abdomen reveals an anastomotic leak. An initial attempt at CT-guided drainage and bowel rest fail to control sepsis over the next 48 hours. She returns to the operating room on the twelfth postoperative day for a Hartmann’s procedure, end descending colostomy and washout/drainage of her pelvic abscess. Initially, she improves and is extubated the next day. Three days later, she becomes tachypneic and develops oliguria. A CT-guided drain is placed in a new pelvic collection. Between 2-3 weeks after her original procedure she now presents sedated on a ventilator with adult respiratory distress syndrome (ARDS) and dialysis-dependent acute renal failure (ARF). As her course progresses in the intensive care unit over the next 3 weeks, the patient shows no major changes in her overall condition. The family expresses concerns that “she is not going to get better” and that she would not want to be treated with artificial support indefinitely. The team caring for her is inclined to agree. A family member arrives from a remote location and objects that removing her from the ventilator would be equivalent to killing her.

This case emphasizes the challenges of communication that may occur with some family members when they present after a prolonged absence during a loved one’s advanced illness. Guilt over having been remote from the patient’s life is now expressed in over solicitous concern and occasional demands that “everything must be done !” Such situations underscore the need for a clearly identified surrogate decision-maker and spokesperson for a large family in the event of a patient’s loss of capacity for decision-making. Although the medical team should be available to meet the communication needs of patients and their families, it is unreasonable to expect the team to separately address the needs of each family member, ad nauseam, especially when there is conflict in the family regarding the goals of care. Offering to speak with and update the surrogate decision-maker on a regular (daily) basis is a reasonable compromise approach. Larger group meetings with the family can be organized in consultation with the surrogate decision-maker as needed. Without a structured approach to communication, chaos can ensue, putting into jeopardy all attempts at honoring the patient’s autonomy. A fair and consistent approach to communication will, over time, usually lead to resolution of most conflicts of this nature. Indeed, the family will often resolve the issue privately without the medical team’s direct intervention.

Second case scenario

A patient who had a prior resection of a rectosigmoid colon cancer now presents with advanced metastatic disease, nausea, and vomiting from an obstructing recurrence at 15 cm from the anal verge. An endoscopic stent is placed to relieve the malignant obstruction. Unfortunately, it perforates the patient’s colon and he rapidly succumbs to sepsis.

This is an example of the rule of “double effect.” As noted above, too much focus has probably been placed on the use of opioids in symptom relief as the “classic” example of the rule of “double effect.” As this example illustrates, clinicians and their patients with advanced illnesses are often confronted with choices that center on treatments intended to help bring relief of suffering but are also attended by significant risks (in this case bowel perforation and sepsis) that might hasten death. Clearly, these known complications of endoscopic stent placement were unintended consequences of a procedure performed to palliate this patient’s symptoms. It may be helpful to think of the rule of “double effect” in another context as in this illustrative case, thereby avoiding the ambiguities that have been created by some regarding the use of opioids for symptom relief in the debate over physician-assisted death [20].

Third case scenario

A consultant endoscopist is asked to place a feeding gastrostomy tube in an eighty-five-year old female who has a several year history of Alzheimer’s dementia. Her family is concerned that she is now taking very little per oral nutrition voluntarily and that she will “starve to death.” She has been bedfast for several months, has lower extremity contractures, a sacral decubitus, and can not utter more than a few intelligible words during a 15-minute encounter.

The endoscopist is confronted with an ethical dilemma. He wants to be helpful to this unfortunate patient and her concerned family but at the same time he wonders if placing a feeding tube would be of any real benefit or rather be a potential source of harm to this patient. Surgeons, endoscopists, and interventional radiologists are not infrequently asked to place feeding tubes under similar circumstances. Key issues that must be clarified include the patient’s prognosis, the nature of the feeding impairment due to her disease, her current quality of life, likely quality of life after such a procedure, and any relevant guidance she may have given (e.g., advanced directive) while she still retained capacity for decision-making. For physician consultants to ignore the patient in her larger context and serve merely as technicians is unethical [12]. Rarely, if ever, are feeding tubes or artificial nutrition indicated in patients with progressive advanced illness. If the family or patient is requesting a feeding tube or artificial nutrition, one should explore their concerns/reasons for the request. It usually should lead to a discussion of prognosis. The Alzheimer’s patient presented above is in the late stages of the disease with likely fewer than 3-6 months to live.

A natural part of disease progression that is common to many advanced illnesses, including cancer, is a gradual decrease in voluntary oral intake. With care, assisted oral feedings can continue until very late in Alzheimer's disease making feeding tubes essentially irrelevant in its management. It is important to reassure families and patients that decreased voluntary oral intake is an expected part of the process of disease progression in advanced illness. In this context, attempts to "force feed" with tube feedings do not prolong life. Rather, they cause discomfort with increasing peripheral edema and may result in vomiting and aspiration pneumonia [24]. Clearly, feeding tubes may be very useful, even essential, during treatment for cancers that by their location (e.g., head and neck or esophageal cancers) or because of anticipated treatment-associated side effects (e.g., radiation-induced pharyngitis and esophagitis) limit nutritional intake during the active phase of treatment. They may also be useful as conduits for medication delivery in the same context. If prognosis is less certain and the patient is unable to take oral nutrition and hydration and yet may experience hunger or thirst (e.g., after a major stroke) then consideration of placement of a feeding tube may be appropriate, depending on the patient's known preferences and using the "best interests standard."

SUMMARY

Patients and their physicians together face a number of challenging ethical issues at the end of life. Although some issues (e.g., the role of physician-assisted death in addressing suffering) remain very controversial, there is much common ground based on the application of the four major principles of medical ethics, nonmaleficence, beneficence, autonomy, and justice.

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