

Part III

Chart Notes

Once the participants in a bioethics mediation have reached principled resolution on a recommended course of treatment, the role of the bioethics mediator shifts to a more standard function of the clinical ethics consultant. That function is the creation of a chart note that accomplishes three tasks:

1. Communicates the agreement reached and explains the ethical bases for that agreement couched in a recommendation that reflects the nature of the principled resolution
2. Explains the resolution/consensus in terms of commonly agreed upon ethical concepts
3. Elucidates the process and the product so that staff members who were not present will be able to understand and implement the agreement

Communicating the mediation consensus agreement regarding treatment and the rationale for that consensus, or the failure to reach agreement and the reasons for the failure, is essential to understanding the dynamics of the case. Thus, when the clinical ethics consultant writes the chart note, she takes on roles that in many ways diverge from that of neutral mediator. She becomes an advocate for the resolution as well as an educator and norm enforcer. Part III provides a framework for writing chart notes that permits effective oversight and quality improvement for clinical ethics services, as well as guidance about the goals and structure of chart notes. The chapter also contains a number of short analyses of common ethical issues that can be used as a guide for a principled resolution and for the substance of educational sections in the chart note.

How to Write a Bioethics Chart Note

Introduction

The bioethics mediation chart note has a special place in the medical record. As a subset of a note on clinical ethics consultation, it must adhere to conventions of ethical analysis and standards for and best practice in clinical medicine. It must be knowledgeable, readable, clear, and descriptive of the narrative history of the case, compelling in its identification and analysis of ethical issues, and respectful throughout to patients, family members, and the staff. It should lead by example.

The chart note should: (1) reflect and discuss the process of the mediation; (2) relate the story of what happened to the patient and how the family and significant others were involved; (3) explain and analyze the ethical issues in the context of the case; (4) detail the options that were generated by the mediation; (5) discuss the consensus reached; and (6) present the agreement as the basis for the recommendations for the future care of the patient. The note should also educate the reader about the ethical issues that were involved in the consultation, as part of the ongoing augmentation of staff knowledge and awareness.

This chapter, like others in the book, reflects our heightened awareness of how bioethics mediation relates to clinical ethics consultation. As discussed earlier, it is our contention that many, if not most, clinical ethics consultations involve the resolution of conflicts, and that those involved in the conflict are best served by a mediative approach and the specific techniques and skills that mediation offers. There are times, however, when clinical ethics consultants must address factual or policy questions, or aid in clarification that stops short of intervention as a mediator. The chart note needs to be clear about what the issue or problem was, about the process

used in reaching a decision, and about the implications of this consultation for like situations in the future.

First, bioethics mediation is a subset of clinical ethics consultation in that it recognizes that the presenting bioethics dilemma is really a conflict and therefore is best addressed with awareness of the dynamics of conflict and with tools for resolution. But it is also a conflict that occurs within a complex institution that provides health care. Thus bioethics mediation must respond to the patient's values, expressed preferences for health care, needs, wants, and desires, generally as represented by the family, and to the understood ethics of providing care as expressed by the care providers. However, the mediation must do so in a context affected by the organizational ethics of providing care as defined by institutional arrangements and policies structured by case law and state and federal regulation. What happens during the consultation is most important, but how it is conveyed and communicated is also critical.

Second, more than most consultations, one that carries the label bioethics comes (often mistakenly) with an aura of right and wrong, good and bad, ethical or not ethical—territory that must be addressed cautiously. How issues are resolved in clinical ethics disputes is subject to the same vagaries of dynamics as are other consultation areas of medicine in which there can be good-faith disagreements among equally talented professionals. Professionals of goodwill, skill, and intelligence can disagree about the label and the subsequent analysis that applies in any patient care situation. The recommendation of the clinical ethics consultant or the consensus reached in a principled resolution of bioethics mediation must still be implemented by the care team as part of the plan of care. A clinical ethics consultation, like any other consultation in the care of a patient, is but a recommendation to the attending physician, who is legally responsible for the course and conduct of the patient's care. A bioethics mediation that reaches a consensus is also a recommendation to the physician. Almost always the physician is a part of the mediation and thus has bought into the process and the outcome as it develops.

