Breaking Bad News

Breaking bad news is not something that most medical students are eager to try. Dilbert's adviser Dogbert says: "Never break bad news...it will only get you in trouble." And stories abound about how unskilled physicians blundered their way through an important conversation, sometimes resulting in serious harm to the patient. Many patients with cancer, for example, can recall in detail how their diagnosis was disclosed, even if they remember little of the conversation that followed, and they report that physician competence in these situations is critical to establishing trust.

Some physicians contend that breaking bad news is an innate skill, like perfect pitch, that cannot be acquired otherwise. This is incorrect. Physicians who are good at discussing bad news with their patients usually report that breaking bad news is a skill that they have worked hard to learn. Furthermore, studies of physician education demonstrate that communication skills can be learned, and have effects that persist long after the training is finished.

Robert Buckman's Six Step Protocol for Breaking Bad News

Robert Buckman, in an excellent short manual, has outlined a six step protocol for breaking bad news. The steps are:

1) Getting started.

The physical setting ought to be private, with both physician and patient comfortably seated. You should ask the patient who else ought to be present, and let the patient decide--studies show that different patients have widely varying views on what they would want. It is helpful to start with a question like, "How are you feeling right now?" to indicate to the patient that this conversation will be a two-way affair.

2) Finding out how much the patient knows.

By asking a question such as, "What have you already been told about your illness?" you can begin to understand what the patient has already been told ("I have lung cancer, and I need surgery"), or how much the patient understood about what's been said ("the doctor said something about a spot on my chest x-ray"), the patients level of technical sophistication ("I've got a T2N0 adenocarcinoma"), and the patient's emotional state ("I've been so worried I might have cancer that I haven't slept for a week").

3) Finding out how much the patient wants to know.

It is useful to ask patients what level of detail you should cover. For instance, you can say, "Some patients want me to cover every medical detail, but other patients want only the big picture--what would you prefer now?" This establishes that there is no right answer, and that different patients have different styles. Also this question establishes that a patient may ask for something different during the next conversation.

4) Sharing the information.

Decide on the agenda before you sit down with the patient, so that you have the relevant information at hand. The topics to consider in planning an agenda are: diagnosis, treatment, prognosis, and support or coping. However, an appropriate agenda will usually focus on one or two topics. For a patient on a medicine service whose biopsy just showed lung cancer, the agenda might be: a) disclose diagnosis of lung cancer; b) discuss the process of workup and formulation of treatment options ("We will have the cancer doctors see you this afternoon to see whether other tests would be helpful to outline your treatment options"). Give the information in small chunks, and be sure to stop between each chunk to ask the patient if he or she understands ("I'm going to stop for a minute to see if you have questions"). Long lectures are overwhelming and confusing. Remember to translate medical terms into English, and don't try to teach pathophysiology.

5) Responding to the patient's feelings.

If you don't understand the patient's reaction, you will leave a lot of unfinished business, and you will miss an opportunity to be a caring physician. Learning to identify and acknowledge a patient's reaction is something that definitely improves with experience, if you're attentive, but you can also simply ask ("Could you tell me a bit about what you are feeling?").

6) Planning and follow-through.

At this point you need to synthesise the patient's concerns and the medical issues into a concrete plan that can be carried out in the patient's system of health care. Outline a step-by-step plan, explain it to the patient, and contract about the next step. Be explicit about your next contact with the patient ("I'll see you in clinic in 2 weeks") or the fact that you won't see the patient ("I'm going to be rotating off service, so you will see Dr. Back in clinic"). Give the patient a phone number or a way to contact the relevant medical caregiver if something arises before the next planned contact.

What if the patient starts to cry while I am talking?

In general, it is better simply to wait for the person to stop crying. If it seems appropriate, you can acknowledge it ("Let's just take a break now until you're ready to start again") but do not assume you know the reason for the tears (you may want to explore the reasons now or later). Most patients are somewhat embarrassed if they begin to cry and will not continue for long. It is nice to offer Kleenex if they are readily available (something to plan ahead); but try not to act as if tears are an emergency that must be stopped, and don't run out of the room--you want to show that you're willing to deal with anything that comes up.

I had a long talk with the patient yesterday, and today the nurse took me aside to say that the patient doesn't understand what's going on! What's the problem?

Sometimes patients ask the same question of different caregivers, sometimes they just didn't remember it all, and sometimes they need to go over something more than once because of their emotional distress, the technical nature of the medical interventions involved, or their concerns were not recognised and addressed.

I just saw another caregiver tell something to my patient in a really insensitive way. What should I do?
First, examine what happened and ask yourself why the encounter went badly. If you see the patient later, you might consider acknowledging it to the patient in a way that doesn't slander the insensitive caregiver ("I thought you looked upset when we were talking earlier and I just thought I should follow up on that--was something bothering you?")

Case 1
Jose is a 62-year-old man who just had a needle biopsy of the pancreas showing adenocarcinoma. You run into his brother in the hall, and he begs you not to tell Jose because the knowledge would kill him even faster. A family conference to discuss the prognosis is already scheduled for later that afternoon.

How should you handle this?

Discussion
It is common for family members to want to protect their loved ones from bad news, but this is not always what the patient himself would want. It would be reasonable to tell Jose's brother that withholding information can be very bad because it creates a climate of dishonesty between the patient and family and medical caregivers; also, that the only way for Jose to have a voice in the decision making is for him to understand the medical situation. Ask Jose how he wants to handle the information in front of the rest of the family, and allow for some family discussion time for this matter.
In some cultures it is considered dangerous to talk about prognoses and to name illnesses (eg. the Navajo). If you suspect a cultural issue it is better to find someone who knows how to handle the issue in a culturally sensitive way than to assume that you should simply refrain from providing medical information. For many invasive medical interventions, which require a patient to critically weigh burdens and benefits, a patient, will need to have some direct knowledge of their disease in Western terms in order to consider treatment options.

Case 2
You are a 25-year-old female medical student doing a rotation in an HIV clinic. Sara is a 30-year-old woman with advanced HIV who dropped out of college after she found that she contracted HIV from her husband, who has haemophilia. In talking to Sara, it turns out you share a number of things--you are from the same part of Montana originally, also have young children, and like to cook. Later in the visit, when you suggest that she will need some blood tests, she gets very angry and says, "What would you know about this?"

What happened?

Discussion

Although the protocol for breaking bad news is helpful, it doesn't cover everything. There are instances when you may provoke a reaction from a patient because you remind them of someone else--or, as in this case, themselves. In these instances it can be helpful to step back, get another perspective (perhaps from someone in clinic who has known Sara), and try not to take this reaction too personally--even though it is likely that Sara will know how to really bother you.

End-of-Life Issues

As care of the dying involves so much of one's self, in this topic page I will describe my approach as an example of how clinicians think about end-of-life care. I remember, the first time one of my patients died, feeling a chill of horror and fascination. I wasn't prepared for it. The resident yawned--a long night, then a long code. "We better go talk to the family." What in the world would we say? The dead patient, now dusky blue, looked unreal and unfamiliar. I was so wrapped up in my own feelings that I can't recall much else.

Now I find care of the dying to be one of the richest parts of my clinical life. But it is demanding in a different, more personal way, than, say, treating pneumococcal pneumonia with penicillin. Here I will describe some ways of thinking about care of the dying that have helped me figure out where I am going as I guide someone who is really sick.

Many medical students first encounter care of the dying as an unsuccessful code or a strategic withholding of CPR. Of course, an ethically sound understanding of withdrawing and withholding treatment is crucial to good care of the dying. Yet "withholding and withdrawing" only describe what we, as clinicians, decide not to do. To provide excellent care of the dying requires that we also decide what we should do. What should be the goals of medical care for people who are dying? What makes a good death?

What is a "good death"? A medical perspective

The good death is not a familiar idea in American culture. Some experts in palliative care describe the United States as a "death-defying" culture, with a mass media that spotlights only youth and beauty. Yet public interest in care of the dying is currently high. The striking public

interest in physician-assisted suicide is one obvious reason. But there are other reasons: over the past 100 years, there has been an epidemiologic shift in the reasons people die. In the pre-antibiotic era, people most often died young, of infectious diseases; now, thanks to medical technology, most Americans (and others with access to this technology) live much longer, to die of degenerative, neoplastic, and even man-made diseases. Finally, there is a marked public fear that a medical death, depicted in TV shows like "ER" as an unresponsive, uncommunicative body hooked up to an array of flashing monitors, represents an irresponsible use of technology and a dishonourable way to treat a person.

Interestingly, contemporary medical literature contains little that might characterise what makes a death "good." Recently, a large, expensive empirical study of intensive care unit deaths suggested that medical care for a common type of in-hospital death is "bad" (the SUPPORT study, referenced below). In this study of dying patients, severe pain was common, decisions to withhold invasive treatments were made at the last minute, and physicians often had no knowledge of patient preferences not to have CPR. Even worse, an intervention designed to provide physicians with better prognostic information had no effect on medical decision making prior to death. While the SUPPORT authors did not actually describe these deaths as "bad," we could certainly agree that they were not "good deaths."

In caring for a person who is dying, knowing what would make the experience of dying "good" is an important goal for physicians and other members of the care team. I find it doesn't take fancy techniques-you just need to be sincere and patient and interested. Listen more and talk less. Try asking something like, "Knowing that all of us have to think about dying at some point, what would be a good death for you?" What people choose when they think about a good death for themselves is often beyond what medicine can provide-for instance, an affirmation of love, a completion of important work, or a last visit with an important person. As a physician, I can't always make those things happen. But I can help the dying person get ready-and in this way, contribute to a death that is decent.

What goals should I have in mind when working towards a decent death for my patient?

I have several working clinical goals when I am caring for someone near the end of life. I work towards:

> **1) Control of pain and other physical symptoms.** The physical aspects of care are a prerequisite for everything that follows.
>
> **2) Involvement of people important to the patient.** Death is not usually an individual experience; it occurs within a social context of family, significant others, friends, and caregivers.
>
> **3) A degree of acceptance by the patient**. Acceptance doesn't mean that the patient likes what is going on, and it doesn't mean that a patient has no hopes--it just means that he can be realistic about the situation.

4) A medical understanding of the patient's disease. Most patients, families, and caregivers come to physicians in order to learn something about what is happening medically, and it is important to recognise their need for information.

5) A process of care that guides patient understanding and decision-making. One great physician does not equal great care--it takes a coordinated system of providers.

How do you know when someone is dying?

This question is not as simple as it might sound. The SUPPORT study demonstrated that even for patients with a high probability of dying, it is still difficult for a clinician to predict that a particular patient is about to die. Thus it may be more useful for clinicians to give up relying on their predictive skills, and look at the common clinical paths (or trajectories) taken by dying patients, and design medical care that includes "contingency plans" for clinical problems that a person with incurable lung cancer (for example) is likely to experience. Such contingency plans might include advance directives and perhaps DNAR orders, as well as lines such as: "You will probably die from this, although we can't predict exactly when. What is really important for you in the time you have left?"

What should I know about the hospice approach?

In order to help someone towards a decent, or even good, death, the hospice framework is very helpful. Hospice started as a grassroots effort, as a view of dying that lets go of the possibility of cure. Instead, hospices emphasise symptom control and attention to psychological and spiritual issues. Pathophysiology becomes less important and personal meaning becomes more important. Thus this framework analyses a person's medical care into four major topics, and this can be used to outline day-to-day care plans for a patient:

1. **Pain** - *one of the things most feared by patients with life-threatening illness.*

2. ***Symptoms control*** - *including dyspnoea, nausea, confusion, delirium, skin problems, and oral care.*

3. ***Psychological issues*** - *especially depression, sadness, anxiety, fear, loneliness.*

4. ***Spiritual or existential issues*** - *including religious or non-religious beliefs about the nature of existence*, the possibility of some type of afterlife.

Hospice care in Washington State is most often provided by multidisciplinary teams who go to patients' homes. This care is covered by Medicaid for patients judged to have less than six months to live. Hospice care is generally under utilised, and even though most hospice teams feel

that at least six weeks of hospice care is optimal, most patients receive much less because they are either referred very late or have not wanted hospice. A major problem in connecting hospice care to acute medical care is that referral implies a "switch" from curative to palliative medicine- a model that does not fit comfortably in many illnesses.

What you need to understand to care for the dying

Another useful framework was outlined by Joanne Lynn, who was one of the principal investigators of SUPPORT. She suggests that there are four things clinicians must know to care for the dying.

1. **The patient's story** - including how that person has viewed her life, the other persons important to her, and how she could bring her life to a close in a way that would be true to herself.

2. **The body** - which covers the biomedical understanding of disease, and what limits and possibilities, exist for that person.

3. **The medical care system available for this particular patient** - knowing how you can make the system work for the patient, as well as the relevant law and ethics.

4. **Finally, you must understand yourself** - because you, as a physician, can be an instrument of healing, or an instrument that does damage.

Obviously, learning how to do all this is beyond the scope of this web page--these are goals that guide a career of learning and reflection. But this framework provides guidelines for you as you develop your own approach to caring for dying patients.

How do physicians who care for the dying deal with their own feelings?

It is not hard to find physicians who are burned out - ask any nurse. What is difficult is to find for yourself a type of self-care that will enable you to develop your gifts as a physician, and continue to use them in practice. It helps to learn your strengths and weaknesses, and to actively seek whatever will nurture you - in or out of medicine. A strategy of detachment may not serve you well in the long run. There are indeed rewards for physicians who care for the dying, but as a Zen master once observed of a bingo game, "you must be present to win."

Case

Skip is a 50-year-old man with metastatic non-small cell lung cancer. He decided to try palliative chemotherapy because "otherwise I might just as well roll over and give up." After the first cycle of carboplatin and taxol, he requires hospitalisation for fever and neutropenia (a complication of the chemotherapy). You stop by for a visit, and he says he feels terrible, wonders "if the chemo is worth all this", but that he's too scared to stop.

How would you respond?

Discussion

For metastatic non-small cell lung cancer, palliative chemotherapy is an intervention providing, on average, a small benefit at considerable toxicity (a consideration for the Medical Indications box in a Clinical Ethics 4-box analysis). Yet for a patient who is well informed, understands the benefits and burdens, and wishes to proceed, a trial of palliative chemotherapy is justified. However, now Skip is voicing concern: the most important thing to do is hear him out. Find out what he is worried about, how he rates his quality of life, and what his goals are. This information will help you sort out what is going through his mind and help you guide him to a decision that will be the best for him.

As Skip thinks through his situation, ask him if he wants you to describe what would happen if he decides to have more chemotherapy, or stops his chemo and starts hospice care. Eventually you might ask him what a good death would be for him--he may not be able to answer immediately, but it might help him (and you) shape a care plan later. When you talk with Skip, keep in mind the goals for a decent death.

Futility

While you will hear colleagues referring to particular cases or interventions as "futile", the technical meaning and moral weight of this term is not always appreciated. As you will make clinical decisions using futility as a criterion, it is important to be clear about the meaning of the concept.

What is "medical futility"?

"Medical futility" refers to interventions that are unlikely to produce any significant benefit for the patient. Two kinds of medical futility are often distinguished:

1. ***Quantitative futility,*** where the likelihood that an intervention will benefit the patient is exceedingly poor, and

2. ***Qualitative futility,*** where the quality of benefit an intervention will produce is exceedingly poor.

Both quantitative and qualitative futility refers to the prospect of benefiting the patient. A treatment that merely produces a physiological effect on a patient's body does not necessarily confer any benefit that the patient can appreciate.

What are the ethical obligations of physicians when an intervention is clearly futile?

The goal of medicine is to help the sick. You have no obligation to offer treatments that do not benefit your patients. Futile interventions are ill advised because they often increase a patient's pain and discomfort in the final days and weeks of life, and because they can expend finite medical resources.

Although the ethical requirement to respect patient autonomy entitles a patient to choose from among medically acceptable treatment options (or to reject all options), it does not entitle patients to receive whatever treatments they ask for. Instead, the obligations of physicians are limited to offering treatments that are consistent with professional standards of care.

Who decides when a particular treatment is futile?

The ethical authority to render futility judgments rests with the medical profession as a whole, not with individual physicians at the bedside. Thus, futility determinations in specific cases should conform to more general professional standards of care.

While a patient may decide that a particular outcome is not worth striving for (and consequently reject a treatment), this decision can be based on personal preferences and not necessarily on futility.

What if the patient or family requests an intervention that the health care team considers futile?

In such situations, you have a duty as a physician to communicate openly with the patient or family members about interventions that are being withheld or withdrawn and to explain the rationale for such decisions. It is important to approach such conversations with compassion for the patient and grieving family. For example, rather than saying to a patient or family, "there is nothing I can do for you," it is important to emphasise that "everything possible will be done to ensure the patient's comfort and dignity."

In some instances, it may be appropriate to continue temporarily to make a futile intervention available in order to assist the patient or family in coming to terms with the gravity of their situation and reaching a point of personal closure. For example, a futile intervention for a terminally ill patient may be continued temporarily in order to allow time for a loved one arriving from another state to see the patient for the last time.

What is the difference between futility and rationing?

Futility refers to the benefit of a particular intervention for a particular patient. With futility, the central question is not, "How much money does this treatment cost?" or "Who else might benefit from it?" but instead, "Does the intervention have any reasonable prospect of helping this patient?"

What is the difference between a futile intervention and an experimental intervention?

Making a judgment of futility requires solid empirical evidence documenting the outcome of an intervention for different groups of patients. Futility establishes the negative determination that the evidence shows no significant likelihood of conferring a significant benefit. By contrast, treatments are considered experimental when empirical evidence is lacking and the effects of an intervention are unknown.

Case 1

A young accident victim has been in a persistent vegetative state for several months and family members have insisted that "everything possible" be done to keep the patient alive.

Should you honour the family's request?

What are your professional obligations?

Case 2

An elderly patient with irreversible respiratory disease is in the intensive care unit where repeated efforts to wean him from ventilatory support have been unsuccessful. There is general agreement among the health care team that he could not survive outside of an intensive care setting. The patient has requested antibiotics should he develop an infection and CPR if he has a cardiac arrest.

Should a distinction be made between the interventions requested by the patient?

Discussion

Both Case 1 and Case 2 illustrate the possible conflicts that can arise with patients or family members about withholding or withdrawing futile interventions. If you and other members of the health care team agree that the interventions in question would be futile, the goal should be to withdraw or withhold these interventions. Achieving this goal requires working in tandem with the patient and/or family, as well as drawing upon resources, such as social workers, hospital chaplains, and ethics committees. If there is no professional consensus about the futility of a particular intervention, then there is no ethical basis for overriding the requests of patients and/or family members for that intervention.

HIV and AIDS

The Acquired Immunodeficiency Syndrome (AIDS) epidemic has had an enormous impact on health care provision in the United States. This impact has occurred largely because the AIDS epidemic has forced the medical community to openly address the needs of populations who have historically been marginalised in our society: gay men and intravenous drug users. The influence of the epidemic was felt on many levels. On the federal level AIDS activists forced the more rapid approval of medicines by the Federal Food and Drug Agency (FDA). State and city departments of public health had to organise culturally sensitive, anonymous HIV counselling and testing centres and on the individual practice level, physicians were forced to confront their own biases to provide ongoing care for a new and possibly transmissible epidemic.

AIDS cases seen by the author in his own practice are used to try to demonstrate some, but certainly not all, of the many ethical issues that confront the practitioner in the day-to-day care of people with AIDS.

Case 1 addresses these questions:

- What is the legal decision-making status of a long-term partner?
- How should I facilitate communication between family members?
- Who are some other staff members who may be able to help?

- How should I deal with any prejudices I may have in this case?

Case 2 addresses:

- What should you do if a patient refuses to be tested?

Case 3 addresses:

- When should you report a patient's HIV status to the Public Health Department?

Case 4 addresses:

- Should you prescribe protease inhibitors to a patient who is unlikely to follow through on the treatment regimen?

Case 1

You are the ICU attending physician taking care of a 40-year-old gay man with AIDS who is intubated with his third bout of Pneumocystis pneumonia. His condition is worsening steadily and he has not responded to appropriate antibiotic therapy. The patient's long-time partner, Richard, has a signed durable power of attorney (DPOA) and states that if the patient's condition becomes futile the patient would not want ongoing ventilation. As the ICU attending you decide that ongoing intubation is futile. You consult with Richard and decide to remove the patient from the ventilator to allow him to die in the morning. The patient's Roman Catholic parents arrive from Kansas and threaten a lawsuit if the ventilator is withdrawn.

There are several key questions, which come out of this case:

- Who is the legal decision maker here?
- What are some of the pertinent social influences in this case?
- Who are some other staff members who may be able to help?
- How should the physician deal with any prejudices they have in this case?

Discussion

What is the legal decision making status of a long-term partner?

Richard, the durable power of attorney is the legal decision maker in this case. The document is a legally binding agreement that states Richard is the final arbiter of all medical decisions once the patient becomes incapacitated. This creates a legal foundation for Richard to keep his role as the final medical decision maker in conjunction with the attending physician while allowing room for discussion with the family on this difficult topic.

How should I facilitate communication between family members?

This is an unfortunate situation for everybody involved. The physician can help diffuse this situation by trying to understand the different perspectives that each of the involved individuals brings to the situation. The family arrives to see their dying son and may be confronted with multiple issues for the first time. First they may be finding out that their son is gay, that he has AIDS, and that he is immanently dying all at the same time. Any of these issues may be a shock to the family, so it is important to keep this perspective in mind when making difficult care decisions and to communicate clearly and honestly with them. Communication regarding the patient's care should be consented to by the patient whenever possible.

Alternatively, individuals in the gay communities in metropolitan areas that have been severely affected by AIDS have watched many of their friends' die of their disease and are very well educated about end of life issues. It is likely that Richard as your patient's DPOA has spent significant time considering these issues with the patient before becoming the patient's surrogate. His role as the patient's significant other is not legally defined in many areas of the United States at this time. This relationship is often the equivalent of marriage in the gay community and should be respected by the hospital personnel in all points of medical care.

Who are some other staff members who may be able to help?

This is a case where several members may help with the decision. ICU nurses often have experience and perspective in dealing with grieving families of terminally ill patients as do staff social workers or grief counsellors. Another invaluable resource in this case is a hospital chaplain or spiritual counsellor who may be able to provide spiritual support and guidance to the family. It is important here to find out what resources are available in the hospital for Richard and the patient's family and after discussing the case with them, seek help from these other skilled professionals. If you as a physician have cultivated a relationship with these services it is often appropriate to invite them to a family meeting so that they can help you focus the discussion on the care of the patient, who is always your first priority as a physician.

How should I deal with any prejudices I may have in this case?

Much has been written on the responsibility of the physician in taking care of the patient with AIDS. The AMA position is "A physician may not ethically refuse to treat a patient whose condition is within the physician's realm of competence.... neither those who have the disease or are infected by the virus should be subject to discrimination based on fear or prejudice, least of all from members of the health care community." From this quote it is safe to say that the physician has a fiduciary responsibility toward the care of the HIV infected patient and there is no room within the profession for prejudice for people with AIDS. This stand on prejudice should cover not only gay men with AIDS, but also all other patients that a physician takes care of, even the next two cases (Case 2 and Case 3). (See also Personal Beliefs.)

Case 2

A 22-year-old woman is admitted to the hospital with a headache, stiff neck and photophobia but an intact mental status. Lab test reveal Cryptococcal meningitis, an infection commonly associated with HIV infection. When given the diagnosis, she adamantly refuses to be tested for HIV.

Should the medical staff test her anyway?

Discussion

Testing for HIV, as for any other medical procedure should be done only with the informed consent of the patient. Testing without consent is unethical in this setting. The physician's role in the care of this patient is ongoing support, education and guidance about her various options for care.

Case 3
Your patient with Cryptococcal meningitis eventually agrees to be tested for HIV and her test comes back positive. Due to her opportunistic infection she receives the diagnosis of AIDS.

Should she be reported to the department of public health?

Discussion

AIDS is a currently a reportable diagnosis in all 50 states of the union. Her diagnosis should be reported to the department of public health. Notably, HIV positivity without the diagnosis of AIDS is not reportable in all states. Currently, 30 of 50 states require reporting of a positive test. It is important to find out the local states laws where you are practicing to know how to approach this problem. (See also Confidentiality.)

Case 4

One of your clinic patients is a 35-year-old man with AIDS on Medicare who is an active intravenous drug user. He uses heroin and cocaine, but he never shares needles and is reliably present at all his clinic visits. He admits that he is often unable to take his medicines regularly when he is using drugs. He is asking about antiretroviral therapy with protease inhibitors. You have just read that HIV viral resistance to protease inhibitors occurs rapidly when patients are unable to take their medicines reliably.

Should you prescribe protease inhibitors to this patient?

Discussion

This is a difficult and ongoing debate in the care of patients with HIV. Protease inhibitors used in combination with nucleoside analogues have proven a powerful weapon in the fight against HIV. The problem of resistance is a real concern in a patient who cannot take his medicines reliably. Many public health advocates feel that these medicines should not be offered to patients who are admittedly noncompliant because they would be creating resistant clones of virus which could then be passed on to others, or make the individual unable to benefit later if they were able to become compliant. They also argue that the cost of these medications on the health care system is so extreme that they should only be used by those who can fully benefit from them. Others argue the principle of justice, which espouses equitable distribution of resources amongst all available people in need, and if the patient wants the medications he should have equal access to them.

There is no answer to this debate at this time. The only clear principle that should be followed here is that of non-abandonment. Whatever your choice is with the patient, the physician's responsibility is to remain available to the patient and continue an ongoing therapeutic relationship and encourage him with information and guidance about his HIV disease and issues of addiction.

Informed Consent

Opportunities to "consent" a patient abound on the wards. The aim of this section is to provide you with the tools required for the "basic minimum" as well as providing a more complete picture of the ideal informed consent process. You will find that the particular circumstances (eg. the patient's needs or the procedure) will determine whether a basic or complete informed consent process is necessary. (See also Informed Consent in the OR.)

What is informed consent?

Informed consent is the process by which a fully informed patient can participate in choices about her health care. It originates from the legal and ethical right the patient has to direct what happens to her body and from the ethical duty of the physician to involve the patient in her health care.

What are the elements of full informed consent?

The most important goal of informed consent is that the patient has an opportunity to be an informed participant in his health care decisions. It is generally accepted that complete informed consent includes a discussion of the following elements:

1. The nature of the decision/procedure
2. Reasonable alternatives to the proposed intervention
3. The relevant risks, benefits, and uncertainties related to each alternative
4. Assessment of patient understanding
5. The acceptance of the intervention by the patient

In order for the patient's consent to be valid, he must be considered competent to make the decision at hand and his consent must be voluntary. It is easy for coercive situations to arise in medicine. Patients often feel powerless and vulnerable. To encourage voluntariness, the physician can make clear to the patient that he is participating in a decision, not merely signing a form. With this understanding, the informed consent process should be seen as an invitation to him to participate in his health care decisions. The physician is also generally obligated to provide a recommendation and share her reasoning process with the patient. Comprehension on the part of the patient is equally as important as the information provided. Consequently, the discussion should be carried on in layperson's terms and the patient's understanding should be assessed along the way.

Basic consent entails letting the patient know what you would like to do and asking them if that will be all right. Basic consent is appropriate, for example, when drawing blood. Decisions that merit this sort of basic informed consent process require a low-level of patient involvement because there is a high-level of community consensus.

How much information is considered "adequate"?

How do you know when you have said enough about a certain decision? Most of the literature and law in this area suggest one of three approaches:

1. **Reasonable physician standard:** what would a typical physician say about this intervention? This standard allows the physician to determine what information is appropriate to disclose. However, it is probably not enough, since most research in this area shows that the typical physician tells the patient very little. This standard is also generally considered inconsistent with the goals of informed consent as the focus is on the physician rather than on what the patient needs to know.

2. **Reasonable patient standard:** what would the average patient need to know in order to be an informed participant in the decision? This standard focuses on considering what a patient would need to know in order to understand the decision at hand.

3. **Subjective standard:** what would this patient need to know and understand in order to make an informed decision? This standard is the most challenging to incorporate into practice, since it requires tailoring information to each patient.

Most states have legislation or legal cases that determine the required standard for informed consent. In the state of Washington, we use the "reasonable patient standard." The best approach to the question of how much information is enough is one that meets both your professional obligation to provide the best care and respects the patient as a person with the right to a voice in health care decisions. (See also Truth-Telling and Law and Medicine.)

What sorts of interventions require informed consent?

Most health care institutions, including UWMC, Harbourview, and VAMC have policies that state which health interventions require a signed consent form. For example, surgery, anaesthesia, and other invasive procedures are usually in this category. These signed forms are really the culmination of a dialogue required to foster the patient's informed participation in the clinical decision.

For a wide range of decisions, written consent is neither required nor needed, but some meaningful discussion is needed. For instance, a man contemplating having a prostate-specific

antigen screen for prostate cancer should know the relevant arguments for and against this screening test, discussed in layman's terms. (See also Research Ethics.)

When is it appropriate to question a patient's ability to participate in decision making?

In most cases, it is clear whether or not patients are competent to make their own decisions. Occasionally, it is not so clear. Patients are under an unusual amount of stress during illness and can experience anxiety, fear, and depression. The stress associated with illness should not necessarily preclude one from participating in one's own care. However, precautions should be taken to ensure the patient does have the capacity to make good decisions. There are several different standards of decision-making capacity.

Generally you should assess the patient's ability to:

- Understand his or her situation,
- Understand the risks associated with the decision at hand, and
- Communicate a decision based on that understanding.

When this is unclear, a psychiatric consultation can be helpful. Of course, just because a patient refuses a treatment does not in itself mean the patient is incompetent. Competent patients have the right to refuse treatment, even those treatments that may be life-saving. Treatment refusal may, however, be a flag to pursue further the patient's beliefs and understanding about the decision, as well as your own.

What about the patient whose decision making capacity varies from day to day?

Patients can move in and out of a coherent state as their medications or underlying disease processes ebb and flow. You should do what you can to catch a patient in a lucid state - even lightening up on the medications if necessary - in order to include him in the decision making process.

What should occur if the patient cannot give informed consent?

If the patient is determined to be incapacitated/incompetent to make health care decisions, a surrogate decision maker must speak for her. There is a specific hierarchy of appropriate decision makers defined by state law (also see the DNR topic page). If no appropriate surrogate decision maker is available, the physicians are expected to act in the best interest of the patient until a surrogate is found or appointed.

Is there such a thing as presumed/implied consent?

The patient's consent should only be "presumed", rather than obtained, in emergency situations when the patient is unconscious or incompetent and no surrogate decision maker is available. In general, the patient's presence in the hospital ward, ICU or clinic does not represent implied consent to all treatment and procedures. The patient's wishes and values may be quite different than the values of the physician's. While the principle of respect for person obligates you to do your best to include the patient in the health care decisions that affect his life and body, the principle of beneficence may require you to act on the patient's behalf when his life is at stake.

Case 1

A 64-year-old woman with MS is hospitalised. The team feels she may need to be placed on a feeding tube soon to assure adequate nourishment. They ask the patient about this in the morning and she agrees. However, in the evening (before the tube has been placed), the patient becomes disoriented and seems confused about her decision to have the feeding tube placed. She tells the team she doesn't want it in. They revisit the question in the morning, when the patient is again lucid. Unable to recall her state of mind from the previous evening, the patient again agrees to the procedure.

Is this patient competent to decide? Which preference should be honoured?

Discussion

This patient's underlying disease is impairing her decision making capacity. If her wishes are consistent during her lucid periods, this choice may be considered her real preference and followed accordingly. However, as her decision making capacity is questionable, getting a surrogate decision maker involved can help determine what her real wishes are.

Case 2

A 55-year-old man has a 3-month history of chest pain and fainting spells. You feel his symptoms merit cardiac catheterisation. You explain the risks and potential benefits to him, and include your assessment of his likely prognosis without the intervention. He is able to demonstrate that he understands all of this, but refuses the intervention.

Can he do that, legally? Should you leave it at that?

Discussion

This patient understands what is at stake with his treatment refusal. As he is competent to make this decision, you have a duty to respect his choice. However, you should also be sure to explore his reasons for refusing treatment and continue to discuss your recommendations. A treatment refusal should be honoured, but it should also not be treated as the end of a discussion.

Informed consent in the OR

The informed consent process for surgery usually begins long before the patient enters the operating room environment, with the patient's first visit to the surgeon's office. In contrast, the informed consent for anaesthesia is often obtained in the minutes before surgery in which the anaesthesiologist and patient meet for the first time.

What are some common situations in which a patient's ability to make decisions about surgery and anaesthesia may be questioned?

Many situations commonly arise around the time of surgery, in which a patient's ability to make health care decisions may be, rightfully or wrongfully, called into question. Some of them include:

- the premedicated patient
- the patient in labour
- the patient under stress
- the patient with known mental illness
- the patient with organic brain disease
- the immature patient (ie. patient who is minor in age, or who has immature mental capacity, such as some forms of mental handicap)

How does medication affect a patient's ability to give valid consent to a procedure?

It is common to encounter patients who have received sedation and/or pain medication prior to coming to surgery, and it is also common for such medications to be deliberately withheld prior to surgery in anticipation of the necessity to obtain consent. When pain medications are withheld, patients may feel pressured to consent in order to obtain medication to relieve their suffering.

In some instances, premedication may actually enhance a patient's ability to make decisions, by providing pain relief or relief from emotional distress, so that they can focus on the choices they are making. Clearly, if premedication has rendered the patient unable to listen, to understand their situation, the need for care, the risks, and alternatives, or to communicate a decision, then it has negated the informed consent process. But pain medication should never be withheld from a suffering patient under the guise of obtaining informed consent.

How does the physical or mental stress of the OR affect the informed consent process?

Many studies have examined the ability of labouring patients to give informed consent. While many patients do not later remember the informed consent process, labouring patients in general demonstrate the capacity to understand their situation, understand proposed care, risks, and alternatives, and express consent. Legal cases have recognised the complex voluntary physical control required from a labouring woman to permit epidural placement, and cite the physical cooperation of the woman in the process as an indication of motivation and consent for the procedure.

While many, if not most patients coming to the OR are experiencing stress, there is little evidence that most are not able to meet the standards mentioned on the main topic page to make decisions regarding their health care.

Patient immaturity can be relevant when the patient is of a very young age (minor) and presumed to not have the cognitive development to make meaningful decisions, or when the patient suffers from mental handicap which impairs her cognitive development. Once again, neither condition in itself precludes participation of the patient in decision making, but expert consultation may be needed to determine whether the patient is capable of understanding their situation and options, and making a decision based on them. In the case of minor patients, legal precedents determine when a minor can give legal consent, but do not address the issues of when a minor patient should be invited ethically to participate in the informed consent process.

What information should be provided to surgical patients in the consent process?

General rules to follow in consent for surgery and anaesthesia are to inform the patient of common risks even if they are not serious and very serious risks, such as death, even if they are not common. By asking the patient if they have any specific concerns, you can invite the patient

to let you know of any "special" informational needs that they may have which are not obvious to you.

When discussing risks with patients, understand that mere recitation of statistical risks may mean little to patients, and it can be helpful to relate the information to risks which have some meaning for the patient. The approximately one in 50,000 risk of death during general anaesthesia in a healthy patient can be compared to that of the risk of death in an automobile accident (about twice that), as a way of putting perspective on the information being provided.

Can I influence patients during the informed consent process?
Influence can be applied to the information given to patients, and generally falls into three categories:

- coercion
- manipulation
- persuasion

Coercion is the application of a credible threat to the patient, and is always unethical. Manipulation involves incomplete or non-truthful presentation of information, such as lying, omitting vital information, or deliberately deceiving. Manipulation is always ethically suspected. Persuasion involves the presentation of a rational argument for a choice, and is permissible, even desirable during the consent process. Patients recognise that physicians have expertise and advice to offer about their care, and expect physicians to be forthright with recommendations.

Do we harm patients by causing stress and anxiety when we tell them about the risks of anaesthesia and surgery?

"Therapeutic privilege," or the idea that information may harm patients, is often cited as a reason to curtail the discussion of risks with patients about to undergo anaesthesia and surgery. Multiple studies have failed to demonstrate differences in the way patients and observers rate the stress levels of patients who receive detailed information when compared with patients who received little or no information about risks.

What do I do in an emergency, or when the patient is incapable of making a decision?

Conscious, competent patients have the right to make choices regarding their health care in emergencies, just as in routine care.

When patients are incapacitated, it is important to seek the advice of appropriate surrogate decision makers and others who know the patient and are aware of his or her usual choices. When such information cannot be obtained, the physician should try to act in the best interest of the patient until such a surrogate can be found.

Is the surgical consent sufficient to cover anaesthesia care?

Principles involving the informed consent process require that the best available information about procedures and risks be provided to patients. Just as Anaesthesiologists lack the expertise to discuss risks of surgery, surgeons lack expertise to discuss the nature and risks of anaesthesia. While the surgical consent form does contain a phrase regarding consent for anaesthesia care, the informed consent process requires that a separate discussion of anaesthesia risks be carried out by the anaesthesia provider.

What if the patient requests not to hear about risks?

Patients have the right to refuse information, but the request must originate from the patient and not the physician.

Case 1

A 28-year-old man presents to the emergency room with testicular torsion, in extreme pain. Emergency surgery is scheduled, but the urologist will be unable to see the patient for at least one hour. He asks that the patient not be given any pain medication, so that "consent can be obtained" when he sees the patient.

Are the surgeon's concerns about informed consent valid? What ethical issues should be considered with regard to pain treatment for this patient?

Discussion

The surgeon has the common misconception that informed consent is somehow invalidated by the presence of specific medications. Patients who present for surgery may have taken a variety of medications, many of which can have effects on mental function. The issue is not whether the patient has been premedicated, but whether premedication has impaired the patient's ability to participate in the informed consent process.

The ethical issues involved in this case include assessment of the patient's capacity to make decisions, and whether the patient is deliberately or otherwise, being coerced into consenting for surgery. The patient's capacity to provide consent is determined not by what recent medications

have been given, but by whether the patient understands the need for treatment, can listen to and understand treatment options and risks, and can then express a choice regarding their care. Respect for patient autonomy requires that we promote a patient's ability to make an "unencumbered" choice. Severe pain, by impairing a patient's ability to listen and understand, is an encumbrance to the informed consent process. Further, withholding pain medication for the purpose of obtaining consent might be coercive.

Case 2

A 36-year-old man presents for bone marrow donation for transplantation. His primary care physician contacts the anaesthesiologist to report that the patient is extremely anxious about the procedure. The primary doctor requests that the anaesthesiologist not discuss risks with the patient, since it might "scare" the patient into not providing bone marrow for a sick cousin.

Should you curtail risk discussion? What should you tell this anxious patient?

Discussion

This request to curtail discussion of risks is not originating with the patient. To avoid discussion for the purpose of improving the likelihood that the patient will cooperate with bone marrow harvest not only carries some mistaken assumptions about the effects of risks discussions, but it "uses" the patient to meet the ends of another individual, rather than to further his own goals, a distinctly unethical practice.

Since the patient is anxious, it is reasonable to offer to discuss risks with him, but inform him that he has the choice to not have a detailed discussion if he thinks it might unduly stress him.

More importantly, a well-done discussion of risks with this patient can be reassuring, and serve to decrease his anxiety about the upcoming procedure. The patient may be suffering from unreasonable fears about the risks of the procedure. Since the patient is healthy, anaesthesia and procedure risks are minimal. He can be reassured that the procedure presents him with less risk than many things he does every day without much concern--such as driving a car to his appointment in your office.

Team Issues

Because of the increasing complexity and scope of patient problems presenting to the health care environment, patient care now routinely combines the efforts of physicians of different disciplines, skilled nursing professionals, and other health care professionals. Comprehensive

patient care often involves trying to solve problems which are beyond the scope of expertise and training of any one provider. Thus, the organisation of professionals involved in one patient's care has evolved from that of a hierarchy, with the physician in a "command" position, to that of a multidisciplinary team, interfacing many different kinds of health care professionals, each with separate and important knowledge, technical skills, and perspectives. In a teaching hospital, team membership becomes that much more complex with the presence of students, interns, residents, and fellows.

How do teams work together?

Working together as a team, professionals must balance responsibilities, values, knowledge, skills, and even goals about patient care, against their role as a team member in shared decision-making. Because many physicians, in particular, are accustomed to a practice environment in which decisions are "made" by the doctor, and "carried out" by other professionals, it is difficult sometimes for physicians to adjust to a team approach, in which majority opinion, deference to more expert opinion, unanimity, or consensus may be more appropriate methods of decision-making than autocratic choice. Further, physicians who maintain a hierarchical concept of medical care may face serious problems when disagreements arise with other physicians of equal "stature" on the medical team. Interdisciplinary conflicts are seen in all areas of medical practice, but the operating room environment is particularly rich in examples in which patient care involves interdisciplinary cooperation, conflict, and compromise.

Who is in charge in the operating room? Isn't the surgeon "Captain of the Ship"?

You will certainly hear at some point in your medical training that the surgeon is "captain of the ship" in the operating room. While recent legal decisions have essentially "sunk" the concept, it is important to understand the ethical and legal terrain. The phrase "captain of the ship" was first used by the Pennsylvania Supreme Court in 1949 in McConnell vs. Williams. In that case, an intern at a charity hospital was responsible for blinding a newborn by improperly applying silver nitrate drops to her eyes. Laws in widespread application at the time provided many hospitals with "charitable immunity" from legal damages, and the parents of the newborn were unable to get money from the intern because he acted as a hospital employee. They therefore brought suit against the obstetrician. The Pennsylvania Supreme Court allowed a finding of negligence against the obstetrician, despite the fact that the obstetrician had had no direct part in the negligent act, specifically so that someone would pay money to the parents. In its decision, the court used an analogy from maritime law, in which a captain can be held liable for the action of all members of the crew of his ship.

Since 1949, several key changes have taken place. Hospitals are no longer immune from liability in most jurisdictions, in part because hospitals generally carry insurance against the negligent acts of their employees. Courts also recognise that the scope and complexity of medical practice is such that no single provider generally has complete control over a patient's medical care. The

diversity of medical practice and the different forms of training and certifications required for specialty practice testify that different professionals have different expertise and therefore diverse levels of responsibility for individual acts in patient care. In this aspect the law is fair: the greater the authority and expertise asserted in a given act, the greater an individual's legal responsibility becomes.

In recent years, many state Supreme Courts have specifically thrown out the "captain of the ship" doctrine in disgust. Cases in which the captain of the ship doctrine has been specifically discarded include those in which plaintiffs have asserted that the surgeon was responsible for the acts of nurses, nurse anaesthetists, anaesthesiologist, radiologists, and radiology technologists, and in which plaintiffs asserted that the anaesthesiologist was responsible for the acts of surgeons, nurses, and nurse anaesthetists. Ironically, some recent law suits have been successfully pursued against surgeons for the actions of other operating room personnel, only because the surgeon himself asserted that he had, or should have had, complete control over everyone in the room at the time of the negligent act!

What are the ethical obligations of members of the interdisciplinary team in patient care?

Ethically, every member of the operating room team has separate obligations, or duties, toward patients, which are based on the provider's profession, scope of practice and individual skills. Team members also have ethical obligations to treat each other in a respectful and professional manner.

Relationships between professionals on the multidisciplinary team are by their nature unequal ones. Different knowledge and experience in specific issues both ethically and legally imparts unequal responsibility and authority to those care providers with the most knowledge and experience to handle them. But also because of differences in training and experience, each member of the team brings different strengths. Team members need to work together in order to best utilise the expertise and insights of each member.

Do I have to do whatever I am told by the attending physician, even if I disagree with their plans?

Professional relationships not only exist between different professions and specialties within similar professions, but between students and teachers as well. The student-teacher relationship is also an unequal one, not merely because teachers generally have more authority than students, based on their training and years of experience, but much greater responsibility as well. An attending physician, for example, may be held both morally and legally liable for the actions of students or residents, whether or not she approved of those actions. Ethically, teachers have obligations to observe and control the actions of junior members of the medical team, both to prevent harm to patients from inexperienced care-givers, and to educate students in appropriate care. Students and residents, conversely, have obligations to their patients and to their teachers,

to not act recklessly or without the knowledge and approval of supervisors. Whenever a student or resident disagrees with an attending physician's plans, he should seek input from the attending physician, both about the reasoning to pursue the plan, and about the reasoning for rejecting her own. A respectful exchange of views may provide both parties with new information, and certainly serves to further education.

What is meant by "respectful" exchange of views?

Precisely because of the inequality of authority and responsibility in inter-professional, inter-physician, and student-teacher relationships, obligations of mutual respect are particularly important on the multidisciplinary team.

Disagreements between professionals are common and expected, because of different knowledge, experience, values, and perspectives of the various team members. While disagreements might be settled in a number of ways, mutual respectful behaviour is a mandatory feature of professionalism. Thus, while it is not only possible, but expected, that members of the patient care team will disagree at times, it is never acceptable for disagreements to be verbalised in an unprofessional manner.

Respectful behaviour begins with both listening to and considering the input of other professionals. Ask yourself whether your perception of whether you are respected depends more upon whether the other party agrees with you, or whether, despite disagreeing, they listened and acknowledged your point of view.

Respect is demonstrated through language, gestures, and actions. Disagreement can and should be voiced without detrimental statements about other members of the team, and without gestures or words that impart disdain. Both actions and language should impart the message: "I acknowledge and respect your perspective in this matter, but for the following reasons. I disagree with your conclusions, and believe I should do something else..."

It should go without saying that disrespectful behaviour from a colleague does not justify disrespectful behaviour in return.

How can disagreements on the multidisciplinary team be handled?

In the best situations, disagreement leads to a more complete inter-professional discussion of the patient's care, resulting in a new consensus about the best course of action. The new consensus may require compromises from each individual.

When members of a team cannot arrive at a consensus of what should be done, it may be helpful to consult other professionals who are not directly involved in the patient's care team for

objective input. If the disagreement still cannot be resolved, another resource may be the hospital's ethics committee, which can listen to disagreements and help suggest solutions.

Case 1

An otherwise healthy 54-year-old man presents for radical retropubic prostatectomy, and expresses interest to his anaesthesiologist in having postoperative epidural narcotic pain management. The anaesthesiologist believes it provides superior pain control, but is informed by the surgeon that the patient "is not to have an epidural."

Is the anaesthesiologist obliged to "take an order" from the surgeon?
Should the anaesthesiologist provide the anaesthetic he feels is best, regardless of the surgeon's input?

Discussion

The answer to both questions is no. Anaesthesiologists have special knowledge and training, which are not shared by the surgeon with regard to the safe administration of anaesthesia. They also have direct obligations to the patient to provide safe medical care which is as far as possible in keeping with the patient's wishes. When medical issues of safety or specific patient goals are in conflict with the surgeon's desires, the anaesthesiologist is first ethically obliged to provide the best care to the patient. But the anaesthesiologist would be incorrect to proceed at this point without some discussion with the surgeon, for at least two reasons. First, ignoring the surgeon's communication is disrespectful. Second, the surgeon may have valuable information to impart, such as "my patients achieve very good pain control with intravenous and oral medication, and end up being discharged two days sooner than epidural patients, because they do not require prolonged urinary catheterisation from epidural-associated urinary retention." This dialogue between team members can result in improved team relations, and better care for the patient.

Case 2

A 28-year-old woman presents for diagnostic laparoscopy for pelvic pain. During laparoscopy, the surgeon announces that she intends to proceed to hysterectomy for multiple uterine myomata. The anaesthesiologist then declares that he will "wake the patient up" rather than allow the surgeon to proceed, due to lack of consent for the procedure, and questionable medical necessity.

Can the anaesthesiologist "tell" the surgeon what to do? Who is in charge when two physicians on the team disagree?

Discussion

The anaesthesiologist can stop the surgery, and may even have an ethical obligation to the patient to do so, but should take such action only after discussing several issues with the surgeon.

- Is the surgery in fact included in the consent?

- If not, is the surgery medically necessary at this moment (ie. would delay place the patient's life in significant danger) or can it be postponed until the patient can be awakened and asked for consent?

If the surgery is not emergent, and there is no consent, the anaesthesiologist is morally obliged to protect the patient's autonomy and right to give consent. Anaesthesiologists have been also held legally liable for harm done to patients during elective surgery, for which they did not consent, because the anaesthesiologist renders the patient insensate and unable to protect themselves from unwanted intrusion.

Often, in a case like this one, consensus can be obtained from the health care team, which in this case could consult the hospital legal counsel and the hospital ethics committee prior to proceeding.

Law & Ethics

Law and Medical Ethics are disciplines with frequent areas of overlap, yet each discipline has unique parameters and a distinct focus.

To better understand the relationship between law and medical ethics, these materials will briefly review:

1. Definitions - Sources of Authority

2. Conceptual Models

3. Roles of Medical Ethics and the Law

4. How can I find out what the law says on a particular subject?

The two cases further explore this topic, and check out the additional readings for bibliographic references.

Definitions - Sources of Authority

In the course of practicing medicine, a range of issues may arise that require consultation from a lawyer, a risk manager, or an ethicist. The following discussion will outline key distinctions between these roles.

The role of lawyers and risk managers are closely linked in many health care institutions. Indeed, in some hospitals the Risk Manager is an attorney with a clinical medicine background. There are, however, important distinctions between law itself and risk management.

- Law is the established social rules for conduct; a violation of law may create criminal or civil liability.

- Risk Management is a method of reducing risk of liability through institutional policies/practices.

Risk Management is guided by legal parameters but has a broader institution specific mission. It is not uncommon for a hospital policy to go beyond the minimum requirements set by the legal standard.

When legal and risk management issues arise in the delivery of health care, there may be ethical issues, too. Conversely, what is originally identified as an ethical problem may raise legal and risk management concerns.
Medical ethics may be defined as follows:

- Medical ethics is a discipline/methodology for considering the implications of medical technology/treatment and what ought to be.

To better understand the significant overlap among these disciplines, consider the sources of authority and expression for each.

Law is derived/expressed through:

- Federal and state constitutions

- Federal and state statutes (ex. Revised Code of WA.)

- Federal and state regulations (ex. WA. Administrative Code)

- Federal and state case law (individual lawsuits-decisions at appellate level.)

Risk Management is derived from law and professional standards and is expressed through institutional policies/practices.

Medical Ethics is derived/expressed through:

- law
- institutional policies/practices
- policy of professional organisations
- professional standards of care, fiduciary obligations

Conceptual Models of Law and Ethics

Conceptual Model - Linear

Conceptual Model - Distinctions

Conceptual Model - Interconnectedness

Roles of Medical Ethics and the Law

Within their distinctive roles, the disciplines of law and medical ethics nevertheless significantly overlap. Consider that both disciplines address:

- access to medical care (provision of care, emergency treatment, stabilisation and transfer)
- informed consent
- confidentiality of health care information and exceptions to confidentiality (mandatory reporting obligations such as: child and elder abuse, duty to warn)
- privileged communications with health care providers
- advance directives
- abortion
- physician-assisted suicide

There are, however, significant distinctions between law and medical ethics in philosophy, function and power. A court ruling is a binding decision that determines the outcome of a particular controversy. A statute or administrative code sets a general standard of conduct, which must be adhered to or civil/criminal consequences may follow a breach of the standard. Conversely, an ethics pronouncement which is not adopted into law may be a significant professional and moral guidepost but it is generally unenforceable. Lawmakers (courts and legislatures) frequently do turn to the policy statements (including any medical ethics statements) of professional organisations when crafting laws affecting that profession. Thus, health care providers may greatly influence legal standards by their work in creating professional ethics standards.

Good ethics has been described as beginning where the law ends. The moral conscience is a precursor to the development of legal rules for social order. Law and medical ethics thus share the goal of creating and maintaining social good and have a symbiotic relationship as expressed in this quote:

> "Conscience is the guardian in the individual of the rules which the community has evolved for its own preservation"; William Somerset Maugham.

How can I find out what the law says on a particular subject?

Law and medical ethics are both dynamic and are in a constant state of change, ie. new legislation and court decisions occur and medical ethics responds to challenges created by new technology, law or other influences. To locate information about what the law on a particular topic is or to get copies of statutes, regulations or case law you may need to go to a law library. There are also legal search tools available on the Internet. Other potential resources are medical journals, which frequently have articles on ethical issues that mention relevant legal authority.

Case 1

A 32 year old woman was admitted to the Trauma Intensive Care Unit following a motor vehicle accident; she had multiple injuries and fractures, with several complications which continued to develop over the first couple of weeks. The patient rapidly developed Adult Respiratory Distress Syndrome, was on a ventilator, and was continuously sedated. Shortly after the patient's admission, her parents were contacted and remained vigilant at her bedside. The parents reported that the patient was one month away from having her divorce finalised. The patient's husband was reportedly physically and emotionally abusive to her throughout their five years of marriage. The parents had not notified this man of the patient's hospitalisation, and reported that visit by him would be distressing to the patient if she were aware of it. The patient's soon to be ex-husband is her legal next of kin.

Should the husband be responsible for treatment decisions which the patient cannot make?

What are the legal and ethical parameters?

Discussion

Some key legal and ethical issues raised by Case #1 are informed consent and surrogate decision-making. While the details of each case will determine the advice provided, Case #1 raises a number of issues with legal ramifications.

Specific legal issues:

- There is implied consent by law for provision of "emergency" medical treatment. The Washington law (statute-RCW 7.70.050(4)) uses the term "emergency" but doesn't define it. However, the hospital policy in the UW/HMC Medical Centres Consent Manual (p. A-5) defines what the University's hospitals will consider an "emergency" and sets an institutional documentation standard:

  > Consent for care is implied by law when immediate treatment is required to preserve life or to prevent serious impairment of bodily functions and it is impossible to obtain the consent of the patient, his/her legal guardian, or next-of-kin.
  >
  > In such emergency situations, the physician should consult, whenever possible, with the patient's attending physician or with another physician faculty member about the existence of an emergency. This must be noted in the patient's medical record, together with statements by each physician that the emergency treatment was necessary for the reasons specified. These notations should clearly identify the nature of the threat to life or health, its immediacy, and its magnitude.

  Thus, if a medical emergency exists and implied consent is relied on by the health care providers, it should be documented in the patient's medical record in accordance with legal and institutional standards.

- The patient may have provided her own consent to treatment either at the time of her admission or earlier in her hospitalisation. At that time, she may have expressed her ongoing wishes for care. The patient's own previous statements/consent may therefore be the basis for continued consent for her ongoing care. Also, it is important to note that neither the law nor our UW institutional policy sets an explicit time limitation on implied consent based on an "emergency."

- If there is a need for informed consent for a new treatment decision on behalf of the patient, the patient's previously expressed wishes may still be relevant to her legally authorised surrogate decision-maker and her treatment plan.

- If the patient already filed for divorce, it is likely that there is a temporary court order in effect and this order may affirmatively remove the patient's estranged husband from making medical decisions for her. Also, it is common in divorce paperwork to have mutual restraining orders which prevent both spouses from contacting each other. The patient's parents should be asked to provide the name of her divorce attorney to obtain copies of the relevant legal papers - which can then be placed in the legal section of the patient's medical record. With the husband thus removed as her surrogate decision-maker, it appears the patient's parents would become the highest level class of surrogate decision-maker and could provide informed consent for her care if the patient is unable to do so.

- Even if the patient's husband remains as her legal surrogate decision-maker, his decisions on the patient's behalf are constrained by legally imposed standards. First, a surrogate is legally required to provide "substituted judgment" on behalf of the patient. This means that the surrogate must act in accordance with the patient's wishes. If substituted judgment isn't possible (ie. unknown what the patient would want under the current medical circumstances), then the law requires the surrogate to act in the patient's "best interests". Since the medical team has significant input about what would medically be in the patient's interest, a decision by a surrogate which doesn't adhere to this standard should not be automatically followed and may need to be reviewed by the institutional ethics committee, risk management, or legal counsel.

- The patient's husband may be willing to waive his surrogate decision-maker role to his estranged wife. If this occurs, then he would agree to remove himself from the list of potential surrogate decision-makers and the next highest level surrogate decision-maker(s) would be contacted as necessary to provide informed consent for the patient.

- A final option may be for the patient's parents to file to become the patient's legal guardians for health care decision-making.

Case 2

A 72-year-old woman was admitted to the Neurological Intensive Care Unit following a cerebral haemorrhage, which left her with severe brain damage and ventilator dependent. One year before this event, the patient and her husband had drawn up "living wills" with an attorney. The patient's living will specified that the patient did not want ventilator support, or other artificial life supports, in the event of a terminal condition or a permanent vegetative state.

The patient's husband is her legal next of kin and the person with surrogate decision-making authority. When the living will was discussed with him, he insisted that the patient had not intended for the document to be used in a situation like the present one. By this, the husband apparently meant that although the patient would not be able to recover any meaningful brain function, her condition was not imminently terminal. The husband did not consider his wife to be in a permanent vegetative state.

The treatment team allowed a week to pass, with the goal of providing the husband more time to be supported in his grief and to see how ill his wife was. Nevertheless, at the end of this time, the husband was unwilling to withdraw life support measures consistent with the patient's wishes as expressed in her living will.

What should be done?

What are the legal and ethical parameters?

Discussion

The legal parameters and the ethical parameters in Case #2 are informed consent, surrogate decision-making and the patient's ability to direct her care - expressed in law as a liberty or privacy right and in ethics as respect for patient autonomy. While the details of each case will determine the advice provided, Case #2 raises a number of issues with legal ramifications.

Specific legal issues:

- Patient is unable to provide her own informed consent for medical care. Informed consent means making a medical treatment choice and includes the choice of non-treatment. What is known about the patient's wishes for continued medical treatment under her current circumstances?

- The patient's Advance Directive is strong evidence and significant in determining what the patient would want for substituted judgment. Since the patient's husband (her legal surrogate) only made vague statements as to why he thought she would want continued care under these circumstances and the husband's perspective was contradicted by their adult children - it appears the situation requires further communication efforts, eg. patient care conference, ethics consult.

- If these additional communication efforts fail to resolve the impasse - one legal/risk management approach may be to go forward with withdrawal of life support under the following conditions:

    1. Verify that the content of the patient's Advance Directive is consistent with a decision to forego further life-sustaining measures. Check, if possible, with those persons who were present when she prepared/signed the document to gather further information about the patient's intentions.

    2. Affirm that the requisite clinical determination(s) were made ("terminal" or "permanent unconscious" conditions) to activate the patient's Advance Directive. Check to make sure the clinical determination is well-documented in the patient's chart.

3. Affirm consensus among the medical team about: the clinical determinations; the appropriateness of withdrawing life support as in the patient's best interests; and that withdrawal is consistent with her Advance Directive.

4. Set a final patient care conference with the family members to review the patient's prognosis and the medical team's decision to withdraw care at a specific future date and time. This advance notice of planned future action allows the patient's husband an opportunity to seek judicial review or arrange for a transfer of care to another medical facility before the withdrawal of care. Under the circumstances, if the husband sought such review or transfer, the patient would need to be continued on life support pending completion of review or transfer. The legal benefit of this notice and time to act is it eliminates any claim that the hospital unilaterally took irreversible action without the family's consent or at least without their acquiescence. This course of action would also break the stalemate of the patient's situation and force a resolution.

Mistakes

Errors are inevitable in the practice of medicine. Sometimes these result from medicine's inherent uncertainty. Occasionally they are the result of mistakes or oversights on the part of the individual provider. In either case, a physician will face situations where she must address mistakes with her patient.

How do mistakes occur?

All physicians make mistakes, and most mistakes are not the result of negligence. A physician may make a mistake because of an incomplete knowledge base, an error in perception or judgment, or a lapse in attention. Making decisions on the basis of inaccurate or incomplete data may lead to a mistake. The environment in which the physicians practice may also contribute to errors. Lack of sleep, pressures to see patients in short periods of time, and distractions may all impair an individual's ability to avoid mistakes.

Do physicians have an ethical duty to disclose information about medical mistakes to their patients?

Physicians have an obligation to be truthful with their patients. That duty includes situations in which a patient suffers serious consequences because of a physician's mistake or erroneous judgment. The fiduciary nature of the relationship between a physician and patient requires that a physician deal honestly with his patient and act in her best interest.

How do I decide whether to tell a patient about an error?

In general, even trivial medical errors should be disclosed to patients. Any decision to withhold information about mistakes requires ethical justification. If a physician believes there is justification for withholding information about medical error from a patient, his judgment should be reviewed by another physician and possibly by an institutional ethics committee. The physician should be prepared to publicly defend a decision to withhold information about a mistake from the patient.

Won't disclosing mistakes to patients undermine their trust in physicians and the medical system?

Some patients may experience a loss of trust in the medical system when informed that a mistake has been made. Many patients experience a loss of trust in the physician involved in the mistake. However, nearly all patients desire some acknowledgment of even minor errors. Loss of trust will be more serious when a patient feels that something is being hidden from them.

By disclosing a mistake to my patient, do I risk having a malpractice suit filed against me?

It has been shown that patients are less likely to consider litigation when a physician has been honest with them about mistakes. Many lawsuits are initiated because a patient does not feel they have been told the truth. Litigation is often used as a means of forcing an open and honest discussion that the patient feels they have not been granted. Furthermore, juries look more favourably on physicians who have been honest from the beginning than those who give the appearance of having been dishonest.

What if I see someone else make a mistake?

A physician may witness another health care provider making a major error. This places the physician in an awkward and difficult position. Nonetheless, the observing physician has some

obligation to see that the truth is revealed to the patient. This should be done in the least intrusive way. If the other health care provider does not reveal the error to the patient, the physician should encourage her to disclose her mistake to the patient. Should the health care provider refuse to disclose the error to the patient, the physician will need to decide whether the error was serious enough to justify taking the case to a supervisor or the medical staff office, or directly telling the patient. The observing physician also has an obligation to clarify the facts of the case and be absolutely certain that a serious mistake has been made before taking the case beyond the health care worker involved.

Case 1

An 18-month-old child presents to the clinic with a runny nose. Since she is otherwise well, the immunisations due at 18 months are administered. After she and her mother leave the clinic, you realise that the patient was in the clinic the week before and had also received immunisations then.

Should you tell the parents about your mistake?

Discussion

The error is a trivial one. Aside from the discomfort of the unnecessary immunisation, no harm has resulted. Nonetheless, an open and honest approach to errors is most appropriate. While the parents may be angry initially about the unnecessary injection, they will appreciate your candour. On the other hand, should they discover the error and believe you have been dishonest; their loss of trust will be significant.

Case 2

A 3-month-old has been admitted to the hospital with a newly diagnosed ventricular septal defect. She is in early congestive heart failure and digoxin is indicated. After discussing the proper dose with the attending physician, you write an order for the drug. Thirty minutes later the baby vomits and then has a cardiac arrest and dies. You discover that in writing the digoxin order you misplaced the decimal point and the child got 10 times too much digoxin.

What is your duty here?

Will you get sued if you tell the truth?

Discussion

This unfortunate event represents a serious error with profound implications for the patient and family. You owe this family an honest explanation. They need to hear you say that you're sorry. Any attempt to hide the details of the event would be dishonest, disrespectful, and wrong. Though a lawsuit may follow, these parents are less likely to litigate if you deal with them honestly and take responsibility for the error.

Case 3

A 3-year-old presents to the emergency department. She was diagnosed with pyelonephritis by her physician yesterday, treated with an intramuscular injection of antibiotic and sent home on an oral antibiotic. She is vomiting today and unable to keep the antibiotic down. As you prepare to admit her, you feel she should have been admitted yesterday.

Should you tell the parents that their physician made a mistake? How should you handle this disagreement?

Discussion

The practice of medicine is not an exact science. Frequently physicians will disagree about what constitutes the most appropriate management in a given case. Often these are legitimate disagreements with more than one acceptable course of action. Simply because you would have managed a patient differently does not mean the other physician made a mistake. In this case, you may wish to discuss the case with the other physician and explain why you manage children with pyelonephritis differently. However, in situations where standard practice varies, the parents should not be told that a mistake has been made.

Parental decisions

Adult patients have the moral and legal right to make decisions about their own medical care. Because young children are not able to make complex decisions for them, the authority to make medical decisions on behalf of a child usually falls to the child's parents.

Who has the authority to make decisions for children?

Parents have the responsibility and authority to make medical decisions on behalf of their children. This includes the right to refuse or discontinue treatments, even those that may be life-sustaining. However, parental decision making should be guided by the best interests of the child. Decisions that are clearly not in a child's best interest can and should be challenged.

What is the basis for granting medical decision making authority to parents?

In most cases, a child's parents are the persons who care the most about their child and know the most about him. As a result, parents are expected to make the best medical decisions for their children. Furthermore, since many medical decisions will also affect the child's family, parents can factor family issues and values into medical decisions about their children.

When can parental authority to make medical decisions for their children be challenged?

Medical caretakers have an ethical and legal duty to advocate for the best interests of the child when parental decisions are potentially dangerous to the child's health, imprudent, neglectful, or abusive. When satisfactory resolution cannot be attained through respectful discussion and ethics consultation, seeking a court order for appropriate care might be necessary.

What if parents are unavailable and a child needs medical treatment?

When parents are not available to make decisions about a child's treatment, medical caretakers may provide treatment necessary to prevent harm to the child's health.

Should children be involved in medical decisions even though their parents have final authority to make those decisions?

Children with the developmental ability to understand what is happening to them should be allowed to participate in discussions about their care. As children develop the capacity to make decisions for themselves, they should be given a voice in medical decisions.

What happens when an older child disagrees with her parents about a medical treatment?

The wishes of competent older children regarding their medical care should be taken seriously. If the medical caretaker judges a child competent to make the medical decision in question, she

should first attempt to resolve the issue through further discussion. If that fails, the medical caretaker should assure that the child's voice has been heard and advocate for the child. In intractable cases, an ethics consultation or judicial hearing should be pursued.

Under what circumstances can minors make medical decisions for themselves?
Minors have the ethical and legal authority to make medical decisions for themselves when they have reached the legal age of majority or become "emancipated." Most states recognise an emancipated minor as a person who meets one of the following criteria:

- self-supporting and not living at home
- married
- pregnant
- a parent
- in the military

In addition, most states allow treatment without parental consent for sexually transmitted diseases, pregnancy, and drug or alcohol abuse.

Case 1

A 4-year-old with an obviously broken forearm is brought to the emergency department by her baby-sitter. Both the baby-sitter and emergency room staff have attempted to reach her parents without success.

Can you treat this child without parental permission?

Discussion

Your first duty is to the health and welfare of the child. Having attempted to reach her parents for consent without success, you should proceed with x-rays and treatment of her fractured forearm. Rapid treatment of the child's pain and fracture are clearly in her best interest. When optimal treatment requires immediate intervention, treatment should not be delayed even if consent has not been obtained.

Case 2

An ill-appearing 2-year-old with a fever and stiff neck appears to have meningitis. His parents refuse a lumbar puncture on the grounds that they have heard spinal taps are extremely dangerous and painful.

What are your obligations in this case? How should you proceed?

Discussion

A lumbar puncture is the only way to diagnose meningitis and a delay in treatment could cause significant harm to the child. Complications from the procedure are very rare, and the benefit in this case is likely to be substantial. There is not time to obtain an ethics consult or court order. The physician should attempt to address the parents' misconceptions about lumbar punctures and to reassure them about the safety of the procedure and perhaps offer to use appropriate pain control methods. A second opinion from another physician may prove helpful.

Should these efforts not result in parental permission, the physician is justified in proceeding with the procedure and treatment of the child. While parental authority to make medical decisions for their children is broad, it does not include choices that may seriously harm their children. As long as the physician has used reasonable clinical judgment in determining the need for the lumbar puncture, legal liability should be minimal.

Case 3

A 5-year-old child has just had his second generalised tonic-clonic seizure in a 4-month period. You have recommended starting an anticonvulsant. The parents have concerns about the recommended medication and would prefer to wait and see if their son has more seizures.

How should you respond to the parents’ request?

Discussion

The parents have the authority to make a choice of this sort. In general, courts have been reluctant to overrule against parental wishes in most situations where that decision does not place the child at considerable risk. Though failure to start an anti-convulsant may increase the risk of further seizures, this does not pose a substantial enough risk to the child to justify overriding the parents' wishes, especially given the potential risks associated with the medication. Though you may not agree with their decision, the decision is a reasonable one that does not place their child at substantial risk of increased harm.

Personal beliefs

Several of our bioethics topic pages discuss various situations in which the personal views of the physician can play a key role. Strategies for how to recognise and approach these situations are offered. To begin to familiarise yourself with this important feature of clinical practice, we invite you to review the following topics:

- Cross-Cultural Issues
- HIV and AIDS
- Physician-Patient Relationship
- Spirituality and Medicine

Physician assisted suicide

Physician-assisted suicide (PAS) generally refers to a practice in which the physician provides a patient with a lethal dose of medication, upon the patient's request, which the patient intends to use to end his or her own life (For related discussion, see also End of Life Issues).

Is physician-assisted suicide the same as euthanasia?

No. Physician-assisted suicide refers to the physician providing the means for death, most often with a prescription. The patient, not the physician, will ultimately administer the lethal medication. Euthanasia generally means that the physician would act directly, for instance by giving a lethal injection, to end the patient's life. Some other practices that should be distinguished from PAS are:

- Terminal sedation: This refers to the practice of sedating a terminally ill competent patient to the point of unconsciousness, then allowing the patient to die of her disease, starvation, or dehydration.

- **Withholding/withdrawing life-sustaining treatments**: When a competent patient makes an informed decision to refuse life-sustaining treatment, there is virtual unanimity in state law and in the medical profession that this wish should be respected.

- Pain medication that may hasten death: Often a terminally ill, suffering patient may require dosages of pain medication that impair respiration or have other effects that may hasten death. It is generally held by most professional societies, and supported in court decisions, that this is justifiable so long as the primary intent is to relieve suffering.

Is physician-assisted suicide ethical?

The ethics of PAS continue to be debated. Some argue that PAS is ethical (see arguments in favour). Often this is argued on the grounds that PAS may be a rational choice for a person who is choosing to die to escape unbearable suffering. Furthermore, the physician's duty to alleviate suffering may, at times, justify the act of providing assistance with suicide. These arguments rely a great deal on the notion of individual autonomy, recognising the right of competent people to choose for themselves the course of their life, including how it will end.

Others have argued that PAS is unethical (see arguments against). Often these opponents argue that PAS runs directly counter to the traditional duty of the physician to preserve life. Furthermore, many argue if PAS were legal, abuses would take place. For instance, the poor or elderly might be covertly pressured to choose PAS over more complex and expensive palliative care options.

What are the arguments in favour of PAS?

Those who argue that PAS is ethically justifiable offer the following sorts of arguments:

1. Respect for autonomy: Decisions about time and circumstances death are very personal. Competent person should have right to choose death.

2. Justice: Justice requires that we "treat like cases alike." Competent, terminally ill patients are allowed to hasten death by treatment refusal. For some patients, treatment refusal will not suffice to hasten death; only option is suicide. Justice requires that we should allow assisted death for these patients.

3. Compassion: Suffering means more than pain; there are other physical and psychological burdens. It is not always possible to relieve suffering. Thus PAS may be a compassionate response to unbearable suffering.

4. Individual liberty vs state interest: Though society has strong interest in preserving life, that interest lessens when person is terminally ill and has strong desire to end life. A complete prohibition on assisted death excessively limits personal liberty. Therefore PAS should be allowed in certain cases.

5. Openness of discussion: Some would argue that assisted death already occurs, albeit in secret. For example, morphine drips ostensibly used for pain relief may be a covert form of assisted death or euthanasia. That PAS is illegal prevents open discussion, in which patients and physicians could engage. Legalisation of PAS would promote open discussion.

What are the arguments against PAS?

Those that argue that PAS should remain illegal often offer arguments such as these:

1. Sanctity of life: This argument points out strong religious and secular traditions against taking human life. It is argued that assisted suicide is morally wrong because it contradicts these beliefs.

2. Passive vs. Active distinction: The argument here holds that there is an important difference between passively "letting die" and actively "killing." It is argued that treatment refusal or withholding treatment equates to letting die (passive) and is justifiable, whereas PAS equates to killing (active) and is not justifiable.

3. Potential for abuse: Here the argument is that certain groups of people, lacking access to care and support, may be pushed into assisted death. Furthermore, assisted death may become a cost-containment strategy. Burdened family members and health care providers may encourage option of assisted death. To protect against these abuses, it is argued, PAS should remain illegal.

4. Professional integrity: Here opponents point to the historical ethical traditions of medicine, strongly opposed to taking life. For instance, the Hippocratic oath states, "I will not administer poison to anyone where asked," and "Be of benefit, or at least do no harm." Furthermore, major professional groups (AMA, AGS) oppose assisted death. The overall concern is that linking PAS to the practice of medicine could harm the public's image of the profession.

5. Fallibility of the profession: The concern raised here is that physicians will make mistakes. For instance there may be uncertainty in diagnosis and prognosis. There may be errors in diagnosis and treatment of depression, or inadequate treatment of pain. Thus the State has an obligation to protect lives from these inevitable mistakes.

Is PAS illegal?

In most states, including the state of Washington, aiding in a suicide is a crime, while suicide or attempted suicide itself is not illegal. The state of Oregon is the only state that currently has legalised PAS.

However, several major court decisions have been made regarding PAS. In the case of Compassion in Dying v. Washington, the Ninth US Circuit Court of Appeals held that individuals have a right to choose how and when they die. Later, the Second Circuit Court found a New York law on PAS in conflict with the 14th amendment, which says that no state shall "deny to any person within its jurisdiction the equal protection of the laws." The Court held that competent patients were being treated differently than incompetent patients. The US Supreme Court has ruled that there is no constitutional right to assisted suicide, and made a legal distinction between refusal of treatment and PAS. However, the Court also left the decision of whether to legalise PAS up to each individual state.

There have also been a couple of high-profile cases related to specific PAS incidents. Dr. Timothy Quill was investigated but not indicted for his participation in the suicide of a patient after he published his account of the incident. In November of 1998, 60 Minutes aired a tape of Dr. Jack Kevorkian administering a lethal injection. His patient, 52 years-old Thomas Youk, suffered from Amyotrophic Lateral Sclerosis (ALS), otherwise known as Lou Gehrig's disease. As a result of the show, Kevorkian was tried for first degree murder in Oakland County, Michigan. Prosecutors argued that, in giving a lethal injection, Kevorkian stepped over the line of PAS into euthanasia, and that his actions amounted to murder. Kevorkian was convicted of second degree murder, and is currently serving a 10 to 25 year prison sentence.

What does the medical profession think of PAS?

Surveys of individual physicians show that half believe that PAS is ethically justifiable in certain cases. However, professional organisations such as the American Medical Association have generally argued against PAS on the grounds that it undermines the integrity of the profession.

Surveys of physicians in practice show that about 1 in 5 will receive a request for PAS sometime in their career. Somewhere between 5-20% of those requests are eventually honoured.

What do patients and the general public think of PAS?

Surveys of patients and members of the general public find that the vast majority think that PAS is ethically justifiable in certain cases, most often those cases involving unrelenting suffering.

What should I do if a patient asks me for assistance in suicide?

One of the most important aspects of responding to a request for PAS is to be respectful and caring. Virtually every request represents a profound event for the patient, who may have agonised over his situation and the possible ways out. The patient's request should be explored, to better understand its origin, and to determine if there are other interventions that may help ameliorate the motive for the request. In particular, one should address:

1. **Motive and degree of suffering:** are there physical or emotional symptoms that can be treated?

2. **Psychosocial support:** does the patient have a system of psychosocial support, and has she discussed the plan with them? Accuracy of prognosis: every consideration should be given to acquiring a second opinion to verify the diagnosis and prognosis.

3. **Degree of patient understanding:** the patient must understand the disease state and expected course of the disease. This is critical since patient may misunderstand clinical information. For instance, it is common for patients to confuse "incurable" cancer with "terminal" cancer.

What if the request persists?

If a patient's request for aid-in-dying persists, each individual clinician must decide his or her own position and choose a course of action that is ethically justifiable. Careful reflection ahead of time can prepare one to openly discuss your position with the patient, acknowledging and respecting difference of opinion when it occurs. Organisations exist which can provide counselling and guidance for terminally ill patients. No physician, however, should feel forced to supply assistance if he or she is morally opposed to PAS

Case 1

A recently divorced fifty-five-year-old man with severe rheumatoid arthritis comes in for a routine visit complaining of insomnia. He requests a specific barbiturate, Seconal, as a sleep aid, asking for a month's supply. On further questioning, he states that he wakes up every morning at four, tired but unable to go back to sleep. He admits that he rarely leaves his house during the day, stating that he has no interest in the activities he used to find enjoyable.

What is an appropriate course of action?

Discussion

The request for a specific quantity of a specific barbiturate suggests that this patient is contemplating suicide. This concern should be addressed explicitly with the patient. His sleep pattern (early morning awakening) and lack of interest in previously enjoyable pastimes (anhedonia) suggest major depression. This should be fully evaluated and treated. In addition, pain management and long term care options should be fully revisited in a patient with complaints such as his.

Even if the patient were fully competent, most proponents of PAS would object to aiding his suicide as he is not terminally ill. This said, rheumatoid arthritis can be a painful and debilitating chronic condition and it is unclear whether there is any relevant ethical or legal distinction between such a patient and one who is terminally ill.

Case 2

A middle-aged woman diagnosed with acute myelogenous leukemia has refused chemotherapy for her condition. She is educated, articulate and quite aware that she will certainly die without treatment. She is upset by her diagnosis, but is not depressed. Her close family wishes she would accept treatment because they do not want her to die, but even so, they honour her refusal. She understands that her death will likely be painful and may be prolonged and requests a supply of barbiturates that she might use to take her life when the appropriate time comes.

What is an appropriate course of action?

Discussion

This is the story of "Dianne," related by Dr. Timothy Quill (cite below). It represents the sort of case that advocates cite when making the argument for PAS. Suicide appears rational, the condition undeniably terminal. Dr. Quill provided the prescription and the patient ultimately used it. Others have argued that appropriate palliative care would have been sufficient to provide for a peaceful death and that the focus on PAS actually simply points to the failure of physicians to use palliative measures effectively.

Ultimately, the choice of action in such a case depends on the strength and soundness of the particular physician-patient relationship and the values of the individuals involved.

Physician-Patient Relationship

There is considerable healing power in the physician-patient alliance. A patient who entrusts himself to a physician's care creates ethical obligations that are definite and weighty. Working together, the potential exists to pursue interventions that can significantly improve the patient's quality of life and health status.

What is a fiduciary relationship?

Fiduciary derives from the Latin word for "confidence" or "trust". The bond of trust between the patient and the physician is vital to the diagnostic and therapeutic process. It forms the basis for the physician-patient relationship. In order for the physician to make accurate diagnoses and provide optimal treatment recommendations, the patient must be able to communicate all relevant information about an illness or injury. Physicians are obliged to refrain from divulging confidential information. This duty is based on accepted codes of professional ethics, which recognise the special nature of these medical relationships.

How has the physician-patient relationship evolved?

The historical model for the physician-patient relationship involved patient dependence on the physician's professional authority. Believing that the patient would benefit from the physician's actions, a patient's preferences were generally overridden or ignored. For centuries, the concept of physician beneficence allowed this paternalistic model to thrive.

During the second half of the twentieth century, the physician-patient relationship has evolved towards shared decision making. This model respects the patient as an autonomous agent with a right to hold views, to make choices, and to take actions based on personal values and beliefs. Patients have been increasingly entitled to weigh the benefits and risks of alternative treatments, including the alternative of no treatment, and to select the alternative that best promotes their own values (for further discussion, see the topic page on Informed Consent).

Will the patient trust me if I am a student?

Students may feel uncertain about their role in patient care. However, it is crucial for building trust that you begin this relationship in an honest and straightforward manner. A critical part of this is being honest about your role and letting the patient know you are a physician-in-training. In some settings, an attending physician or resident can introduce the student to initiate a trusting relationship. In other settings, students may need to introduce themselves. One form of introduction would be "Hello, I am Mary Jones. I'm a third year medical student who is part of the team that will be caring for you during your hospitalisation. I'd like to hear about what

brought you into the hospital." (For further discussion of this issue, see the Student Issues topic page.)

Many patients will feel quite close to the student on the team. Students usually have more time to spend with a patient, listening to the patient's history and health concerns, and patients certainly notice and appreciate this extra attention.

How much of herself should the physician bring to the physician-patient relationship?

Many patients appreciate a physician who brings a personal touch to the physician-patient encounter. They may feel more connected to a physician whose extracurricular activities and interests make her seem more alive. Physicians choose to share parts of their life stories according to their level of comfort. However, it is essential that the patient, and the patient's concerns, be the focus of every visit.

What role should the physician's personal feelings and beliefs play in the physician-patient relationship?

Occasionally, a physician may face requests for services, such as contraception or abortion, which raise a conflict for the physician. Physicians do not have to provide medical services in opposition to their personal beliefs. In addition, it is acceptable to have a non-judgmental discussion with a patient regarding her need for the service, and to ensure that the patient understands alternative forms of therapy. However, it is never appropriate to proselytise. While the physician may decline to provide the requested service, the patient must be treated as a respected, autonomous individual. Where appropriate, the patient should be provided with resources about how to obtain the desired service.

What can hinder physician-patient communication?

There may be many barriers to effective physician-patient communication. Patients may feel that they are wasting the physician's valuable time; omit details of their history which they deem unimportant; be embarrassed to mention things they think will place them in an unfavourable light; not understand medical terminology; or believe the physician has not really listened and, therefore, does not have the information needed to make good treatment decisions.

Several approaches can be used to facilitate open communication with a patient. Physicians should:

- sit down

- attend to patient comfort
- establish eye contact
- listen without interrupting
- show attention with nonverbal cues, such as nodding
- allow silences while patients search for words
- acknowledge and legitimise feelings
- explain and reassure during examinations
- ask explicitly if there are other areas of concern

What happens when physicians and patients disagree?

One third to one half of patients will fail to follow a physician's treatment recommendations. Labelling such patients "noncompliant" implicitly supports an attitude of paternalism, in which the physician knows best. Patients filter physician instructions through their existing belief system; they decide whether the recommended actions are possible or desirable in the context of their everyday lives.

Compliance can be improved by using shared decision making. For example, physicians can say, "I know it will be hard to stay in bed for the remainder of your pregnancy. Let's talk about what problems it will create and try to solve them together." Or, "I can give you a medication to help with your symptoms, but I also suspect the symptoms will go away if you wait a little longer. Would you prefer to try the medication, or to wait?" Or, "I understand that you are not ready to consider counselling yet. Would you be willing to take this information and find out when the next support group meets?" Or, "Sometimes it's difficult to take medications, even though you know they are important. What will make it hard for you to take this medication?"

Competent patients have a right to refuse medical intervention. Dilemmas may arise when a patient refuses medical intervention, but does not withdraw from the role of being a patient. For instance, an intrapartum patient, with a complete placenta praevia, who refuses to undergo a Caesarean delivery, often does not present the option for the physician to withdraw from participation in her care (see the Maternal/Fetal Conflict topic page). In most cases, choices of competent patients must be respected when the patient cannot be persuaded to change them.

What can a physician do with a particularly frustrating patient?

Physicians will sometimes encounter a patient whose needs, or demands, strain the therapeutic alliance. Many times, an honest discussion with the patient about the boundaries of the relationship will resolve such misunderstandings. The physician can initiate a discussion by saying, "I see that you have a long list of health concerns. Unfortunately, our appointment today is only for fifteen minutes. Let's discuss your most urgent problem today and reschedule you for a longer appointment. That way, we can be sure to address everything on your list." Or, "I know that it has been hard to schedule this appointment with me, but using abusive language with the staff is not acceptable. What do you think we could do to meet everybody's needs?"

There may be occasions when no agreeable compromise can be reached between the physician and the patient. And yet, physicians may not abandon patients. When the physician-patient relationship must be severed, the physician is obliged to provide the patient with resources to locate ongoing medical care.

When is it appropriate for a physician to recommend a specific course of action or override patient preferences?

Under certain conditions, a physician should strongly encourage specific actions. When there is a high likelihood of harm without therapy, and treatment carries little risk, the physician should attempt, without coercion or manipulation, to persuade the patient of the harmful nature of choosing to avoid treatment.

Court orders may be invoked to override a patient's preferences. However, such disregard for the patient's right to noninterference is rarely indicated. Court orders may have a role in the case of a minor; during pregnancy; if harm is threatened towards oneself or others; with concern for mental incompetence; or when the patient is a sole surviving parent of dependent children. However, the use of such compulsory powers is inherently time-limited, and often alienates the patient, making him less likely to comply once he is no longer subject to the sanctions.

What is the role of confidentiality?

Confidentiality provides the foundation for the physician-patient relationship. In order to make accurate diagnoses and provide optimal treatment recommendations, the physician must have relevant information about the patient's illness or injury. This may require the discussion of sensitive information, which would be embarrassing or harmful if it were known to other persons. The promise of confidentiality permits the patient to trust that information revealed to the physician will not be further disseminated. The expectation of confidentiality derives from the public oath which the physician has taken, and from the accepted code of professional ethics. The physician's duty to maintain confidentiality extends from respect for the patient's autonomy.

Would a physician ever be justified in breaking a law requiring mandatory reporting?

Legal obligations to break confidentiality may pose difficult choices. While the physician has a moral obligation to obey the law, he must balance this against his responsibility to the patient. It is essential to balance the duty to protect the patient's confidence against the physician's responsibility to the members of the public at risk. (For a discussion on the limits of confidentiality, see the topic page on Confidentiality.)

What happens when the physician has a relationship with multiple members of a family?

Physicians with relationships with multiple family members must honour each individual's confidentiality. Difficult issues, such as domestic violence, sometimes challenge physicians to maintain impartiality. In many instances, physicians can help conflicted families towards healing. At times, physicians work with individual family members; other times, they may serve as a facilitator for a larger group. As always, when a risk for imminent harm is identified, the physician must break confidentiality.

Physicians can be proactive about addressing the needs of changing family relationships. For example, a physician might tell a preteen and her family, "Soon you'll be a teenager. Sometimes teens have questions they would like to discuss with me. If that happens to you, it's okay to tell your parents that you'd like an appointment. You and I won't have to tell your parents what we talk about if you don't want to, but sometimes I might encourage you to talk things over with them."

The physician-family relationship also holds considerable healing power. The potential exists to pursue options that can improve the quality of life and health for the entire family.

Case 1

During a visit to her family physician, a 35-year-old woman discloses that she suffers from anorexia nervosa. She complains of fatigue, dizziness, depression, headaches, irregular menses, and environmental allergies. Each day, she uses 15 to 60 laxatives, exercises for several hours, and eats a salad or half a sandwich. At 5'2", she weighs 88 pounds. She demonstrates a good understanding of the diagnosis and the recommended therapy for anorexia. Despite receiving a variety of resource information, the patient refuses any medical intervention. She continues to present to the family physician, offering a variety of somatic complaints.

When a patient's preferences conflict with a physician's goal to restore health, which ethical principle should prevail, patient autonomy or physician beneficence? Does the patient's depression render her incompetent to refuse treatment for her anorexia?

Discussion

Since this patient could rationally discuss her treatment options and her reasons for declining therapy, she could not be considered incompetent. Respect for autonomy is a central principle of bioethics, and it takes precedence in this case. Although the principle of beneficence could be used to argue for coercion towards treatment, compliance may be better improved by providing an ongoing partnership with the patient. Maintaining a therapeutic relationship with ongoing dialogue is more likely to provide this patient with the eventual ability to pursue therapy.

Case 2

A 16-year-old female presents to a family physician to obtain a referral for family therapy. She is estranged from her mother and stepfather, who see the same physician. For many years, this patient responsibly cared for her four younger siblings while their single mother worked. Since her mother's marriage, the family has become involved in a fundamentalist church. The patient moved out when she felt the social and moral restrictions of the family's religion were too burdensome for her. The patient seemed quite mature; she maintained a 3.5 GPA, along with a part-time job. She demonstrated a genuine desire for reconciliation, and the therapy referral was provided.

She also requested and obtained a prescription for contraceptives during the visit, with the assurance that her sexual activity would be kept confidential. In follow-up, she reported that the therapist had informed her that if she mentioned anything about being sexually active with her adult partner, he would be obliged to report her to the state. The patient was very concerned about the conflict between this statement and the family physician's prior assurance of confidentiality.

Should this patient's confidentiality be broken?

Discussion

While the physician has a moral obligation to obey the law, he must balance this against his responsibility to the patient. In researching the Criminal Code of Washington, the physician learned that sexual intercourse with a minor, at least 16, but under 18, is a class C felony, and a reportable offence, if the offender is at least 90 months older than the victim. This patient's relationship did not actually meet the criteria for mandatory reporting. Had this not been the case however, the physician could be justified in weighing the balance of harms arising from the filing of such a report.

There is little justification for informing the family of the young woman's sexual activity. Due to the family's strong fundamentalist beliefs, significant damage would have occurred in the family

reconciliation process with this discovery. Although they would clearly disapprove of the patient's actions, her choices carry no risk of harm to them.

Professionalism

Because medicine is a *profession* and physicians are *professionals*, it is important to have a clear understanding of what "professionalism" means. As a physician-in-training, you will be developing a personal sense of what it means to be a professional. This topic page outlines some common features. Please see the topic page on the Physician-Patient Relationship for further discussion of the professional responsibilities of physicians.

What does it mean to be a member of a profession?

The words "profession" and "professional" come from the Latin word "professio," which means a public declaration with the force of a promise. Professions are groups which declare in a public way that their members will act in certain ways and that the group and the society may discipline those who fail to do so. The profession presents itself to society as a social benefit and society accepts the profession, expecting it to serve some important social goal. The traditional professions are medicine, law, education and clergy.

The marks of a profession are:

1. Competence in a specialised body of knowledge and skill;

2. An acknowledgment of specific duties and responsibilities toward the individuals it serves and toward society;

3. The right to train, admit, discipline and dismiss its members for failure to sustain competence or observe the duties and responsibilities.

What is the difference between a profession and a business?

The line between a business and a profession is not entirely clear, since professionals may engage in business and make a living by it. However, one crucial difference distinguishes them: professionals have a *fiduciary duty* toward those they serve. This means that professionals have a particularly stringent duty to assure that their decisions and actions serve the welfare of their patients or clients, even at some cost to themselves. Professions have codes of ethics which

specify the obligations arising from this fiduciary duty. Ethical problems often occur when there appears to be a conflict between these obligations or between fiduciary duties and personal goals.

What are the recognised obligations and values of a professional physician?

The American Board of Internal Medicine has been working on a project to develop and promote professionalism since 1990. According to the report, Project Professionalism (1995), professionalism requires that one strive for excellence in the following areas which should be modelled by mentors and teachers and become part of the attitudes, behaviours, and skills integral to patient care:

- **Altruism:** A physician is obligated to attend to the best interest of patients, rather than self-interest.
- **Accountability**: Physicians are accountable to their patients, to society on issues of public health, and to their profession.
- **Excellence:** Physicians are obligated to make a commitment to life-long learning.
- **Duty:** A physician should be available and responsive when "on call," accepting a commitment to service within the profession and the community.
- **Honour and integrity:** Physicians should be committed to being fair, truthful and straightforward in their interactions with patients and the profession.
- **Respect for others**: A physician should demonstrate respect for patients and their families, other physicians and team members, medical students, residents and fellows.

While circumstances may arise that hinder adherence to these values, they should provide guidance for promoting professional behaviour and for making difficult ethical decisions.

Is professionalism compatible with the restrictions sometimes placed on physician's judgments in managed care?

One of the principal attributes of professionalism is independent judgment about technical matters relevant to the expertise of the profession. The purpose of this independent judgment is to assure that general technical knowledge is appropriately applied to particular cases. Managed care may impose conditions on the clinical judgment of professionals who work in such settings but those conditions must be designed to enhance and improve professional judgment, not restrict it. Thus, requiring consultation may often be an obligation; restricting consultation may be ethically inappropriate. Also, requiring physicians to adhere to practice guidelines and to

consult outcome studies may improve professional judgment; requiring blind adherence to those guidelines may be a barrier to the exercise of professional judgment.

Public Health Ethics

Public health practice concerns itself with issues of illness and disease of populations, and as such touches some unique ethical issues. In general, public health practices and policies seek to improve the overall health of the public, a position sometimes at odds with the autonomy of the individual. This conflict may be clinical, as in the case of immunisation, or legal, as in the case of mandatory medical reporting and treatment of communicable diseases. Further, public health involved recognising health and illness in the broader context of social, environmental, political, and economic factors. All health care providers share in public health practice, and have opportunities in their actions to shape public health policy.

When should diseases be reported to Public Health authorities?

Each state has specific statutes that identify specific diseases with public health implications, such as communicable diseases, which require reporting. Beyond this legal requirement lies the question of when it is justified to potentially violate confidentiality to protect the public's health. It is ethically justified to disclose a diagnosis to public health authorities if the risk to the public has the following features:

- the risk is high in probability
- the risk is serious in magnitude
- the risk relates to an identifiable individual or group

For instance, if a food handling restaurant worker with acute hepatitis asks that his diagnosis be held in confidence, the physician should nevertheless disclose this diagnosis to the dining establishment or public health authorities, since the risk to the public is high, serious, and relates to identifiable persons (eg. patron of the eating establishment).

Can patients refuse to undergo routine preventive health measures?

There are a number of preventive health interventions which provide minimal if any benefit to the individual yet provide substantial collective benefit to the public's health. For example,

immunisations provide protection but involve some risk to the individual. However, if a public health program can achieve universal vaccination, the overall public health benefits. If a patient refuses a legally required immunisation (eg. in jurisdictions where immunisation is legally mandated), this becomes a legal matter. If not legally mandated, an adequately informed refusal, expressing compelling personal or religious beliefs, may be respected.

Can a physician refuse to follow public health mandates that he opposes?

Most public health law and regulations reflect a public policy process that involved tradeoffs. There is seldom certainty in the final policy recommendations, which are often the result of compromise positions of divergent advocacy groups. As a result, physicians and other health care workers may find their own positions at odds with regulations or health care laws. Professionals have an obligation to exercise judgment and not follow laws that are grossly unjust or immoral. Most situations are not this extreme, however. Thus, the health care professional should find ways other than outright disobedience to try to influence health care policy with which she disagrees. No health care provider should be forced to provide a service he morally opposes, but he should also not obstruct others who support it. The best and most constructive way to affect health policy is to participate actively in the policy making process.

When can a patient be held for medical treatment against her will?

This is a controversial area in law, and the law varies by state. The ethical justification for treatment of a patient against his will is based on balancing of the risk to the public versus respecting the patient's personal freedom. If the magnitude of risk to the public is great, many states allow for involuntary treatment. For example, a patient with active pulmonary tuberculosis that is resistant to multiple anti-tuberculosis medications presents a grave risk to the public if her condition is untreated. This arises in part because of the high infectivity of active pulmonary tuberculosis and the relatively small risk to the patient from oral medications for TB treatment. Other conditions for which non-treatment pose little or no threat to the public, such as untreated acute leukemia, can rarely have involuntary treatment justified.

Case 1

MG is a 27-year-old graduate student, recently married, who comes into the student health clinic for a routine pelvic exam and PAP smear. During the course of the exam, the gynaecology resident performing the exam obtains the PAP smear, but also obtains cervical cultures for gonorrhoea and chlamydia. The examination concludes uneventfully.

Several weeks later, she receives a postcard indicating that the PAP smear was normal, with no evidence of dysplasia, but that the cervical culture for gonorrhoea was positive. The card

instructs her to come into the clinic to discuss treatment, and that "public health authorities" have been notified for contact tracing. The young woman is terrified that her husband will be contacted.

Does the woman have a right to be informed that the gonorrhoea and chlamydia cultures were being obtained? What should be done if she refuses?

Discussion

The routine of obtaining cervical cultures for gonorrhoea and chlamydia is motivated by the desire to have accurate information on the prevalence of gonorrhoea in the population, and the hope that identification and treatment of asymptomatic carriers could reduce or eradicate gonorrhoea as a public health problem. Yet, in this case the patient was not told about the culture being obtained. When health-related information is obtained from individuals, they should have an opportunity to consent to or refuse such collection. In some instances, individuals may conscript to having their rights disregarded, such as in the military. Similarly, other individuals do not have their rights recognised as a result of due process, such as prisoners. In this case, the physician should inform the woman what tests will be performed and why, and how that information will be handled. If she refuses to have the test obtained, her wish should be respected

Case 2

MW is a 33-year-old man with multi-drug resistant tuberculosis. He is homeless, and has a pattern of missing many of his scheduled clinic visits. Upon starting a multi-drug regimen for his TB, MW initially comes to his scheduled clinic visits, but after a few weeks begins missing them. The physician contacts the social work case manager, who arranges supervised drug administration. Nevertheless, MW often cannot be found and this approach is deemed to be failing.

Should MW be forced into treatment against his will? What are the ethical considerations behind your answer?

Discussion

This is a case in which the health of the public is clearly threatened. Multi-drug resistant tuberculosis has the potential of causing substantial morbidity and mortality for the population, particularly in large urban areas. Thus the need for the individual patient to be treated for the good of the public is high.

Similarly, the patient himself stands to benefit from the treatment. Ordinarily, patients have the right to refuse potentially beneficial treatment, provided they are competent and make an informed decision to do so. The tension created in this case is that the patient's refusal to follow the medication regimen puts others at substantial risk of harm. Hence it may be justifiable to compromise his autonomy to protect the health of others.

In such cases, every effort should be exhausted to enlist the patient's cooperation with the medical regimen. Interventions such as supervised medication administration are often effective ways to achieve the desired result without compromising the patient's autonomy. Failing this, it would be justifiable to seek court permission to confine and treat the patient against his will. In the legal process that ensues, considerations will include the magnitude of harm, the degree to which specific individuals are exposed to harm, and the probability of harm.

Research Ethics

The ethical issues in human subjects' research have received increasing attention over the last 50 years. Institutional Review Boards for the Protection of Human Subjects (IRB's) have been established at most institutions that undertake research with humans. These committees are made up of scientists, clinical faculty, and administrators who review research according to the procedures set out in the Federal Regulations at 45 CFR 46.

What are the main ethical issues in human subjects' research?

There are several ethical issues that must be considered when designing research that will utilise participants who are human beings.

- The primary concern of the investigator should be the safety of the research participant. This is accomplished by carefully considering the risk/benefit ratio, using all available information to make an appropriate assessment and continually monitoring the research as it proceeds.

- The scientific investigator must obtain informed consent from each research participant. This should be obtained in writing (although oral consents are sometimes acceptable) after the participant has had the opportunity to carefully consider the risks and benefits and to ask any pertinent questions. Informed consent should be seen as an ongoing process, not a singular event or a mere formality.

- The investigator must enumerate how privacy and confidentiality concerns will be approached. Researchers must be sensitive to not only how information is protected from

unauthorised observation, but also if and how participants are to be notified of any unforeseen findings from the research that they may or may not want to know.

- The investigator must consider how adverse events will be handled; who will provide care for a participant injured in a study and who will pay for that care are important considerations.

- In addition, before enrolling participants in an experimental trial, the investigator should be in a state of "equipoise," that is, if a new intervention is being tested against the currently accepted treatment, the investigator should be genuinely uncertain which approach is superior. In other words, a true null hypothesis should exist at the onset regarding the outcome of the trial.

What are the main ethical principles that govern research with human subjects?

There are three primary ethical principles that are traditionally cited when discussing ethical concerns in human subjects' research. (A more complete enumeration of these principles is available in the Belmont Report, written by The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research in 1979.)

- The first ethical principle cited by the influential Belmont Report is autonomy, which refers to the obligation on the part of the investigator to respect each participant as a person capable of making an informed decision regarding participation in the research study. The investigator must ensure that the participant has received a full disclosure of the nature of the study, the risks, benefits and alternatives, with an extended opportunity to ask questions. The principle of autonomy finds expression in the informed consent document.

- The second ethical principle is beneficence, which refers to the obligation on the part of the investigator to attempt to maximise benefits for the individual participant and/or society, while minimising risk of harm to the individual. An honest and thorough risk/benefit calculation must be performed.

- The third ethical principle invoked in research with human subjects is justice, which demands equitable selection of participants, ie. avoiding participant populations that may be unfairly coerced into participating, such as prisoners and institutionalised children. The principle of justice also requires equality in distribution of benefits and burdens among the population group(s) likely to benefit from the research.

What are the components of an ethically valid informed consent for research?

For an informed consent to be ethically valid, the following components must be present:

- **Disclosure:** The potential participant must be informed as fully as possible of the nature and purpose of the research, the procedures to be used, and the expected benefits to the participant and/or society, the potential of reasonably foreseeable risks, stresses, and discomforts, and alternatives to participating in the research. There should also be a statement that describes procedures in place to ensure the confidentiality or anonymity of the participant. The informed consent document must also disclose what compensation and medical treatment are available in the case of a research-related injury. The document should make it clear whom to contact with questions about the research study, research subjects' rights, and in case of injury.

- **Understanding:** The participant must understand what has been explained and must be given the opportunity to ask questions and have them answered by one of the investigators. The informed consent document must be written in lay language, avoiding any technical jargon.

- **Voluntariness:** The participant's consent to participate in the research must be voluntary, free of any coercion or promises of benefits unlikely to result from participation.

- **Competence:** The participant must be competent to give consent. If the participant is not competent due to mental status, disease, or emergency, a designated surrogate may provide consent if it is in the participant's best interest to participate. In certain emergency cases, consent may be waived due to the lack of a competent participant and a surrogate.

- **Consent:** The potential human subject must authorise his/her participation in the research study, preferably in writing, although at times an oral consent or assent may be more appropriate.

Is informed consent required by law?

According to 21 CFR 50.20,

"No investigator may involve a human being as a subject in research covered by these regulations unless the investigator has obtained the legally effective informed consent of the subject or the subject's legally authorised representative."

The potential participant must be given the opportunity to give full consideration regarding the decision whether or not to participate in the research study without undue influence from his or her physician, family, or the scientific investigator. No informed consent may contain any exculpatory language by which the participant waives any legal rights or releases the investigator or sponsor from liability for negligence.

Can I use deception when doing research?

As a general rule, deception is not acceptable when doing research with humans. Using deception jeopardises the integrity of the informed consent process and can potentially harm your participants. Occasionally exploring your area of interest fully may require misleading your participants about the subject of your study. For example, if you want to learn about decision-making practices of physicians without influencing their practice-style, you may consider telling them you are studying "communication behaviours" more broadly. The IRB will review any proposal that suggests using deception or misrepresentation very carefully. They will require an in-depth justification of why the deception is necessary for the study and the steps you will take to safeguard your participants.

I'm just doing a simple survey! Do I need IRB approval?

Some research with humans is eligible for "exempt" status from the IRB. If your research is part of a routine educational experience, or if your participants will remain completely anonymous (with no identifying code to link them to their identity), you may apply to the IRB for a certificate of exemption. Your study proposal will still be reviewed by a member of the IRB, but the application process is considerably shorter.

Your study may also qualify for "expedited review" if an IRB reviewer determines that it meets assessment criteria for minimal risk, and involves only procedures that are commonly done in clinical settings, such as taking hair, saliva, excreta or small amounts of blood. A study that qualifies for expedited review is still held to the same standards used in full board review, but the approval process may take less time. Contact the University IRB if you have questions about the eligibility of your study.

Case 1

Mrs. Franklin, an 81-year-old Alzheimer's patient hospitalised under your care has been asked to participate in a clinical trial testing a new drug designed to help improve memory. You were present when the clinical investigator obtained a signed informed consent from Mrs. Franklin a few days ago. However, when you visit Mrs. Franklin today and ask her if she is ready to begin the study tomorrow, she looks at you blankly and seems to have no idea what you are talking about.

What should you do?

Discussion

The competence of Mrs. Franklin to give an ethically valid informed consent is in doubt. You should contact the primary investigator to discuss Mrs. Franklin's participation in the trial. There may be a surrogate who can give consent for her participation if it is deemed to be in her best interests. Although she may be considered a vulnerable research subject because of her mental status, Mrs. Franklin does belong to the population the intervention is designed to assist, and her participation may benefit herself and other Alzheimer's patients. However, a careful balancing of risks and benefits should occur.

Resource Allocation

“Physicians should merit the confidence of the patients entrusted to their care, rendering to each a full measure of service and devotion." This is the first statement in the Principles of Ethics of the American Medical Association. Often it is difficult, if not impossible, to provide every patient everything each one needs for optimal medical care. When these conditions of scarcity occur, we look for guidance to make painful tradeoffs in a fair and compassionate manner. This topic page raises some issues to consider when facing these difficult allocation decisions.

What rules guide rationing decisions?

Rationing occurs when many persons are in need of an intervention but that intervention is in short supply for some reason. The reasons vary: there are many more patients with end stage cardiac disease or liver disease than there are cadaver organs available; expensive equipment may be lacking in a particular region; tertiary care hospital beds may be limited; a particular medication may be extremely costly; few personnel might be trained for a certain technical procedure, insurance coverage is unavailable or of prohibitive cost.

Every physician must "ration," at least his or her own time available to provide medical services. For the most part, this personal rationing is done by rules of common sense: I will take only as many patients as I can care for competently; I will assure that my attendance is sufficient to guarantee high quality medical care to my patients, etc. For other kinds of rationing, for instance rationing of ICU beds, these rules of thumb are not enough. More articulate principles are required.

In one highly publicised instance of resource allocation, the Seattle Artificial Kidney Centre appointed a committee to decide who would receive dialysis treatments, in 1962 a rare and expensive resource. "Likelihood of medical benefit" was the first criteria used to determine eligibility. Even so, many more patients required dialysis than there were machines available. The committee turned to "social worth" criteria and began weighing the anticipated contributions the patients would make to society were their lives saved. Many have argued that a lottery or a “first-come, first-served” criterion would have been more equitable and ethically justifiable. We know from recent UNOS decisions that the criterion now in favour is "greatest (medical) need."

The allocation of organs for transplant was organised several years ago into a national system with criteria that strive for fairness. The criteria attempt to match available organs with recipients on presumed "objective" grounds, such as tissue type, body size, time on waiting list, seriousness of need. However, even in this system, it is obvious that such a criterion as "serious need" can be used in a manipulative way. Still, this system is preferable to the subjective use of criteria of social worth and status that would unfairly skew the distribution of organs.

Are there ethical criteria for making triage decisions?

Triage is one situation in which specific principles must be applied. Triage (which means "choice" or "selection") is required when many patients simultaneously need medical attention and medical personnel cannot attend to all at the same time. Again, the common sense rule is to serve persons whose condition requires immediate attention and, if this attention is not given, will progress to a more serious state. Others, whose condition is not as serious and who are stable, may be deferred. This sort of triage is often necessary in busy emergency departments.

A second sort of triage is indicated in disasters, such as earthquakes, or in military action. The rules of military triage, developed centuries ago, direct the physician to attend first to those who can be quickly and successfully treated in view of a speedy return to the battlefield, or to treat commanders before troops in order to assure leadership. This sort of disaster triage is applied to civilian disasters by treating persons, such as firefighters or public safety officers, who can quickly return to duty and help others. Disaster triage implies that the most seriously injured may be relegated to the end of the line and left untreated, even at risk of death, if their care would absorb so much time and attention that the work of rescue would be compromised. This is one of the few places where a "utilitarian rule" governs medicine: the greater good of the greater number rather than the particular good of the patient at hand. This rule is justified only because of the clear necessity of general public welfare in a crisis.

Can I make allocation decisions based on judgments about "quality of life"?

Under conditions of scarcity, the question may arise whether a patient's quality of life seems so poor that use of extensive medical intervention appears unwarranted. When this question is raised, it is important to consider a few questions. First, who is making this quality of life

judgment, the care team, the patient, or the patient's family? Several studies have shown that physicians often rate the patient's quality of life much lower than the patient himself does. If the patient is able to communicate, you should engage her in a discussion about her own assessment of her condition.

When considering quality of life, you should also ask: What criteria are being used to make the judgment that the quality of life is unacceptable? These criteria are often unspoken and can be influenced by bias or prejudice. A dialogue between care givers and the patient can surface some underlying concerns that may be addressed in other ways. For example, residents on a medical floor in an urban public hospital may get discouraged with the return visits of a few chronically ill alcoholic patients and suggest that money is being wasted that could be used for prenatal care or other medically beneficial projects. While the residents' frustration is understandable, it would be helpful to consider other ways they might interrupt this vicious cycle of repeat admissions. How could this patient population be supported in ways that might improve health?

Quality of life judgments based on prejudices against age, ethnicity, mental status, socioeconomic status, or sexual orientation generally are not relevant to considerations of diagnosis and treatment. Furthermore, they should not be used, explicitly or implicitly, as the basis for rationing medical services.

What about "macro-allocation" concerns?

Some situations involve what is often called "macro-allocation," that is, broad policies to distribute resources across populations, as distinguished from "micro-allocation" decisions, such as in the above triage examples, to give priority to one patient over another.

Many of these reasons for shortage are the result of deliberate decisions to ration. Even such shortages as vital organs result from social policies that favour voluntary donation over routine salvaging or a commercial market in organs. Other shortages result from broad social and cultural institutions: our country has left health care largely in the private sphere and the availability of care for individuals is conditioned by their ability to pay or their employment status. The social "safety net" that acknowledges a moral duty to assure health care to those unable to pay is strengthened or weakened according to prevailing societal commitments.

The theoretical ethical question is: can a fair and just way of allocating health care resources be devised? The practical ethical question is: can a fair and just allocation be actually implemented in a particular social, economic and medical climate?

Can we ethically qualify a "right to health care"?

Several ethical theories have been elaborated to formulate criteria for fair and just distribution and to examine the arguments for a "right to health care." At present, little agreement exists on any of these issues. Ideally, all persons should have access to a "decent minimum" of health care necessary to sustain life, prevent illness, and relieve distress and disability, so that, in the words

of Norman Daniels, "each person may enjoy his or her fair share of the normal opportunity range for individuals in his or her society."

Debates over this issue have been lengthy and serious. Many policy proposals have been considered: some implemented and others rejected. However, as systems of managed health care are created, the question of fair and just allocation of resources must be raised and the various proposals, theories and criteria must be reviewed for their applicability to the policies of managed care organisations. Similarly, government policy must be formulated in ways that take into account the needs of those who are not served by such organisations in the private sector.

Some specific examples of public policy in devising an allocation system concentrate on the criteria of efficiency and cost-effectiveness. The state of Oregon is unique in having such a system for its Medicaid patients: a long list of medical procedures, ranked in terms of their cost/benefit ratio, determines the reimbursement policy. Even with such a system, ethical criteria must also be considered: what is to be done if life-saving and life-sustaining interventions rank low on cost-effectiveness? Is it ethical to omit the rescue of a person from death because their rescue by, say, bone marrow transplantation is less cost-effective than some preventive measures? How is cost-effectiveness to be applied to persons with shorter natural life expectancy, such as the elderly?

Case 1

A 28-year-old male is admitted with bacterial endocarditis and needs a replacement of his prosthetic heart valve. After his first replacement, he continued to abuse intravenous drugs. The medical team feels it would be "futile" and a waste of medical resources to replace this heart valve yet again.

Is the team's judgment appropriate in this case?

Discussion

While it is likely that this patient will require additional counselling and support services to improve his health outcomes, replacing the heart value is not "futile" in this case. It is also likely that the medical team is using biased criteria to judge "wasted" vs. "properly used" medical resources. Thoughtful discussion may provide an opportunity for the team to voice their frustration and think through a treatment plan that will maximally support this patient's recovery.

Case 2

On a busy night in the ER a member of the hospital board comes in with her sick child and asks that you see him right away. The child has a sore throat and red eye and he appears subdued, but alert. You have a full waiting room.

What should you do?

Discussion

Cases where famous or influential people are asking for special treatment ask that we review our ethical criteria for resource allocation. Do some people "deserve" special treatment over others? What would justify such a claim? In this case, the ER staff might be swayed by the powerful position the board member holds in their institution and want to do their best for her. However, the other people waiting in the ER have been subject to triage criteria based on medical need. It would be unjust to waive these criteria on the basis of social position. While this may seem unrealistic, one might also consider the effect on the hospital if the board member faces a long, tedious wait in the waiting room along with everyone else. A complaint voiced by this powerful person may enact change on staffing considerations more effectively than a number of patient complaints. To let her sail through would be to create an impression of smoothness that is most likely not part of the everyday ER experience.

For further discussion of this case, please refer to Douglas S. Diekema's article, "The preferential treatment of VIPs in the emergency department," American Journal of Emergency Medicine 1996; 14(2):226-229.

Spirituality and Medicine

Religious beliefs and practices are important in the lives of many patients seeking medical care, yet many physicians are uncertain about whether, or how, to address spiritual or religious issues. Often physicians are trained to diagnose and treat disease and have little or no training in how to relate to the spiritual side of the patient. In addition, the physician's ethic requires that the physician not impinge her beliefs on patients who can be particularly vulnerable when supplicants for health care. Complicating it further, in our culture of religious pluralism, there is a wide range of belief systems ranging from atheism, agnosticism, to a myriad assortment of religions. No physician could be expected to understand the beliefs and practices of so many differing faith communities.

At first glance, the simplest solution suggests that physicians avoid religious or spiritual content in the doctor-patient interaction. As with many issues, however, the simple solution may not be the best. This topic page inquires into the possibility that within the boundaries of medical ethics and empowered with sensitive listening skills, the physician may find ways to engage the spiritual beliefs of patients in the healing process, and come to a clearer understanding of ways in which the physician's own belief system can be accounted for in transactions with patients. Appropriate referral to the hospital chaplain will be explored as well as ways in which the physician and clergy may best work together for the good of the patient.

How pervasive is religiosity in the United States?

Surveys of the US public in the Gallup Report consistently show a high prevalence of belief in God (95%) while 84% claim that religion is important to their lives. Approximately 40% of Americans attend religious services at least once a week. One survey in Vermont involving 115 family physicians and 135 patients showed that 91% of the patients reported belief in God as compared with 64% of the physicians. A 1975 survey of psychiatrists showed that 43% professed a belief in God.

These surveys remind us that there is a high incidence of belief in God in the US public. It also appears from surveys that physicians as a group are somewhat less inclined to believe in God.

Why is it important to attend to spirituality in medicine?

Regardless of their own belief system, physicians should not allow their own bias to blind them to the appreciation of the possibility that religion and spiritual beliefs play an important role for many of their patients. When illness threatens the health, and possibly the life of an individual, that person is likely to come to the physician with both physical symptoms and spiritual issues in mind. An article in the Journal of Religion and Health claims that through these two channels, medicine and religion, humans grapple with common issues of infirmity, suffering, loneliness, despair, and death, while searching for hope, meaning, and personal value in the crisis of illness.

Persons may hold powerful spiritual beliefs, and may or may not be active in any institutional religion. Spirituality can be defined as ". . . a belief system focusing on intangible elements that impart vitality and meaning to life's events". Many physicians and nurses have intuitive and anecdotal impressions that the beliefs and religious practices of patients have a profound affect upon their experiences with illness and the threat of dying. It is generally accepted that religious affiliation is correlated with a reduction in the incidence of some diseases such as cancer and coronary artery disease. For patients facing a terminal illness, religious and spiritual factors often figure into important decisions such as the employment of advance directives such as the living will and the Durable Power of Attorney for Health Care. Considerations of the meaning, purpose and value of human life are used to make choices about the desirability of CPR and aggressive

life-support, or whether and when to fore-go life support and accept death as appropriate and natural under the circumstances.

How should I take a "spiritual history"?

In courses such as the "Introduction to Clinical Medicine," medical students learn the various components of the doctor-patient interview, often beginning with a history of the present illness, a psycho-social history, and a review of systems. Students-in-training are often hesitant to ask questions regarded as intrusive into the personal life of the patient until they understand there are valid reasons for asking about sexual practices, alcohol use, and the use of tobacco or non-prescription drugs. Religious belief and practice falls into that "personal" category that students-in-training often avoid, yet when valid reasons are offered by teachers and mentors for obtaining a spiritual history, students can learn to incorporate this line of questioning into the patient interview.

Often, the spiritual history can be incorporated into what we may now want to call the "psycho-social-spiritual" patient history. Students are taught to make a transition by simply stating something like the following: "As physicians, (or, as physicians-in-training,) we have discovered that many of our patients have strong spiritual or religious beliefs that have a bearing on their perceptions of illness and their preferred modes of treatment. If you are comfortable discussing this with me, I would like to hear from you about any beliefs or practices that you would want me to know as your care giver."

In my experience as a tutor, students learning the patient interview have returned from a patient interview on many occasions with a sense of excitement and gratification in discovering that this line of questioning opened a discussion with the patient that disclosed the patient's faith in God as a major comforting factor in the face of a life-threatening illness. Some patients have described their gratitude to their church community for bringing meals to their family while at least one parent was at the hospital with a sick child. Others spoke of a visit from a priest, a rabbi, or a minister during their hospitalisation as a major source of comfort and reassurance. One patient, self-described as a "non-church-goer," described his initial surprise at a visit from the hospital chaplain which turned into gratitude as he found in the chaplain a skilled listener with a deep sense of caring to whom he could pour out his feelings about being sick, away from home, separated from his family, frightened by the prospect of invasive diagnostic procedures and the possibility of a painful treatment regimen.

Todd Maugans offered a mnemonic in the Archives of Family Medicine as a technique to assist students in framing an approach to spiritual history taking:

S Spiritual Belief System

P Personal Spirituality

I Integration and Involvement in a Spiritual Community

R Ritualised Practices and Restrictions

I Implications for Medical Care

T Terminal Events planning (advance directives)

The mnemonic is of course suggestive of a broader line of questioning that may follow from open-ended questions organised around the topics identified above.

How can respect for persons involve a spiritual perspective?

The emphasis on listening to the patient and learning of the patient's beliefs and values as well as the signs and symptoms of illness is timely. A variety of features related to cost containment seem to work adversely against the patient's needs. The typical office visit grows shorter and more curtailed as physicians are pressured to see more patients within a working day. In managed care organisations the physician is responsible for a pool of patients, not just the individual patient who is standing before the physician at this particular moment. Increasingly, the physician is the "gatekeeper" in terms of referral to specialists and to expensive diagnostic procedures or hospitalisation decisions. These pressures toward economy have been created by the upward spiralling of health care costs. However, they must not come at the sacrifice of respect for persons, a fundamental moral obligation in the profession of medicine.

The principle of respect for persons leads to actions designed to safeguard the autonomy of the patient, to limit the risks of harm while providing a medical benefit, and to treat persons fairly in the allocation of health care resources. Such respect for persons is a guiding principle of the healing profession and flows from the professions fundamental ethical commitment in serving the sick and injured. This principle is reinforced for the physician with a religious perspective, who in most religions, views the patient as a part of the creation of God. Likewise, it is reinforced in religious hospitals where the mission is to care for persons individually and equally as "children of God."

How should I work with hospital chaplains?

It is heartening to know that the physician is not alone in relating to the spiritual needs of the patient, but enjoys the team work of well trained hospital chaplains who are prepared to help when the needs of the patient are outside the competence of the physician. Consultation frequently may involve clergy serving the patient and his family. The onset of serious illness often induces spiritual reflection as patients wonder, "what is the meaning of my life now?". Others ponder questions of causation, or "why did this happen to me?". Still others are concerned

as to whether the physician's recommendations for treatment are permissible within the faith community of the patient. Practical questions concerning the permissibility of procedures such as in vitro fertilisation, pregnancy termination, blood transfusion, organ donation, or the removal of life supports such as ventilators, dialysis, or artificially administered nutrition and hydration, arise regularly for persons of faith. In many cases, the chaplain will have specialised knowledge of how medical procedures are viewed by various religious bodies. In each case, the chaplain will first attempt to elicit the patient's current understanding or belief about the permissibility of the procedure in question.

The chaplain is also a helpful resource in providing or arranging for certain rituals that are important for patients under particular circumstances. Some patients may wish to hear the assurances of Scripture, others may want the chaplain to lead them in prayer, and still others may wish for the sacrament of communion, baptism, anointing, or the last rites, depending upon their faith system. The chaplain may provide these direct services for the patient, or may act as liaison with the patient's clergy person. In one case, the surgeon called for the chaplain to consult with a patient who was inexplicably refusing a life-saving surgical procedure. The chaplain gently probed the patient's story in an empathic manner, leading the patient to "confess" to a belief that her current illness was God's punishment for a previous sin. The ensuing discussion revolved around notions of God's forgiveness and the patient's request for prayer. In this case, the chaplain became the "embodiment" of God's forgiveness as he heard the patient's confession, provided reassurance of God's forgiving nature, and offered a prayer acknowledging her penitence and desire for forgiveness and healing. In another case, the neonatologist summoned the chaplain to the NICU when it became apparent that a premature infant was not going to live and the parents were distraught at the notion that their baby would die without the sacrament of baptism. In this case, the chaplain was able to discuss the parents' beliefs, to reassure them that their needs could be met, and to provide an infant baptism service with the parents, the neonatologist and the primary nurse all in attendance. The chaplain also notified their home town pastor and helped make arrangements for the parents to be followed back home in their grieving process.

What role should my personal beliefs play in the physician-patient relationship?

Whether you are religious, or irreligious, your beliefs may affect the doctor-patient relationship. Care must be taken that the nonreligious physician not underestimates the importance of the patient's belief system. Care must be taken that the religious physician who believes differently than the patient, not impose his or her beliefs onto the patient at this time of special vulnerability. In both cases, the principle of respect for the patient should transcend the ideology of the physician.

It is clear that religious beliefs are important to the lives of many physicians. Some physicians attest to a sense of being "called" by God to the profession of medicine, a definite sense of vocation in the religious sense of a calling. In fact, in a much earlier time in the history of the world, the priest and the medicine man were one and the same in most cultures, until the

development of scientific medicine led to a division between the professions. Modern physicians wonder whether, when and how to express themselves to patients regarding their own faith.

In one study reported in the Southern Medical Journal in 1995, physicians from a variety of religious backgrounds reported they would be comfortable discussing their beliefs if asked about them by patients. The study shows that physicians with spiritual beliefs that are important to them integrate their beliefs into their interactions with patients in a variety of ways. Some devout physicians shared their beliefs with patients, discussed the patient's beliefs, and prayed either with or for the patient. These interactions were more likely in the face of a serious or life-threatening illness and religious discussions did not take place with the majority of their patients.

Four guidelines are offered for physicians regarding religious issues:

- Physicians may enter such a dialogue, but they are not obligated to do so.
- The dialogue must be at the invitation of the patient, not imposed by the physician.
- Physicians must be open and nonjudgmental in claiming that their beliefs are personally helpful, without claiming ultimate truth
- The guiding principle should be "do no harm," the purpose of the dialogue should be burden-lifting, not burden-producing.

Some physicians find a number of reasons to avoid discussions revolving around the spiritual beliefs, needs and interests of their patients. Reasons for not opening this subject include the scarcity of time in office visits, fear of imposing upon the patient, lack of familiarity with the subject matter of spirituality, or the lack of knowledge and experience with the varieties of religious expressions in our pluralistic culture. On the other hand, some physicians do incorporate spiritual history taking into the bio-psycho-social-spiritual interview, and others find opportunities where sharing their own beliefs or praying with a particular patient in special circumstances has a unique value to that patient. Certainly issues in modern medicine raise a host of questions such as whether or not to prolong life through artificial means, whether it is licit to shorten life through the use of pain medications, or what duty one has to a new born with fatal genetic anomalies. These and a myriad of other questions have religious and spiritual significance for a wide spectrum of our society and deserve a sensitive dialogue with physicians attending to patients facing these troubling issues.

How can I approach spirituality in medicine with physicians-in-training?

In one approach at the University Of Washington School Of Medicine, the course "Spirituality in Medicine" goes beyond teaching the spiritual history taking. The purpose of the course is to provide an opportunity for interactive learning about relationships between spirituality and the practices in medicine and health care. Some of the goals of the class are as follows:

- To heighten student awareness of ways in which their own faith system provides resources for encounters with illness, suffering and death.

- To foster student understanding, respect and appreciation for the individuality and diversity of patients' beliefs, values, spirituality and culture regarding illness, its meaning, cause, treatment, and outcome.

- To strengthen students in their commitment to relationship-centred medicine that emphasises care of the suffering person rather than attention simply to the pathophysiology of disease, and recognises the physician as a dynamic component of that relationship.

- To facilitate students in recognising the role of the hospital chaplain and the patient's clergy as partners in the health care team in providing care for the patient.

- To encourage students in developing and maintaining a program of physical, emotional and spiritual self-care which includes attention to the purpose and meaning of their lives and work.

Until recently, there were all too few medical schools that offered a formal forum to discuss humanistic aspects of medicine for medical students and residents. This situation is changing. Like the University of Washington, some thirty medical schools around the country have recently added new courses addressing spirituality in medicine. Increasingly, residency programs, particularly those with a primary care focus, are also incorporating this view in the training of residents. In addition, CME has been offered to practicing physicians through three annual conferences on "Spirituality in Medicine," the first of which was hosted by Harvard Medical School with Herbert Benson, MD, as facilitator.

Student Issues

As a medical student, you may encounter some troubling issues specifically related to your position as a physician-in-training. Often, these issues can arise unexpectedly or in time pressured settings. It can be helpful to think through what you will do (and become familiar with some respected opinions) before you feel you are stuck between a rock and a hard place. This topic page addresses some of these concerns and allows you the opportunity to think through what you might do in these situations.

What should I do when my preceptor introduces me as "Dr. Miller"?

Some community preceptors prefer to introduce their medical students as "doctor" because they feel it encourages patient trust. However, it is important to recognise that by calling yourself "doctor," you are misrepresenting yourself to the patient. As with other truth-telling and informed consent issues, it is appropriate to disclose to the patient what he or she needs to know. In this case, the patient needs to know you are a physician-in-training! Students have found themselves in awkward situations once the patient begins asking questions that a physician should know how to answer. At this stage, even if you clarify, "Actually, I'm a medical student, not yet a physician," patient trust may be damaged.

It can be a difficult conversation to have with your preceptors, but it is best to discuss this matter in advance. Find out what his or her expectations are. If they feel strongly about introducing you as "doctor," it remains your responsibility to explain tactfully that you cannot misrepresent yourself to patients. In the long run, patients' trust will be secured if they realise you are both being straightforward. If the preceptor insists, you may need to find polite ways to reintroduce yourself to the patient, modelling for the preceptor that direct communication is often the best foundation for a strong physician (and student-physician) patient relationship. For example, you might say, "Yes, I am a physician-in-training from University of Washington."

How should I respond when an intern asks if I want to practice a procedure on a patient who just died? How should I respond when an intern asks if I want to practice a procedure on a patient who just died?

Practicing procedures on newly dead patients is a highly contentious issue. For some procedures, like intubation, students can benefit from practicing first on a cadaver. Weighing the risks and benefits, the student is more likely to harm a living patient were she to try to intubate without practicing first. No physical harm can occur to the cadaver. However, some are appropriately concerned about the disrespect that "practicing" procedures may show to the deceased patient or to the patient's family. It remains your responsibility to assure that your interactions with the cadaver are respectful and only as invasive as necessary. Most likely, the time you take to practice a simple procedure will not add significantly to the usual amount of time needed to prepare the patient's body for viewing by the family if they are waiting nearby. This is important to be cognisant of, however. (See our reference list for further discussion of this difficult issue.)

What if I see my resident or attending doing something "unethical"?

You will encounter many positive role models during your medical training. However, you will also see some behaviours and actions that are downright troubling or offensive. Because of the "team hierarchy," you may feel unable to confront someone who is "above" you or, more concerning, in control of your evaluation. However, you do still have several duties in this case. Ideally, you could talk with your resident about what you observed. Everyone has a unique perspective and your resident may have a rationale for his behaviour that was unknown to you.

Approaching him honestly, with simple questions, may allow him the benefit of the doubt and open up a dialogue between you.

The nature of the observed 'unethical' act determines what your obligations are. In simpler cases, it can be a matter of treating it as a negative lesson in how NOT to be a physician. In more complex instances, patient care may be in jeopardy and you may have an obligation to report the resident's behaviour if he refuses to discuss it with you directly. Your attending physician or clerkship coordinator can be valuable resources as you make these judgment calls. Discussing these instances with your peers can also be helpful.

Is it ever appropriate to do a procedure for the first time without supervision?

The "see one, do one, teach one" model of medical training has become something of an urban legend. However, on a busy service, you will probably be asked to "go consent Mr. Jones" or "just start a line on Mrs. Smith." If you have never done either of these activities before, it is your responsibility to ask for appropriate supervision before beginning the procedure. Emphasise your interest in learning the new skill as well as your interest in learning it under the best conditions possible.

I'm not sure how I feel about "using" vulnerable patients as teaching patients. Are we taking unfair advantage of people?

A necessary part of learning to be a physician, "practicing" on people sometimes feels uncomfortable. You can keep a few things in mind to minimise the discomfort you might feel. First, as with all your future patients, treat them with respect and ask permission before doing any observations, tests, or procedures. Second, remember that it is a privilege to learn medicine. When appropriate, convey your gratitude to the patients, acknowledging the crucial role they play in your education.

Listen to your instincts as well. Sometimes it may not be appropriate to do an unnecessary duplicate examination or, for example, try more than three times to start an IV line in a patient. If the patient is uncomfortable with your presence, you must respect that and ask a more senior person on your team to complete the procedure or the exam. Unfortunately, you may notice a difference in how some housestaff or attending physicians treat patients from different socioeconomic classes. It is your responsibility to attend to these patients needs with respect and compassion. The homeless man in the ER could be very lucky to have you be the one to stitch his lacerations if you are the one who will be gentle and kind. Sometimes you can put a patient at ease if you convey that you are the member of the team with the most time and attention at the moment.

Other students have (unauthorised) access to last year's killer exam. Should I look at it?

In a survey of students from the late 1980's, 58% reported cheating at least once during medical school. There have been disincentives for reporting cheating, and perhaps a general sense that "this is just the way it is." On the contrary, cheating in class is an example of unprofessional behaviour. It represents a lack of fairness, lack of integrity, and can foreshadow lying in other contexts during your medical training.

As a member of a profession, you are accountable for your own behaviour and for the behaviour of your colleagues. The Assistant Dean for Student Affairs or the Medical Student Association (MSA) representative can field your concerns and help you develop a plan for confronting your classmates.

I'm noticing what looks like addictive behaviour in one of my classmates. What should I do?

Impaired students become impaired physicians. You are entering a profession that carries an obligation to its members for self-regulation. As a student, your classmate has an opportunity to seek help before serious harm comes to himself or herself, or to one of his or her patients.

Once licensed, you will have a legal obligation to report colleagues to the medical board if they are "unable to practice medicine with reasonable skill and safety to patients by reason of illness, drunkenness, excessive use of drugs, narcotics, chemicals, or any other type of material, or as a result of any mental or physical conditions (Revised Code of Washington 18.72.165)." The UW Counselling Office or the Assistant Dean for Student Affairs can help you arrange an intervention if you have these concerns.

Termination of Critical Life-Sustaining Treatment

On the medicine wards, you will have patients who are receiving treatments or interventions that keep them alive, and you will face the decision to discontinue these treatments. Examples include dialysis for acute or chronic renal failure and mechanical ventilation for respiratory failure. In some circumstances, these treatments are no longer of benefit, while in others the patient or family no longer want them.

When is it justifiable to discontinue life-sustaining treatments?

- If the patient has the ability to make decisions, fully understands the consequences of their decision, and states they no longer want a treatment, it is justifiable to withdraw the treatment.

- Treatment withdrawal is also justifiable if the treatment no longer offers benefit to the patient.

How do I know if the treatment is no longer "of benefit?"

In some cases, the treatment may be "futile"; that is, it may no longer fulfil any of the goals of medicine. In general, these goals are to cure if possible, or to palliate symptoms, prevent disease or disease complications, or improve functional status. For example, patients with severe head trauma judged to have no chance for recovery of brain function can no longer benefit from being maintained on a mechanical ventilator. All that continuation would achieve in such a case is maintenance of biologic function. In such a case, it would be justifiable to withdraw mechanical ventilation.

Do different standards apply to withholding and withdrawing care?

Many clinicians feel that it is easier to not start (withhold) a treatment, such as mechanical ventilation, than to stop (withdraw) it. While there is a natural tendency to believe this, there is no ethical distinction between withholding and withdrawing treatment. In numerous legal cases, courts have found that it is equally justifiable to withdraw as to withhold life-sustaining treatments. Also, most bioethicists, including the President's Commission, are of the same opinion.

Does the patient have to be terminally ill to refuse treatment?

Though in most cases of withholding or withdrawing treatment the patient has a serious illness with limited life expectancy, the patient does not have to be "terminally ill" in order for treatment withdrawal or withholding to be justifiable.

Most states, including Washington State, have laws that guarantee the right to refuse treatment to terminally ill patients, usually defined as those having less than 6 months to live. These laws do not forbid other patients from exercising the same right. Many court cases have affirmed the right of competent patient to refuse medical treatments.

What if the patient is not competent?

In some cases, the patient is clearly unable to voice a wish to have treatment withheld or withdrawn. As with DNR orders, there are two general approaches to this dilemma: Advance Directives and surrogate decision makers.

Advance Directive:

This is a document which indicates with some specificity the kinds of decisions the patient would like made should he/she be unable to participate. In some cases, the document may spell out specific decisions (eg. Living Will), while in others it will designate a specific person to make health care decisions for them (ie. Durable Power of Attorney for Health Care). There is some controversy over how literally Living Wills should be interpreted. In some cases, the document may have been drafted in the distant past, and the patient's views may have changed. Similarly, some patients do change their minds about end-of-life decisions when they actually face them. In general, preferences expressed in a Living Will are most compelling when they reflect long held, consistently stable views of the patient. This can often be determined by conversations with family members, close friends, or health care providers with long term relationships with the patient.

Surrogate decision maker:

In the absence of a written document, people close to the patient and familiar with their wishes may be very helpful (See Advance Care Planning). The law recognises a hierarchy of family relationships in determining which family member should be the official "spokesperson," though generally all close family members and significant others should be involved in the discussion and reach some consensus. The hierarchy is as follows:

1. Legal guardian with health care decision-making authority
2. Individual given durable power of attorney for health care decisions
3. Spouse
4. Adult children of patient (all in agreement)
5. Parents of patient

6. Adult siblings of patient (all in agreement)

What if I'm not sure if the patient is competent?

Sometimes the patient is awake, alert, and conversant, but their decisions seem questionable or irrational. First, it is important to distinguish an irrational decision from simple disagreement. If you feel strongly that a certain course of action is "what's best" for the patient, it can seem irrational for them to disagree. In these situations, it is critical to talk with the patient and find out why they disagree.

Patients are presumed to be "competent" to make a treatment decisions. Often it's better to say they have "decision making capacity" to avoid confusion with legal determinations of competence. In the courts, someone's competence is evaluated in a formal, standardised way. These court decisions do not necessarily imply anything about capacity for making treatment decisions. For example, an elderly grandfather may be found incompetent to manage a large estate, but may still have intact capacity to make treatment decisions.

In general, the capacity to make treatment decisions, including withholding or withdrawing treatment, is considered intact if the patient:

- understands the clinical information presented
- appreciates his/her situation, including consequences with treatment refusal
- is able to display reason in deliberating about their choices
- is able to clearly communicate their choice.

If the patient does not meet these criteria, then their decision to refuse treatment should be questioned, and handled in much the same way as discussed for the clearly incompetent patient. When in doubt, an ethics consultation may prove helpful.

Is a psychiatry consult required to determine decision making capacity?

A psychiatry consult is not required, but can be helpful in some cases. Psychiatrists are trained in interviewing people about very personal, sensitive issues, and thus can be helpful when patients are facing difficult choices with fears or concerns that are difficult to talk about. Similarly, if decision making capacity is clouded by mental illness, a psychiatrist's skill at diagnosis and potential treatment of such disorders can be helpful.

Does depression or other history of mental illness mean a patient has impaired decision making capacity?

Patients with active mental illness including depression should have their decision making capacity evaluated carefully. They should not be presumed to be unable to make treatment decision. In several studies, patients voiced similar preferences for life-sustaining treatments when depressed as they did after treatment of their depression.

Depression and other mental disorders should prompt careful evaluation, which may often be helped by psychiatry consultation.

Is it justifiable to withhold or withdraw food or fluids?

This question underscores the importance of clarifying the goals of medical treatment. Any medical intervention can be withheld or withdrawn, including nutrition and IV fluids. At all times, patients must be given basic humane, compassionate care. They should be given a comfortable bed, human contact, warmth, and be kept as free from pain and suffering as possible. While some believe that food and fluids are part of the bare minimum of humane treatment, both are still considered medical treatments. Several court cases have established that it is justifiable to withhold or withdraw food and fluids.

Is it justifiable to withhold or withdraw care because of costs?

It is rarely justifiable to discontinue life-sustaining treatment for cost reasons alone. While we should always try to avoid costly treatments that offer little or no benefit, our obligation to the patient outweighs our obligation to save money for health care institutions. There are rare situations in which costs expended on one terminally ill patient could be clearly better used on another, more viable patient. For instance, a terminally ill patient with metastatic cancer and septic shock is in the last ICU bed. Another patient, young and previously healthy, now with a self-limited but life-threatening illness, is in the emergency room. In such cases, it may be justifiable to withdraw ICU treatment from the terminally ill patient in favour of the more viable one. Even so, such decisions must be carefully considered, and made with the full knowledge of patients and their surrogate decision makers.

Case 1

Mr. S is a 70-year-old man with end-stage COPD, admitted last month with pneumonia. His course was complicated by respiratory failure needing mechanical ventilation, and multiple efforts to wean him have been unsuccessful. Awake and alert, he now communicates through written notes that he wants the ventilator taken off.

What do you think his prognosis is? What else do you want to know before making this decision? If he is competent, will you honour his request?

Discussion

The prognosis of full recovery from long-term mechanical ventilation is poor, particularly in patients like Mr. S with minimal pulmonary reserve. The approach to his request should start with an evaluation of his decision making capacity. Even though he is awake and alert, you should carefully probe the reasons for his request, with particular attention to making sure he understands the consequences of his decision. If you're concerned about depression or other mental illness affecting his thinking about this decision, you might request a psychiatry consultation. You should ask Mr. S if he's discussed this with his spouse or family. If his decision-making capacity is intact, you should honour his request.

Case 2

Mrs. H is a 62-year-old woman with metastatic breast cancer. She was admitted with dehydration and weakness. Her cancer treatments have failed, as she now has a recurrence. The oncologists are contemplating some new palliative chemotherapy. The nutrition team is concerned about her cachexia and recommends total parenteral nutrition (TPN).

Should the patient be started on TPN?

Discussion

Patients with metastatic cancer often suffer from profound cachexia, attributable to the metabolic effects of their cancer and their inability to get adequate caloric intake from eating alone. TPN is able to provide protein and non-protein nutrients to reverse the catabolic effects of illness. TPN has a number of potential complications, such as those related to infection from the central line catheter site.

In this case, you should carefully evaluate the goals of therapy as they relate to TPN. Is TPN likely to offer the patient any benefit? If her life expectancy can be prolonged with additional chemotherapy, it may be reasonable to give TPN to allow the patient to enjoy that benefit. If

additional chemotherapy offers no substantial increase in quantity or quality of life, TPN could become another burden for the patient without any meaningful benefit, and ought to be withheld.

Telling the truth and withholding information

When physicians communicate with patients, being honest is an important way to foster trust and show respect for the patient. Patients' place a great deal of trust in their physician, and may feel that trust is misplaced if they discover or perceive lack of honesty and candour by the physician. Yet there are situations in which the truth can be disclosed in too brutal a fashion, or may have a terrible impact on the occasional patient. The goal of this summary is to be able to discern the difference.

Do patients want to know the truth about their condition?

Contrary to what many physicians have thought in the past, a number of studies have demonstrated that patients do want their physicians to tell them the truth about diagnosis, prognosis, and therapy. For instance, 90% of patients surveyed said they would want to be told of a diagnosis of cancer or Alzheimer's disease. Similarly, a number of studies of physician attitudes reveal support for truthful disclosure. For example, whereas in 1961 only 10% of physicians surveyed believed it was correct to tell a patient of a fatal cancer diagnosis, by 1979 97% felt that such disclosure was correct.

How much do patients need to be told?

In addition to fostering trust and demonstrating respect, giving patients truthful information helps them to become informed participants in important health care decision. Thus, patients should be told all relevant aspects of their illness, including the nature of the illness itself, expected outcomes with a reasonable range of treatment alternatives, risks and benefits of treatment, and other information deemed relevant to that patient's personal values and needs. Treatment alternatives that are not medically indicated or appropriate need not be revealed. Facts that are not important to the patients ability to be an informed participant in decision making, such as results of specific lab tests, need not be told to the patient. Also, complete and truthful disclosure need not be brutal; appropriate sensitivity to the patient's ability to digest complicated or bad news is important.

What if the truth could be harmful?

There are many physicians who worry about the harmful effects of disclosing too much information to patients. Assuming that such disclosure is done with appropriate sensitivity and tact, there is little empirical evidence to support such a fear. If the physician has some compelling reason to think that disclosure would create a real and predictable harmful effect on the patient, it may be justified to withhold truthful information.

What if the patient's family asks me to withhold the truth from the patient?

Often families will ask the physician to withhold a terminal or serious diagnosis or prognosis from the patient. Usually, the family's motive is laudable; they want to spare their loved one the potentially painful experience of hearing difficult or painful facts. These fears are usually unfounded, and a thoughtful discussion with family members, for instance reassuring them that disclosure will be done sensitively, will help allay these concerns. In unusual situations, family members may reveal something about the patient that causes the physician to worry that truthful disclosure may create real and predictable harm, in which case withholding may be appropriate. These occasions, however, are rare.

When is it justified for me to withhold the truth from a patient?

There are two main situations in which it is justified to withhold the truth from a patient. As noted above, if the physicians has compelling evidence that disclosure will cause real and predictable harm, truthful disclosure may be withheld. Examples might include disclosure that would make a depressed patient actively suicidal. This judgment, often referred to as the "therapeutic privilege," is important but also subject to abuse. Hence it is important to invoke this only in those instances when the harm seems very likely, not merely hypothetical.

The second circumstance is if the patient him- or herself states an informed preference not to be told the truth. Some patients might ask that the physician instead consult family members, for instance. In these cases, it is critical that the patient give thought to the implications of abdicating their role in decision making. If they chose to make an informed decision not to be informed, however, this preference should be respected.

What about patients with different specific religious or cultural beliefs??

Patient with certain religious beliefs or ethnic or cultural backgrounds may have different views on the appropriateness of truthful disclosure. For instance, Carrese and colleagues found that many people with traditional Navajo beliefs did not want to hear about potential risks of treatment, as their beliefs held that to hear such risks was to invite them to occur. Thus, dialogue must be sensitive to deeply held beliefs of the patient. One should not, however, assume that

someone of a particular ethnic background holds different beliefs. Rather, a culturally sensitive dialogue about the patient's role in decision making should take place.

Is it justifiable to deceive a patient with a placebo?

A placebo is any substance given to a patient with the knowledge that it has no specific clinical effect, yet with the suggestion to the patient that it will provide some benefit. The placebo effect is powerful, in many cases providing measurable improvement in symptoms in 20-30% of patients. In general, the deceptive use of placebos is not ethically justifiable. Specific exceptions should be rare and only considered if the following conditions are present:

- the condition is known to have a high placebo response rate
- the alternatives are ineffective and/or risky
- the patient has a strong need for some prescription

Case 1

A 65-year-old man comes to his physicians with complaints of abdominal pain that is persistent but not extreme. Workup reveals that he has metastatic cancer of the pancreas. The man has just retired from a busy professional career, and he and his wife are about to leave on a round-the-world cruise that they've been planning for over a year.

Should you tell him his diagnosis?

Discussion

Several factors tempt one to withhold the diagnosis, and these should be recognised. One would be the concern that the patient would suffer psychological harm that would interfere with his planned trip. There is little empirical evidence that this occurs, and lacking some compelling reason to think it would occur with this man, it is insufficient grounds to withhold information. To the contrary, sensitive disclosure would allow the patient and his wife to decide if the trip is still important to them, versus seeing their grandchildren, for instance, and would spare the patient the inconvenience of suffering advancing symptoms while travelling, perhaps necessitating emergency care in a foreign locale. Finally, physicians should not confuse

discomfort at giving bad news with justification for withholding the truth. In this case, the man should be told his diagnosis, prognosis, and treatment options.

Case 2

An 80-year-old Asian woman is hospitalised with weight loss, generalised weakness, and a pulmonary mass. Work-up reveals that she has pulmonary tuberculosis. Her family approaches the physician and asks that the patient not be told, stating that in her upbringing in mainland China tuberculosis was considered fatal and to tell her would be like giving her "a death sentence."

Should you respect the family's concerns?

Discussion

Some cultures hold different beliefs about truth-telling in the medical encounter. Some assert that in some Asian cultures, members of the family unit may withhold the truth about terminal illness from elders out of respect and a desire to protect them from harm. If a patient and their family members hold such beliefs, they should be respected, and a mechanism for informed decision making in collaboration with the family negotiated. One must not, however, assume that every patient of Asian ancestry holds the beliefs described here. The physician should make an attempt to explore the patient's belief system. If he finds that the patient does hold such beliefs about the harmful nature of truthful disclosure of the truth, then it would be justifiable to withhold the diagnosis of tuberculosis.

Do Not Resuscitate Orders

On the medicine wards, you will come across patients who have a "Do-Not-Resuscitate" order on their chart. You will also be in situations where you are asked to discuss with a patient whether they want to or should have resuscitation following a cardiac arrest or life-threatening arrhythmia. Like many other medical decisions, deciding whether or not to resuscitate a patient who suffers a cardiopulmonary arrest involves a careful consideration of the potential likelihood for clinical benefit with the patient's preferences for the intervention and its likely outcome. Decisions to forego cardiac resuscitation are often difficult because of real or perceived differences in these two considerations.

When should CPR be administered?

Cardiopulmonary resuscitation (CPR) is a set of specific medical procedures designed to establish circulation and breathing in a patient who's suffered an arrest of both. CPR is a supportive therapy, designed to maintain perfusion to vital organs while attempts are made to restore spontaneous breathing and cardiac rhythm.

If your patient stops breathing or their heart stops beating in the hospital, the standard of care is to perform CPR in the absence of a valid physician's order to withhold it. Similarly, paramedics responding to an arrest in the field are required to administer CPR. Since 1994 in Washington State, patients may wear a bracelet that allows a responding paramedic to honour a physician's order to withhold CPR.

When can CPR be withheld?

Virtually all hospitals have policies which describe circumstances under which CPR can be withheld. Two general situations arise which justify withholding CPR:

- when CPR is judged to be of no medical benefit (also known as "medical futility"; see below), and
- when the patient with intact decision making capacity (or when lacking such capacity, someone designated to make decisions for them) clearly indicates that he / she does not want CPR, should the need arise.

When is CPR "futile"?

CPR is "futile" when it offers the patient no clinical benefit. When CPR offers no benefit, you as a physician are ethically justified in withholding resuscitation. Clearly it is important to define what it means to "be of benefit." The distinction between merely providing measurable effects (eg. normalising the serum potassium) and providing benefits is helpful in this deliberation.

When is CPR not of benefit?

One approach to defining benefit examines the probability of an intervention leading to a desirable outcome. CPR has been prospectively evaluated in a wide variety of clinical situations. Knowledge of the probability of success with CPR could be used to determine its futility. For

instance, CPR has been shown to have a 0% probability of success in the following clinical circumstances:

- Septic shock
- Acute stroke
- Metastatic cancer
- Severe pneumonia

In other clinical situations, survival from CPR is extremely limited:

- Hypotension (2% survival)
- Renal failure (3%)
- AIDS (2%)
- Homebound lifestyle (4%)
- Age greater than 70 (4% survival to discharge from hospital)

How should the patient's quality of life be considered?

CPR might also seem to lack benefit when the patient's quality of life is so poor that no meaningful survival is expected even if CPR were successful at restoring circulatory stability. Judging "quality of life" tempts prejudicial statements about patients with chronic illness or disability. There is substantial evidence that patients with such chronic conditions often rate their quality of life much higher than would healthy people. Nevertheless, there is probably consensus that patients in a permanent unconscious state possess a quality of life that few would accept. Therefore, CPR is usually considered "futile" for patients in a persistent vegetative state.

If CPR is deemed "futile," should a DNR order be written?

If CPR is judged to be medically futile, this means that you as the physician are under no obligation to provide it. Nevertheless, the patient and/or their family should still have a role in the decision about a Do-Not-Resuscitate (DNR) order. This involvement stems from respect for all people to take part in important life decisions, commonly referred to as respect for autonomy or respect for person.

In many cases, the patient/family, upon being given a caring but frank understanding of the clinical situation, will agree with the DNR order. In such cases a DNR order can be written. Each hospital has specific procedures for writing a valid DNR order. In all cases, the order must be written or cosigned by the Attending Physician.

What if CPR is not futile, but the patient wants a DNR order?

As mentioned above, a decision to withhold CPR may also arise from a patient's expressed wish that CPR not be performed on her. If the patient understands her condition and possesses intact decision making capacity, her request should be honoured. This position stems from respect for autonomy, and is supported by law in many states that recognise a competent patient's right to refuse treatment.

What if the family disagrees with the DNR order?

Ethicists and physicians are divided over how to proceed if the family disagrees. At the UW, Harbourview, and VA Medical Centres, the policy is to write a DNR order only with patient/family agreement.

If there is disagreement, every reasonable effort should be made to communicate with the patient or family. In many cases, this will lead to resolution of the conflict. In difficult cases, an ethics consultation can prove helpful. Nevertheless, CPR should generally be provided to such patients, even if judged futile.

What about "slow codes"?

It is the policy of the UWMC, Harbourview and VA that so-called "slow-codes," in which a half-hearted effort at resuscitation is made, are not ethically justified. These undermine the right patients have to be involved in inpatient clinical decisions, and violate the trust patients have in us to give our full effort.

What if the patient is unable to say what his/her wishes are?

In some cases, the decision about CPR occurs at a time when the patient is unable to participate in decision making, and hence cannot voice a preference. There are two general approaches to this dilemma: Advance Directives and surrogate decision makers.

- Advance Directive: This is a document which indicates with some specificity the kinds of decisions the patient would like made should he be unable to participate. In some cases, the document may spell out specific decisions (eg. Living Will), while in others it will designate a specific person to make health care decisions for them. Durable Power of Attorney for Health Care). There is some controversy over how literally living wills should be interpreted. In some cases, the document may have been drafted in the distant past, and the patient's views may have changed. Similarly, some patients do change their minds about end-of-life decisions when they actually face them. In general, preferences expressed in a living will are most compelling when they reflect long held, consistently stable views of the patient. This can often be determined by conversations with family members, close friends, or health care providers with long term relationships with the patient.

- Surrogate decision maker: In the absence of a written document, people close to the patient and familiar with his wishes may be very helpful. The law recognises a hierarchy of family relationships in determining which family member should be the official "spokesperson," though generally all close family members and significant others should be involved in the discussion and reach some consensus. The hierarchy is as follows:

    1. Legal guardian with health care decision-making authority
    2. Individual given durable power of attorney for health care decisions
    3. Spouse
    4. Adult children of patient (all in agreement)
    5. Parents of patient
    6. Adult siblings of patient (all in agreement)

Case 1

Mr. H is a 24-year-old man who resides in a skilled nursing facility, where he is undergoing rehabilitation from a cervical spine injury. The injury left him quadriplegic. He has normal cognitive function and no problems with respiration. He is admitted to your service for treatment of pneumonia. The resident suggests antibiotics, chest physiotherapy, and hydration. One day while signing out Mr. H to the cross covering intern, the intern says "he should be a DNR, based on medical futility."

Do you agree? Is his case medically futile, and if so, why?

Discussion

Medical futility means that an intervention, in this case CPR, offers no chance of meaningful benefit to the patient. Interventions can be considered futile if the probability of success (discharged alive from the hospital) is <1%, and/or if the CPR is successful, then the quality of life is below the minimum acceptable to the patient.

In this case, Mr. H would have a somewhat lower than normal chance of survival from CPR, based on his quadriplegia (homebound lifestyle is a poor prognostic factor) and his mild pneumonia (in cases of severe pneumonia and respiratory failure survival is <1%).

Furthermore, his quality of life, while not enviable, is not without value. Since he is fully awake and alert, you could talk with Mr. H about his view of the quality of his life. You could share with him the likely scenarios should he have an arrest and need CPR. After this discussion, Mr. H can tell you if he would like to have CPR in the event of an arrest or not.

One cannot say on the basis of the current situation that CPR is futile. A decision about resuscitation should occur only after talking with the patient about his situation and reaching a joint decision.

Case 2

Mrs. W is an 81-year-old woman with recurrent colon cancer with liver metastases admitted to the hospital for chemotherapy. Because of her poor prognosis, you approach her about a DNR order, but she requests to be "a full code."

Can you write a DNR order anyway?

Discussion

Mrs. W is elderly and has a diagnosis of metastatic cancer. In several prospective outcome studies of CPR in the hospital, patients like Mrs. W had 0% survival. Thus CPR for Mrs. W could be called "futile."

Nevertheless, current policy at UWMC/Harbourview and the VAMC State that one should not write a DNR order, even if CPR is judged to be futile, without patient or family concurrence. Rather, you should allow Mrs. W some time to come to grips with her diagnosis, while periodically re-addressing the CPR question with her. This is best done in the context of other medical decision that occurs during her care. It is important to review other care goals with her, to allay possible fear that a DNR order may mean she will be abandoned or not cared for.

Case 3

Several days go by and Mrs. W still wants to be a "full code." Your intern suggests that you sign her out as a "slow code."

Should you do this?

Discussion

A "slow code" allows the appearance of respecting the patient's desire for CPR while not actually complying with the respect. Slow codes are not ethically justifiable. Rather, you should continue efforts to discuss the DNR order with Mrs. W, perhaps with the help of her family or religious advisers

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Advance Directives

Advance directives are usually written documents designed to allow competent patients the opportunity to guide future health care decisions in the event that they are unable to participate directly in medical decision making. (For related discussion, see Advance Care Planning and Termination of Life-Sustaining Treatment.)

What types of advance directives are currently available?

A 1991 federal law, the Patient Self-Determination Act, requires that patients are informed about their right to participate in health care decisions, including their right to have an advance directive. Advance directives fall into two broad categories: instructive and proxy. Instructive directives allow for preferences regarding the provision of particular therapies or classes of therapies. Living wills are the most common examples of instructive directives, but other types of instructive directives, such as no transfusion and no CPR directives are also employed. The proxy directive, generally a Durable Power of Attorney for Health Care (DPAHC), allows for the designation of a surrogate medical decision maker of the patient's choosing. This surrogate decision maker makes medical care decisions for the patient in the event she is incapacitated.

Why are advance directives important to medical care?

The major argument for the use of instructive directives, such as a living will, is that it allows an individual to participate indirectly in future medical care decisions even if they become decisionally incapacitated, ie. unable to make informed decisions. Instructive directives may extend individual autonomy and help ensure that future care is consistent with previous desires. The living will was created to help prevent unwanted and ultimately futile invasive medical care at the end-of-life.

When patients become incapacitated someone else will be required to make medical decisions regarding their care. Generally a spouse is the legal surrogate. If no spouse is available, the state law designates the order of surrogate decision makers, usually other family members. By designating a DPAHC, the patient's choice of a surrogate decision maker supersedes that of the state. A legal surrogate is particularly valuable for persons in non-traditional relationships or without close family. The DPAHC need not be a relative of the patient, though this person should have close knowledge of the patient's wishes and views.

Are advance directives legally binding?

Advance directives are recognised in one form or another by legislative action in all 50 states (in Washington, see RCW 11.94). If the directive is constructed according to the outlines provided by pertinent state legislation, they can be considered legally binding. In questionable cases, the medical centre’s attorney or ethics advisory committee can provide guidance on how to proceed (see also the topics Law and Ethics and Ethics Committees).

When should I refer to a patient's advance directive?

It is best to ask a patient early on in his care if he has a living will, or other form of advance directives. Not only does this information get included in the patient's chart, but by raising the issue, the patient has an opportunity to clarify his wishes with the care providers and his family (see Advance Care Planning).

However, advance directives take effect only in situations where a patient is unable to participate directly in medical decision making. Appeals to living wills and surrogate decision makers are ethically and legally inappropriate when individuals remain competent to guide their own care. The assessment of decisional incapacity is often difficult and may involve a psychiatric evaluation and, at times, a legal determination.

Some directives are written to apply only in particular clinical situations, such as when the patient has a "terminal" condition or an "incurable" illness. These ambiguous terms mean that directives must be interpreted by caregivers. More recent forms of instructive directives have attempted to overcome this ambiguity by either addressing specific intervention (eg. blood transfusions or CPR) that are to be prohibited in all clinical contexts.

What if a patient changes her mind?

As long as a patient remains competent to participate in medical decisions, both documents are revocable. Informed decisions by competent patients always supersede any written directive.

What if the family disagrees with a patient's living will?

If there is a disagreement about either the interpretation or the authority of a patient's living will, the medical team should meet with the family and clarify what is at issue. The team should explore the family's rationale for disagreeing with the living will. Do they have a different idea of what should be done? Do they have a different impression of what would be in the patient's best interests, given her values and commitments? Or does the family disagree with the physician's interpretation of the living will?

These are complex and sensitive situations and a careful dialogue can usually surface many other fears and concerns. However, if the family merely does not like what the patient has requested, they do not have much ethical power to sway the team. If the disagreement is based on new knowledge, substituted judgment, or recognition that the medical team has misinterpreted the living will, the family has much more say in the situation. If no agreement is reached, the hospital's Ethics Committee should be consulted.

How should I interpret a patient's advance directive?

Living wills generally are written in ambiguous terms and demand interpretation by providers. Terms like "extraordinary means" and "unnaturally prolonging my life" need to be placed in context of the present patient's values in order to be meaningfully understood. More recent forms of instructive directives have attempted to overcome this ambiguity by addressing specific interventions (eg. blood transfusions or CPR) to be withheld. The DPAHC or a close family member often can help the care team reach an understanding about what the patient would have wanted. Of course, physician-patient dialogue is the best guide for developing a personalised advance directive.

What are the limitations of living wills?

Living wills cannot cover all conceivable end-of-life decisions. There is too much variability in clinical decision-making to make an all-encompassing living will possible. Persons who have written or are considering writing advance directives should be made aware of the fact that these documents are insufficient to ensure that all decisions regarding care at the end-of-life will be made in accordance with their written wishes. They should be strongly encouraged to

communicate preferences and values to both their medical providers and family/surrogate decision makers.

Another potential limitation of advance directives is possible changes in the patient's preferences over time or circumstance. A living will may become inconsistent with the patient's revised views about quality of life or other outcomes. This is yet another reason to recommend that patients communicate with their physicians and family members about their end-of-life wishes.

Case 1

An elderly man with end-stage emphysema presents to the emergency room awake and alert and complaining of shortness of breath. An evaluation reveals that he has pneumonia. His condition deteriorates in the emergency room and he has impending respiratory failure, though he remains awake and alert. A copy of a signed and witnessed living will is in his chart stipulates that he wants no "invasive" medical procedures that would "serve only to prolong my death." No surrogate decision maker is available.

Should mechanical ventilation be instituted?

Discussion

If the patient has remained awake and alert, his living will is irrelevant to medical decision making. The potential risks and benefits of mechanical ventilation need to be presented to the patient. If he refuses this therapy with an understanding of the consequences, his wishes should be honoured. If he opts for mechanical ventilation, it should be instituted when it becomes medically necessary. The presence of a living will or other advance directive does not obviate the responsibility to involve a competent patient in medical decision making.

Case 2

The same patient described in Case 1 presents confused and somnolent.

Should mechanical ventilation be instituted?

Discussion

If the man has deteriorated to the point that he can no longer communicate, his living will may be a helpful guide to decision-making. The language of the directive, however, is difficult to

interpret in this case. Pneumonia represents a potentially reversible condition from which the patient may recover fully. Mechanical ventilation does not serve only to "prolong death" but offers a significant chance to return to his previous level of functioning. Most patients with even end-stage emphysema can be successfully weaned from mechanical ventilation. The intent of the directive, whether to avoid intubation and ventilation at all costs or simply to withhold such therapies when they are clearly futile, is not evident. In the absence of other information to aid the decision, mechanical ventilation should be instituted, with the plan that it be discontinued if it becomes evident that the patient cannot be weaned.

Do-Not-Resuscitate Orders

during Anaesthesia and Urgent Procedures

It is common to have patients present for surgery, for whom a "Do-Not-Resuscitate" order is written, in their chart. Physicians and patients alike suffer from misconceptions about the potential benefits and harms of resuscitation in the operating room (OR), and even the definition itself of resuscitation in the OR requires clarification prior to surgery. Because the OR environment presents patients with a situation in which cardiopulmonary resuscitation (CPR) carries significantly different risks and benefits than on the medical ward, re-discussion of the implications of the DNR order are necessary. (For a discussion of DNR Orders in other medical settings, see main topic Do Not Resuscitate Orders.)

When should CPR be administered?

Anaesthesiologists and surgeons may be reluctant to accept DNR orders on patients undergoing surgery because of the scope of medical practice, which constitutes "normal care" in the surgical environment. Many surgeries require intubation and mechanical control of respiration for the duration of surgery, to protect the airway from aspiration, prevent anaesthetic-induced hypoventilation, to allow the administration of paralytic agents to prevent muscle contraction during surgery, and for many other reasons. Yet intubation and ventilatory assistance are mainstays of CPR.

It is inaccurate to call anaesthesia "ongoing resuscitation," yet the administration of anaesthetic agents frequently causes initial changes in the autonomic nervous system, such that hypotension, tachycardia, bradycardia, and temporary cardiac dysrrhythmias can result. It is common to administer vasopressive medications and antiarrhythmic agents during the course of "normal" anaesthetic management. Such medications are often considered a vital part of effective administration of CPR.

Finally, both invasive and noninvasive technology in the OR permits easy application of therapeutic measures which might seem extreme on the medical ward, such as external or transvenous pacing and defibrillation. Under most other circumstances, such measures would fall almost exclusively within the realm of CPR.

So where do we draw the line between "normal" and "usual" procedures in the operating room, and "extraordinary" procedures which constitute CPR? Many authorities have suggested that the application of chest compressions is an usual enough occurrence even in the OR setting, that it provides a medical and ethical boundary between CPR and normal anaesthetic care.

What should we do with DNR orders in the OR?

In 1992, the American Society of Anaesthesiologists (ASA) produced Guidelines for the Ethical Care of Patients with Do Not Resuscitate Orders, and Other Orders Limiting Care in the Operating Room. Out of respect for patient autonomy, or the right of competent, adult patients, to determine their own medical care, no specific definition of CPR was provided in the document. Instead, it requires a discussion with the patient to define medical procedures under anaesthesia to which the patient would consent. Shortly after the ASA adopted its guidelines, the American College of Surgeons, and the Association of Operating Room Nurses (AORN) adopted guidelines which drew directly from the ASA's document.

All acknowledged that patients do not check their rights to self-determination at the OR doors, that policies automatically suspending or upholding DNR orders in the OR were ethically suspect, and that re-discussion of the DNR order should occur, whenever possible, prior to undertaking surgery and anaesthesia.

When should CPR be administered?

CPR should be administered in the absence of a valid physician's order to withhold it.

When can CPR be withheld?

As with CPR on the medical wards, two general situations arise in which CPR can be withheld in the operating room:

- When CPR is judged to be of no benefit to the patient (See the main topic page, Do-Not-Resuscitate Orders.)

- When a patient with intact decision-making capacity (or in the case of those without decision making capacity, an appropriate surrogate decision-maker) indicates that they do no want CPR, even if the need arises.

Is the outcome from CPR different in the OR than on the medical ward?

CPR in the OR carries a very different medical prognosis than CPR administered in other hospital areas. While only 4 to 14% of all patients resuscitated in the hospital survive to discharge, 50 to 80% of patients resuscitated in the OR return to their former level of functioning. This is probably due to several differences between arrest on the medical ward and arrest in the OR. In the OR, the event of arrest is always witnessed, and the proximate cause usually known, allowing rapid, effective intervention which is directed toward the specific cause of arrest. Also, causes of arrest in the OR are often reversible effects of anaesthesia or haemorrhage, and not usually due primarily to the patient's underlying disease. Patient and physicians may require correction of the perception that CPR in the OR is just as futile as CPR on the general medical ward.

Does the cause of arrest matter?

Because arrests in the OR are often due to haemorrhage or medication effects, rather than the patient's underlying disease, physicians may feel that their actions "caused" the arrest, and they are ethically obliged to resuscitate the patient, even if the patient has clearly expressed wishes to the contrary. But competent patients, or their appropriate surrogates, have the right to refuse medical procedures and care, even if the care is to counteract the effects of previous medical intervention.

Why do we agree to do surgery on patients with DNR orders?

Many types of surgery provide palliative benefits to patients who either will not survive long-term, or who do not wish resuscitation in the OR. A patient with an oesophageal obstruction from cancer might benefit from gastrostomy placement through reduced pain and improved nutritional status, yet not want CPR if cardiac arrest happens in the OR. Requiring such a patient to suspend their DNR orders to be a candidate for surgery uses their discomfort, pain, and desire to benefit from surgery to coerce them into accepting medical care (CPR) they do not want. Patient refusal of some medical therapy, such as CPR, does not ethically justify physicians denying them other medical therapy, such as surgery, that might benefit them.

What should be included in a discussion of DNR orders in the OR with the patient or patient's surrogates?

As discussed above, surgery and anaesthesia may require the administration of medical therapies, which under other circumstances might be considered resuscitation. It is an ongoing source of discussion about what constitutes appropriate information and choices to present to patients about to undergo surgery who have DNR orders on their charts.

Since the goal of medical therapy is to provide *meaningful* benefits to the patient, discussion of DNR orders in the OR should centre around the patient's goals for surgical therapy. Patients may have fears of "ending up a vegetable" on a ventilator after surgery, for example. In those cases, discussion should centre around the positive prognosis for patients who have CPR in the OR, together with reassurance that the patient's stated wishes in their advanced directive regarding ventilatory support would be followed postoperatively after anaesthetic effects are ruled out as a cause of ventilatory depression. Most authorities now agree that a "smorgasbord" or checklist "yes-or-no" approach to the various procedures in the operating room is confusing and counterproductive to the purpose of DNR discussions.

Anaesthesiologists in particular need to be aware that studies indicate that many patients with DNR orders in their charts (up to 46%) may be unaware that the order exists, even when they are competent. While policies at the University of Washington Medical Centre require documentation of discussion of DNR orders with the patient or appropriate surrogates, Anaesthesiologists and surgeons should nevertheless approach the patient about to undergo surgery with sensitivity to the fact that they may be unaware of their DNR order. If this proves to be the case, a full discussion of the DNR order should be undertaken prior to proceeding.

What about emergencies?

Even in emergencies, physicians have an ethical obligation to recognise and respect patient autonomy. Whenever possible, physicians should obtain input from the patient, or when the patient is incapacitated, from appropriate surrogates, regarding the status of the patient's DNR orders in the OR. In the absence of such input, consensus should be reached among the caregivers about the medical benefits or futility of CPR. In any case, medical care of the patient in the absence of patient input should be directed toward realising, to the best of the physician's ability and knowledge, the patient's goals.

Case 1

Mr. S is a 73-year-old man, with a history of severe coronary artery disease, peripheral vascular disease, and stroke. He suffers from right hemiplegia and mild expressive aphasia. He is awake and alert, and presents for right below the knee amputation (BKA) for vascular insufficiency. His chart carries a DNR order. In the holding area prior to surgery, the Anaesthesiologists discuss the DNR order with Mr. S, who appears depressed. Mr. S states unequivocally, that he does not wish CPR in the OR, regardless of its cause or positive prognosis. He tells his anaesthesiologist that he is willing to go "so far, and no more." The patient agrees to subarachnoid anaesthesia (spinal

block) and sedation. He is not intubated. After about 20 minutes, the patient complains of weakness in his arms, and difficulty breathing. Within 3 minutes, his blood pressure and heart rate fall, and he abruptly arrests.

Should the patient be intubated? Should CPR be commenced?

Discussion

The probable cause of Mr. S's arrest is a cephalad migration of local anaesthetic in the subarachnoid space, leading to a "high spinal block." As a result of migration of the local anaesthetic from the lumbar segments to high thoracic or even cervical segments, weakness or paralysis of respiratory muscles, including intercostal muscles and diaphragmatic muscles can result. The effect of local anaesthetic on segments contributing to the cardiac accelerator fibres can cause bradycardia, and even cardiac arrest. With cardiopulmonary support, prognosis for total recovery from this event is excellent, with only rare cases of central nervous system damage or death reported. CPR would not be futile from a medical standpoint.

Intubation and institution of mechanical ventilation will not alone restore Mr. S's circulation, and these measures alone will be useless. Medications to treat blood pressure and bradycardia will require at least temporary artificial circulation. From the standpoint of medical futility, intubation and mechanical ventilation would be senseless unless accompanied by full CPR, if even briefly.

It is hard to argue ethically for the institution of CPR in this patient, who while neurologically impaired, appeared to have full capacity to understand and make decisions regarding his own medical care. Despite preoperative discussion which included information about the good prognosis from CPR in the OR, the patient stated clearly his wishes to not be resuscitated if an arrest occurs. Instituting CPR in this patient because the cause of arrest is anaesthetic-related, would be like justifying transfusion in a Jehovah's Witness against their will because the surgery was the cause of life-threatening haemorrhage, yet adhering to their wishes if haemorrhage was due to non-surgical injuries.

Case 2

Mrs. P is a 74-year-old woman presenting for emergent treatment of a fracture-dislocation of her right hip, suffered in a fall at her nursing home. She appears frail, but is alert and oriented. She is accompanied by her daughter, and both state that they want her to receive full medical care. On admission two hours earlier, the emergency room physician heard a loud systolic murmur, and echocardiogram revealed critical aortic stenosis, with a valve area of 0.3 cm2. The surgeon suggests that the patient, because of her cardiac status and age, should have a DNR order in the chart.

Do you agree?

Discussion

Cardiac arrest in the setting of critical aortic stenosis carries virtually zero chance of survival, since the tight stenosis of the left ventricular outflow tract makes generation of systemic blood pressures compatible with life virtually impossible. CPR in this setting can easily be termed "medically futile." Current policy at UWMC/ Harbourview and the VAMC require that patient or family agreement accompany DNR orders. A frank discussion with Mrs. P and her daughter about the issue of CPR should be initiated with the hope of establishing understanding with the patient and her family about the question of resuscitation.

Bioethics Tools

This index is a guide to various concepts and methodologies of bioethics. These tools are meant to help you reason through difficult cases or provide a different perspective that may help clarify complex situations. A frequently used ethical decision making framework is included, along with a sample case discussion.

Clinical Ethics

- Summary of Methodology
- Paradigm (4 boxes)
- Sample Case Analysis
- Introduction to Clinical Ethics, 4th edition

Principles of Bioethics

- The place of principles in bioethics

- How do principles "apply" to a certain case?

- What are the major principles of medical ethics?

Summary of Methodology

In a collaborative effort, 3 clinical ethicists (a philosopher - Jonsen, a physician - Siegler, and a lawyer - Winslade) have developed a method with which to work through difficult cases. The process can be thought of as the "ethics workup," similar to the "History and Physical" skills that all medical students come to use when learning how to "workup" a patient's primary complaints. While this method has deep philosophical roots, the clinicians that use this method like about it is the ease with which it fit into how they normally think about tough medical cases.

We will introduce this method briefly here, offer the decision-making tool (the "4 boxes"), and then discuss a sample case to illustrate the method. For a more in depth discussion of this method and for extensive examples of case analysis, students should refer to Jonsen, Siegler, Winslade's Clinical Ethics (see the Introduction to Clinical Ethics from the 4th edition volume of the book).

Jonsen, Siegler and Winslade have identified four "topics" those are basic and intrinsic to every clinical encounter. Focusing our discussion around these four topics gives us a way to organise the facts of the particular case at hand.

- ***Medical Indications*** **-** all clinical encounters include a review of diagnosis and treatment options

- ***Patient Preferences*** **-** all clinical encounters occur because a patient presents before the physician with a compliant. The patient's values are integral to the encounter.

- ***Quality of Life*** - the objective of all clinical encounters is to improve, or at least address, quality of life for the patient

- ***Contextual Features*** - all clinical encounters occur in a wider context beyond physician and patient, to include family, the law, hospital policy, insurance companies, and so forth.

These four topics are present in every case. In the interest of consistency, the order of the review of topics remains the same (again, much like the review of systems in a complete H&P), yet no topic bears more weight than the others. Each will be evaluated from the perspective of the facts of the case at hand.

Once the details of a case have been outlined according to the four topics (using the 4 boxes), there are a series of questions that the clinician should ask.

- What is at issue?
- Where is the conflict?
- What is this a case of? Does it sound like other cases you may have encountered? (Eg. Is it a case of "refusal of potentially life-sustaining treatment by a competent patient"?)
- What do we know about other cases like this one? Is there clear precedent? If so, we call this a paradigm case. A paradigm case is one in which the facts of the case are very clear cut and there has been much professional and/or public agreement about the resolution of the case.
- How is the present case similar to the paradigm case? How is it different? Is it similar (or different) in ethically significant ways?
- The resolution in any particular case will depend on the facts of that case.

After analysing a difficult case in this way, clinicians are usually able to think clearly about what is at issue and to identify the best course of action available to them. If a best course of action remains elusive, a formal ethics consultation can be helpful.

Paradigm

Medical Indications:	Patient Preferences:

Consider each medical condition and its proposed treatment. Ask the following questions:
• Does it fulfil any of the goals of medicine?
• With what likelihood?
• If not, is the proposed treatment futile?
	Address the following:
	• What does the patient want?
	• Does the patient have the capacity to decide? If not, who will decide for the patient?
	• Do the patient's wishes reflect a process that is
	  • Informed?
	  • Understood?

	• Voluntary?
Quality of Life: • Describe the Patient's quality of life **in the patient's terms.** • What is the patient's subjective acceptance of likely quality of life? • What are the views of the care providers about the quality of life? • Is quality of life "less than minimal?" (ie., qualitative futility)	Contextual Features: Social, legal, economic, and institutional circumstances in the case that can: • influence the decision • be influenced by the decision eg., inability to pay for treatment; inadequate social support

Sample Case Analysis
Case

John, a 32 year-old lawyer, had worried for several years about developing Huntington's chorea, a neurological disorder that appears in a person's 30s or 40s, bringing rapid uncontrollable twitching and contractions and progressive, irreversible dementia. It leads to death in about 10 years.

John's mother died from this disease. Huntington's is autosomal dominant and afflicts 50% of an affected parent's offspring. John had indicated to many people that he would prefer to die rather than to live and die as his mother had. He was anxious, drank heavily, and had intermittent depression, for which he saw a psychiatrist. Nevertheless, he was a productive lawyer.

John first noticed facial twitching 3 months ago, and 2 neurologists independently confirmed a diagnosis of Huntington's. He explained his situation to his psychiatrist and requested help committing suicide. When the psychiatrist refused, John reassured him that he did not plan to attempt suicide any time soon. But when he went home, he ingested all his antidepressant medicine after pinning a note to his shirt to explain his actions and to refuse any medical

assistance that might be offered. His wife, who did not yet know about his diagnosis, found him unconscious and rushed him to the emergency room without removing the note.

What should the care team at the emergency room do?

Review of Topics:

Medical Indications

There are 2 diagnoses/prognoses that merit consideration. The underlying chronic disease of Huntington's has no available treatment and a bleak long term prognosis. However, there are effective treatments available for the acute diagnosis of drug overdose. How does the chronic diagnosis affect our response to the acute condition?

Patient Preferences

We know from the patient's suicide note that he is refusing all medical treatment. However, what do we know about these statements of preference? Were they informed? Was the patient competent to make that decision? The answers to these questions remain unclear, but we do know that the patient does not have decision making capacity for the present decision of whether to proceed with the gastric emptying. Is there a surrogate decision-maker available?

Quality of Life

Life with Huntington's can be difficult with the onset of spasms and dementia. John was familiar with the quality of life associated with living with Huntington's as he watched his mother die of this disease. On the other hand, John does have a supportive family and continues to be able to work for the time being. How should the diminished quality of life that is anticipated in the future affect the current decision?

Contextual Features

Several factors in the context of this case are significant. While the patient has a legal right to refuse treatment, he is currently unconscious and his surrogate (his wife) is requesting treatment. There are also certain emergency room obligations to treat emergent conditions. How should the emergency staff weigh the various competing legal and regulatory duties?

Case Analysis:

This is a case of treatment refusal of potentially life-sustaining treatment when the competency of the patient to decide is questionable. Also at issue is the distinction between the acute and chronic conditions of the patient.

The precedent for cases such as this one is fairly clear. When the patient's preferences are unclear, and the acute condition is easily treatable, and the harm of not treating is very great, medical teams can feel comfortable about providing the treatment for the immediate life-threatening condition, creating an opportunity to talk with the patient about his preferences regarding his chronic condition at a later time.

Notice that the facts of this particular case determine if the precedent case is applicable. If the medical team was very familiar with this patient's expressed preference to refuse any medical treatment or if the available treatment for the acute condition was considerably less certain to be effective, the case could be decided differently. The clinicians would look for a different precedent or consider whether it made a significant difference to be very clear about the patient's beliefs and certain about his competency to decide to refuse.

Introduction: Case Analysis in Clinical Ethics

Clinical ethics is a practical discipline that provides a structured approach to assist physicians in identifying, analysing and resolving ethical issues in clinical medicine. The practice of good clinical medicine requires some working knowledge about ethical issues such as informed consent, truth-telling, confidentiality, end-of-life care, pain relief, and patient rights. Medicine, even at its most technical and scientific, is an encounter between human beings, and the physician's work of diagnosing disease, offering advice, and providing treatment is embedded in a moral context. Usually, moral values such as mutual respect, honesty, trustworthiness, compassion, and a commitment to pursue shared goals, make a clinical encounter between physician and patient morally unproblematic. Occasionally, physicians and patients may disagree about values or face choices that challenge their values. It is then that ethical problems arise. Clinical ethics is both about the ethical features that are present in every clinical encounter and about the ethical problems that occasionally arise in those encounters. Clinical ethics relies upon the conviction that, even when perplexity is great and emotions run high, physicians and nurses, patients and families can work constructively to identify, analyse and resolve many of the ethical problems that arise in clinical medicine.

The authors have two purposes in writing this book: first, to offer an approach that facilitates thinking about the complexities of the problems that clinicians actually face and, second, to assemble concise representative opinions about typical ethical problems that occur in the practice of medicine. We think it is more important that clinicians develop skill at analysing the cases they encounter rather than merely have a book in which "to look up answers." Our hope is that every clinician will acknowledge that ethics is an inherent aspect of good clinical medicine and that, ideally, every clinician will become as proficient at clinical ethics as clinical medicine. Our book is intended not only for clinicians and students who provide care to patients, but also for others whose work requires an awareness and sensitivity to the ethical issues raised in clinical

care, such as hospital administrators, hospital attorneys, members of institutional ethics committees, quality reviewers and administrators of health plans. In the complex world of modern health care, all of these persons are responsible for maintain the ethics that lie at the heart of quality care.

Many books on health care ethics are organised around moral principles, such as respect for autonomy, beneficence, non-maleficence and fairness, and the cases are analysed in the light of those principles. Our method is different. While we appreciate the importance of principles, we believe that the practitioner approaching a case needs a method that better fits the realities of the clinical setting and the reasoning of the clinician. Clinical situations are complex since they often involve a wide range of medical facts, a multitude of circumstances and a variety of values. Often decisions must be reached quickly. The authors believe that clinicians need a straightforward way to sort the facts and values of the case at hand into an orderly pattern that will facilitate the discussion and resolution of the ethical problem.

We suggest that every clinical case, when seen as an ethical problem, should be analysed by means of four topics. These four topics are

1 Medical Indications;

2 Patient Preferences;

3 Quality of Life,

4 Contextual Features,

that is, the social, economic, legal, and administrative context in which the case occurs. Every case can be viewed in terms of these four topics; no case can be adequately discussed without reference to them. Although the facts of each case differ, these four topics are always relevant. The topics organise the varying facts of the particular case and, at the same time, the topics call attention to the moral principles appropriate to the case. It is our intent to show readers how the topics provide a systematic way to identify, analyse and resolve the ethical problems arising in clinical medicine.

Clinicians will recall the method of case presentation that they learned at the beginning of their professional training. They were taught to "present" a patient by stating in order the patient's history, including the chief complaint, the history of the present illness, past medical history, family and social history, followed by physical findings and laboratory data. These are the topics that an experienced clinician uses to reach a diagnosis and to formulate a case management plan. While the particular details under each of these topics differ from patient to patient; the topics themselves are constant and always relevant to the task of arriving at a case management plan. Sometimes one topic, for example, the patient's family history or the physical examination, may be particularly important or, conversely, may not be relevant to the problem at hand. Still, clinicians are expected to review all topics in every case. Our four topics -- (1) Medical Indications, (2) Patient Preferences, (3) Quality of Life, and (4) Contextual Features--are the ethical equivalents of these familiar clinical topics.

These topics help clinicians understand where the moral principles meet the circumstances of the clinical case. The general headings of the topics describe the major features that define the ethics of clinical medicine; each of these features takes on specific, concrete form from the circumstances of the particular case. In a given case, a patient comes to a physician, complaining of feeling ill. Medical Indications include a clinical picture of polydipsia and polyuria, nausea, fatigue and some mental confusion, with laboratory studies showing hyperglycaemia, acidosis and elevated plasma ketone concentrations. A diagnosis of diabetic ketoacidosis is made. Fluids and insulin are indicated in specific doses and volumes. These particulars are the occasion for implementing the moral principle of beneficence, that is, the duty of performing actions that benefit the patient. However, in the same case, the patient may be confused and, after hearing the physician's recommendations, rejects further medical attention: these circumstances, noted under Patient Preferences, raise questions about the principle of autonomy, that is, the duty to respect the patient's wishes. As the case is described, circumstances accumulate under all four of the topics and affect the meaning and relevance of the moral principles. It is advisable to review the entire four topics in order to see how the principles and the circumstances together define the ethical problem in the case and suggest a resolution. It is rare that an ethical problem involves only one ethical principle. Every actual ethical problem is a complex collection of many circumstances. Good ethical judgment consists in appreciating how several ethical principles should be evaluated in the actual situation under consideration. We hope our method helps practitioners to do just that.

We divide the book into four chapters, each one devoted to one of these four topics. These four chapters define the major concepts associated with each topic, present typical cases in which the topic under discussion plays a particularly important role, and critically review the arguments commonly offered to resolve the problem. For example, the case of a Jehovah's Witness patient who refuses blood transfusion will demonstrate how the topic of Patient Preferences functions in the analysis of the ethical problem raised by a patient's refusal of an indicated medical treatment. At the same time, the current opinion of medical ethicists on Jehovah's Witness cases will be summarised. Thus, a reader can use this volume as a reference book, looking up, for example "refusal of treatment" or "Jehovah's Witnesses" in the Locater at the front of the book and reading the several pages devoted to that issue in chapter 2.

Those who use the book as a reference will find concise summaries of current opinion on the ethics of certain typical cases, such as those involving refusal of care or a diagnosis of persistent vegetative state. This may be all that they seek at the moment. However, the actual cases that clinicians encounter in practice will be more than typical: they will be a combination of unique circumstances and values. The four topics are, as it were, signposts that guide the way through the complexity of real cases. Thus, mastering the book's four-part method will serve the reader better than using it for occasional reference. We strongly suggest that readers first read the book from beginning to end to get the hang of the method. We hope they will become adept at bringing the method to bear on their own clinical cases.

This book was originally written for physicians specialised in internal medicine and concentrated on the ethical problems encountered by those making clinical decisions for patients in their practice. In subsequent editions, the scope was broadened to adult medicine in general and then

to paediatrics. (The sections particularly relevant to paediatric ethics have **P** after their numbers in the text.) It also became obvious to the authors that many other health care providers, nurses, social workers, medical technicians, as well as chaplains and administrators, found our method useful. In this fourth edition, the original emphasis on clinical decisions made by physicians remains but we believe that others can fit the particular concerns and values of their own professions into the topics of the book.
We illustrate our method by a brief summary of a case familiar to many who have studied medical ethics, namely, the case of Donald "Dax" Cowart, the burn patient who related his experience in the videotape Please Let Me Die and the documentary, Dax's Case.

In 1973, "Dax" Cowart, age 25, was severely burned in a propane gas explosion. Rushed to the Burn Treatment Unit of Parkland Hospital in Dallas, he was found to have severe burns over 65 percent of his body; his face and hands suffered third degree burns and his eyes were severely damaged. Full burn therapy was instituted. After an initial period during which his survival was in doubt, he stabilised and underwent amputation of several fingers and removal of his right eye. During much of his 232 day hospitalisation at Parkland, his few weeks at Texas Institute of Rehabilitation and Research at Houston, and his subsequent six month's stay at University of Texas Medical Branch in Galveston, he repeatedly insisted that treatment be discontinued and that he be allowed to die. Despite this demand, wound care was continued, skin grafts performed and nutritional and fluid support provided. He was discharged totally blind, with minimal use of his hands, badly scarred, and dependent on others to assist in personal functions.

Discussion of a case like this can begin by raising any number of questions. Did Dax have the moral or the legal right to refuse care? Was Dax competent to make a decision? Were the physicians paternalistic? What was Dax's prognosis? All these questions, and many others, are relevant and can give rise to vigorous debate. However, we suggest that an ethical analysis should begin by an orderly review of the four topics. We recommend that the same order be followed in all cases: (l) Medical Indications, (2) Patient Preferences, (3) Quality of Life, (4) Contextual Features. This procedure will lay out the ethically relevant facts of the case (or show where further information is needed) before debate begins It should be noted that this order of review does not constitute an order of ethical priority. The determination of relative importance of these topics will be explained in the four chapters.

Medical Indications. This topic comprises the usual content of a clinical discussion: the diagnosis and treatment of the patient's pathological condition. "Indications" refers to the relation between the pathophysiology presented by the patient and the diagnostic and therapeutic interventions that are "indicated," that is, appropriate to evaluate and treat the problem. Although this is the usual material covered in the presentation of any patient's clinical problems, the ethical discussion will not only review the medical facts, but also attend to the purposes and goals of any indicated interventions.

In Dax's case, the medical indications include the clinical facts necessary to diagnose the extent and seriousness of burns, to make a prognosis for survival or restoration of function, and the options for treatment, including the risks, benefits and probable outcomes of each treatment modality. For example, certain prognoses are associated with burns of given severity and extent. Various forms of treatment, such as fluid replacement, skin grafting and antibiotics are

associated with certain probabilities of outcome and risk. After initial emergency treatment, Dax's prognosis for survival was approximately 20%. After six months of intensive care, his prognosis for survival improved to almost 100%. If his request to stop wound care and grafting during that hospitalisation had been respected, he would almost certainly have died. A clear view of the possible benefits of intervention is the first step in assessing the ethical aspects of a case.

Patient Preferences. In all medical treatment, the preferences of the patient, based on the patient's own values and personal assessment of benefits and burdens are ethically relevant. In every clinical case, the questions must be raised: "What are the patient's goals? What does the patient want?" The systematic review of this topic requires further questions. Has the patient been provided sufficient information? Does the patient comprehend? Does the patient understand the uncertainty inherent in any medical recommendation and the range of reasonable options that exist? Is the patient consenting voluntarily? Is the patient coerced? In some cases, an answer to these questions might be "We don't know because the patient is incapable of formulating a preference or expressing one." If the patient is mentally incapacitated at the time a decision must be made, we must ask "Who has the authority to decide on behalf of this patient? What are the ethical and legal limits of that authority? What is to be done if no one can be identified as surrogate?

In Dax's case, a question about his mental capacity arose in the early days of his refusal of care. Had the physical and emotional shock of the accident undermined his ability to decide for himself? Initially it was assumed that he lacked the capacity to make his own decisions, at least about refusing life-saving therapy. The doctors accepted the consent of Dax's mother in favour of treatment, over his refusal of treatment. Later, when Dax was hospitalised in Galveston, psychiatric consultation was requested which affirmed his capacity to make decisions. Once capacity was established, the ethical implications of his desire to refuse care became central. Should his preference be respected? If not, on what grounds? Did Dax appreciate sufficiently the prospects for his rehabilitation? Are physicians obliged to pursue therapies they believe have promise over the objections of a patient? Would they be cooperating in a suicide if they assented to Dax's wishes? Any case involving the ethics of patient preferences relies on clarification of these questions.

Quality of Life. Any injury or illness threatens persons with actual or potential reduced quality of life, manifested in the signs and symptoms of their disease. The object of all medical intervention is to restore, maintain or improve quality of life. Thus, in all medical situations, the topic of quality of life must be raised. Many questions surround this topic: What does this phrase, "quality of life" mean in general? How should it be understood in particular cases? How do persons other than the patient perceive the patient's quality of life and of what ethical relevance are their perceptions? Above all, what is the relevance of quality of life to ethical judgment? This topic, which is less well worked out in the literature of medical ethics than the two previous ones, is perilous because it opens the door for bias and prejudice. Still, it must be confronted in the analysis of clinical ethical problems.

In Dax's case, we note the quality of his life prior to the accident. He was a popular, athletic young man, just discharged from the Air Force, after serving as a fighter pilot in Vietnam. He worked in a real estate business with his father (who was also injured in the explosion and died

on the way to the hospital). Before his accident, Dax's quality of life was excellent. During the course of medical care, he endured excruciating pain and profound depression. After the accident, even with the best of care, he was confronted with significant physical deficits, including notable disfigurement, blindness and limitation of activity. At some stage in his illness, Dax had the capacity to determine what quality of life he wished for himself. However, in the early weeks of his hospitalisation, he was probably mentally incapacitated at the time critical decisions had to be made. When he was, others would have had to make certain "quality of life" decisions on his behalf. Was the prospect for return to a normal or even acceptable life so poor that no reasonable person would choose to live? Who should make such decisions? What values should guide them? The meaning and import of such considerations must be clarified in any clinical ethical analysis.

Contextual Features. Patients come to physicians because they have a problem that they hope the physician can help to correct. Physicians undertake the care of patients with the intent and the duty to make all reasonable efforts to help them. The topics of medical indications, patient preferences and quality of life bring out these essential features of the case. Yet every medical case is embedded in a larger context of persons, institutions, financial and social arrangements. Patient care is influenced, positively or negatively, by the possibilities and the constraints of that context. At the same time, the context itself is affected by the decisions made by or about the patient: these decisions have psychological, emotional, financial, legal, scientific, educational, religious impact on others. In every case, the relevance of the contextual features must be determined and assessed. These contextual features may be crucially important to the understanding and resolution of the case.

In Dax's case, several of these contextual features were significant. Dax's mother was opposed to termination of medical care for religious reasons. The legal implications of honouring Dax's demand were unclear at the time (they are clearer today). The costs of sixteen months of intensive burn therapy are not insignificant (although this was not emphasised in the various discussions of the case). The distress caused to medical and nursing personnel by Dax's refusal to cooperate with treatment might have influenced their attitudes toward him. These and other contextual factors must be made explicit and assessed for their relevance.

These four topics are relevant to any clinical case, whatever the actual circumstances. They serve as a useful organising device for teaching and discussion. More important, however, is the way in which a review of these topics can help to move a discussion of an ethical problem toward a resolution. Any serious discussion of an ethical problem must go beyond merely talking about it in an orderly way: it must push through to a reasonable and practical resolution. Ethical problems, no less than medical problems, cannot be left hanging. Thus, after presenting a case, the task of seeking a resolution must begin.

The discussion of each topic raises, or presupposes, certain common ethical notions. These notions propose certain standards of behaviour or attitudes that are morally appropriate to the topic. They can be called moral principles or rules: rules tend to be quite specific to particular topics, while principles are stated in broader, more general terms. For example, one version of the principle of beneficence states, "There is an obligation to assist others in the furthering of their legitimate interests." The moral rule, "physicians have a duty to treat patients, even at risk

to themselves," is a specific expression of that broad principle, suited to a particular sphere of professional activity, namely, medical care. The topic of medical indications, in addition to the clinical data that must be discussed, raises the further questions, "How much can we do to help this patient?" "What risks of adverse effects can be tolerated in the attempt to treat the patient?" Answers to these questions, arising so naturally in the discussion of medical indications, can be guided by familiar moral rules applied to medical ethics such as, "Be of benefit and do no harm" or "Risks should be balanced by benefits." Rules such as these reflect in a specific way the broad principle that the philosophers have named beneficence. Similarly, the topic of patient preferences contains rules that instruct clinicians to tell patients the truth, to respect their deliberate preferences, to honour their values, etc. Rules such as these fall under the general scope of the principles of autonomy and respect for persons.

Our method of analysis begins, not with the principles and rules, as do many other ethics treatises, but with the factual features of the case. We refer to relevant principles and rules as they arise in the discussion of the topics. In this way, abstract discussions of principles is avoided as is the tendency to think of only one principle, such as autonomy or beneficence, as the sole guide in the case. Moral rules and principles are best appreciated in the specific context of the actual circumstances of a case. For example, a key issue in Dax's case is the autonomy of the patient. However, the significance of autonomy in Dax's case is derived, not simply from the principle that requires we respect it, but from the confluence of considerations about preferences, medical indications for treatment, quality of life, decisional capacity, and the role of his mother, the doctors, the lawyers and the hospitals. Only when all these are seen and evaluated in relation to each other, will the meaning of the principle of autonomy be appreciated in this case. Competence in clinical ethics depends not only on being able to use a sound method for analysis, but also on familiarity with the literature of medical ethics. Some readers will seek further elaboration of the issues dealt with so briefly in this introductory book. We direct these readers to a few sources where they will find, not only that elaboration, but references to the major literature. Thus, we place in brackets after our discussion of an issue references to The Encyclopedia of Bioethics, Principles of Biomedical Ethics, and Medical Ethics.

Principles of Bioethics

The place of principles in bioethics

In the realm of health care it is difficult to hold rules or principles that are absolute. This is due to the many variables that exist in the context of clinical cases as well as the fact that in health care there are several principles that seem to be applicable in many situations. Even though they are not considered absolute, these rules and principles serve as powerful action guides in clinical medicine. Over the years, these moral principles have won a general acceptance as applicable in the moral analysis of ethical issues in medicine.

How do principles "apply" to a certain case?

Principles in current usage in health care ethics seem to be of self-evident value. For example, the notion that the physician "ought not to harm" any patient appears to be convincing to rational persons. Or, the idea that the physician should develop a care plan designed to provide the most "benefit" to the patient in terms of other competing alternatives, seems self-evident. Further, before implementing the medical care plan, it is now commonly accepted that the patient must indicate a willingness to accept the proposed treatment, if the patient is cognitively capable of doing so. Finally, medical benefits should be dispensed fairly, so that people with similar needs and in similar circumstances will be treated with fairness.

One might argue that we are required to take all of the above principles into account when they are applicable to the clinical case under consideration. Yet, when two or more principles apply, we may find that they are in conflict. For example, consider a patient diagnosed with an acutely infected appendix. Our medical goal should be to provide the greatest benefit to the patient, an indication for immediate surgery. On the other hand, surgery and general anaesthesia carry some small degree of risk to an otherwise healthy patient, and we are under an obligation "not to harm" the patient. Our rational calculus holds that the patient is in far greater danger from harm from a ruptured appendix if we do not act, than from the surgical procedure and anaesthesia if we proceed quickly to surgery.

In other words, we have a "prima facie" duty to both benefit the patient and to "avoid harming" the patient. However, in the actual situation, we must balance the demands of these principles by determining which carries more weight in the particular case. Moral philosopher W.D. Ross claims that prima facie duties are always binding unless they are in conflict with stronger or more stringent duties. A moral person's actual duty is determined by weighing and balancing all competing prima facie duties in any particular case.

What are the major principles of medical ethics?

The commonly accepted principles of health care ethics include:

1. the principle of respect for autonomy,
2. the principle of non-maleficence,
3. the principle of beneficence, and
4. the principle of justice.

1. Respect for Autonomy

Any notion of moral decision making assumes that rational agents are involved in making informed and voluntary decisions. In health care decisions, our respect for the autonomy of the patient would, in common parlance, mean that the patient has the capacity to act intentionally, with understanding, and without controlling influences that would mitigate against a free and voluntary act. This principle is the basis for the practice of "informed consent" in the physician/patient transaction regarding health care. (See also Informed Consent.)

2. The Principle of Non-maleficence

The principle of non-maleficence requires of us that we not intentionally create a needless harm or injury to the patient, either through acts of commission or omission. In common language, we consider it negligence if one imposes a careless or unreasonable risk of harm upon another. Providing a proper standard of care that avoids or minimises the risk of harm is supported not only by our commonly held moral convictions, but by the laws of society as well. In a professional model of care one may be morally and legally blameworthy if one fails to meet the standards of due care. The legal criteria for determining negligence are as follows:

1. the professional must have a duty to the affected party
2. the professional must breach that duty
3. the affected party must experience a harm; and
4. the harm must be caused by the breach of duty.

This principle affirms the need for medical competence. It is clear that medical mistakes occur; however, this principle articulates a fundamental commitment on the part of health care professionals to protect their patients from harm.

3. The Principle of Beneficence

The ordinary meaning of this principle is the duty of health care providers to be of a benefit to the patient, as well as to take positive steps to prevent and to remove harm from the patient. These duties are viewed as self-evident and are widely accepted as the proper goals of medicine. These goals are applied both to individual patients, and to the good of society as a whole. For example, the good health of a particular patient is an appropriate goal of medicine, and the

prevention of disease through research and the employment of vaccines is the same goal expanded to the population at large.

It is sometimes held that non-maleficence is a constant duty, that is, one ought never to harm another individual. Whereas, beneficence is a limited duty. A physician has a duty to seek the benefit of any or all of her patients, however, the physician may also choose whom to admit into his or her practice, and does not have a strict duty to benefit patients not acknowledged in the panel. This duty becomes complex if two patients appeal for treatment at the same moment. Some criteria of urgency of need might be used, or some principle of first come first served, to decide who should be helped at the moment.

4. The Principle of Justice

Justice in health care is usually defined as a form of fairness, or as Aristotle once said, "giving to each that which is his due." This implies the fair distribution of goods in society and requires that we look at the role of entitlement. The question of distributive justice also seems to hinge on the fact that some goods and services are in short supply, there is not enough to go around, thus some fair means of allocating scarce resources must be determined.

It is generally held that persons who are equals should qualify for equal treatment. This is borne out in the application of Medicare, which is available to all persons over the age of 65 years. This category of persons is equal with respect to this one factor, their age, but the criteria chosen says nothing about need or other noteworthy factors about the persons in this category. In fact, our society uses a variety of factors as a criterion for distributive justice, including the following:

1. to each person an equal share
2. to each person according to need
3. to each person according to effort
4. to each person according to contribution
5. to each person according to merit
6. to each person according to free-market exchanges

John Rawls and others claim that many of the inequalities we experience are a result of a "natural lottery" or a "social lottery" for which the affected individual is not to blame, therefore, society ought to help even the playing field by providing resources to help overcome the disadvantaged situation. One of the most controversial issues in modern health care is the question pertaining to "who has the right to health care?" Or, stated another way, perhaps as a society we want to be beneficent and fair and provide some decent minimum level of health care for all citizens, regardless of ability to pay.

Illustrative Cases

1. The Principle of Autonomy

In a *prima facie* sense, we ought always to respect the autonomy of the patient. Such respect is not simply a matter of attitude, but a way of acting so as to recognise and even promote the autonomous actions of the patient. The autonomous person may freely choose loyalties or systems of religious belief that limit other freedoms of that person. For example, Jehovah's Witnesses have a belief that it is wrong to accept a blood transfusion. Therefore, in a life-threatening situation where a blood transfusion is required to save the life of the patient, the patient must be so informed. The consequences of refusing a blood transfusion must be made clear. Desiring to "benefit" the patient, the physician may strongly want to provide a blood transfusion, believing it to be a clear "medical benefit." When properly and compassionately informed, the particular patient is then free to choose whether to accept the blood transfusion in keeping with a strong desire to live, or whether to refuse the blood transfusion in giving a greater priority to his religious convictions about the wrongness of blood transfusions, even to the point of accepting his death.

In analysing the above case, the physician had a *prima facie* duty to respect the autonomous choice of the patient, as well as a *prima facie* duty to avoid harm and to provide a medical benefit. In this case, informed by community practice and the provisions of the law for the free exercise of one's religion, the physician gave greater priority to the respect for patient autonomy than to the other duties. By contrast, if the patient in question happened to be a ten year old child, and the parents were refusing a life saving blood transfusion, in the State of Washington there is legal precedence for overriding the parent's wishes by appealing to the Juvenile Court Judge who is authorised by the state to protect the lives of its citizens, particularly minors, until they reach the age of majority and can make such choices independently. Thus, in the case of the minor child, the principle of avoiding the harm of death, and the principle of providing a medical benefit that can restore the child to health and life, would be given precedence over the autonomy of the child's parents as surrogate decision makers.

2. The Principle of Non-maleficence

In the course of caring for patients, there are some situations in which some type of harm seems inevitable, and we are usually morally bound to choose the lesser of the two evils, although the lesser of evils may be determined by the circumstances. For example, most would be willing to experience some pain if the procedure in question would prolong life. However, in other cases, such as the case of the patient dying of painful intestinal carcinoma, the patient might choose to forego CPR in the event of a cardiac or respiratory arrest, or the patient might choose to forego life sustaining technology such as dialysis or a respirator. The reason for such a choice is based on the belief of the patient that prolonged living with a painful and debilitating condition is

worse than death. It is also important to note in this case that this determination was made by the patient, who alone is the authority on the interpretation of the "greater" or "lesser" harm for him.

There is another category of cases that is also confusing since a single action may have two effects, one that is considered a good effect, the other a bad effect. How does our duty to the principle of non-maleficence direct us in such cases? The formal name for the principle governing this category of cases is usually called the principle of double effect. A typical example might be the question as to how to best treat a pregnant woman newly diagnosed with cancer of the uterus. The usual treatment, removal of the uterus is considered a life saving treatment. However, this procedure would result in the death of the foetus. What action is morally allowable, or, what is our duty? It is argued in this case that the woman has the right to self-defence, and the action of the hysterectomy is aimed at preserving her life. The unintended consequence (though undesired) is the death of the foetus. There are four conditions that usually apply to the principle of double effect:

1. the action itself must not be intrinsically wrong; it must be a good or neutral act.

2. only the good effect must be intended, not the bad effect, even though it is foreseen.

3. the bad effect must not be the means of the good effect,

4. the good effect must outweigh the evil that is permitted.

The reader may apply these four criteria to the case above, and find that the principle of double effect applies and the four conditions are not violated by the prescribed treatment plan.

Other problems arise when the primary patient cannot decide for himself and others must determine what is in the best interest of the patient, or what constitutes the lesser harm. In Washington State, the law actually guides the surrogate to offer "substituted judgment" if known, or to follow the course of action that will serve the "best interests" of the patient as determined by reasonable judgment (see also Advance Directives, Advance Care Planning, and Informed Consent).

3. The Principle of Beneficence

One clear example exists in health care where the principle of beneficence is given priority over the principle of respect for patient autonomy. This example comes from Emergency Medicine. When the patient is incapacitated by the grave nature of accident or illness, we presume that the reasonable person would want to be treated aggressively, and we rush to provide beneficent intervention by stemming the bleeding, mending the broken or suturing the wounded.

In this culture, when the physician acts from a benevolent spirit in providing beneficent treatment that in the physician's opinion is in the best interests of the patient, without consulting the patient, or by overriding the patient's wishes, it is considered to be "paternalistic." The most

clear cut case of justified paternalism is seen in the treatment of suicidal patients who are a clear and present danger to themselves. Here, the duty of beneficence requires that the physician intervene on behalf of saving the patient's life or placing the patient in a protective environment, in the belief that the patient is compromised and cannot act in his own best interest at the moment.