Third, many on the care team may have been present at the bioethics mediation, but they generally represent only one shift of care providers. In most institutions there are three shifts a day, and all the care providers not present at the mediation need to be brought up to date on what has happened, what the reasoning was for the resolution and the consensus, and what the suggested plan is for patient care in light of the mediation. So the chart note is a way of communicating the process and the outcome.

Because of these realities of medical care in institutional settings, the chart note is key to the effective implementation of the resolution arrived at during the bioethics mediation. In the complex authority structure of health care institutions, the mediation consensus must be endorsed and adopted not only by the attending physician, if she or he was not present at the discussion, but also in special cases by others in the institution. If, for example, the family agreed to a palliative plan of care for their dying mother, if she were to be given "special vitamins from her home country" (a mediated solution in one case), the head of the pharmacy would need to vet and agree to that plan. Thus the chart note is key to moving a consensus from theory to reality.

A bioethics mediation chart note tells a story. It explains to the naïve readers—rotating staff members who were not at the mediation but encounter its outcome in the chart—what happened and reinforces the event for the participants in the consultation: what happened, how it happened, who the players/stakeholders are—patient, diverse family members, various providers—what their interests are, how those interests are either in concert or conflict, how the options for care were ethically developed and supported, how the consensus was reached, and how it might be implemented. Much of the narrative perspective presented in this discussion has been honed over the years in scholarly debate among academics and providers and in particular collaboration with Rita Charon, MD, the master of narrative ethics.

It was Dr. Charon who first proposed that any medical chart note could be read as a short story. It has a plot and perhaps a subplot. It has intertwining characters, some of whom have interacted before and have a history together, and some of whom are new to the setting and the issues. It demonstrates the power, and perhaps the prejudice, of providers and the cooperation, compliance, or obstinacy of patient or family (often labels applied to patients or family members who agree with or who challenge the smooth operation of the medical machine and the established culture or various prejudices of the members of the care team). How the players—patient, family, and providers—perceive the situation and their prerogatives, threatened rights, or imperiled interests determine, to some degree, how they play out their roles.

The chart note author, especially in clinical ethics consultation and bioethics mediation, is also a character in the unfolding narrative; she, too, has a role and interests. Her interest is largely conducting the bioethics mediation in light of the issues and the needs of the parties. She “employs expert discussion of bioethical principles, practices, and norms and uses reason, facilitation, negotiation, or mediation to seek a common judgment regarding a plan of care going forward” (Dubler et al. 2009, 26). To the extent that the case requires the mediator to take on a norm-explaining and norm-enforcing role, that intervention should be reflected in the narrative of the chart note and in the section that addresses the ethical issues and analysis. That patient decisions are framed within and constrained by common ethical conventions and laws of modern U.S. health care makes bioethics mediators almost always to some degree norm explainers and sometimes norm enforcers. Bioethics mediators are just that: professionals in bioethics with mediation training, and both sets of expertise must be demonstrated in the chart note.

The bioethics mediator should present the options that encompass, to the degree possible, all the clashing, colliding, and conforming values and interests of the parties. She is the reflector of all the past and recently collected history and the purveyor of the present clashes of perspective, needs, wants, and desires. It is through her eyes, and in her voice, that the chart note takes form. That voice should reflect the reality of the meetings and interactions.

Finally, as part of the hospital chart, the bioethics mediation note is a document with legal implications. It is part of the record of the care of the patient in the institution. It may be subject to subpoena and may be discoverable as a precursor to being introduced as evidence if the care is ever challenged in a court proceeding. The bioethics mediator thus should generally remain silent on the state of the law.

If the chart note is typed—and best practice argues that it should be (Dubler et al. 2009, 26)—it can be an excellent vehicle for transmitting an ethical analysis of the situation, the dynamics of the consensus, and the resolution reached and recommended to other offices in the institution, such as the Office of the Medical Director or the Office of Legal Counsel. Experience indicates that a transparent process in regard to these and other related, allied, and coordinate players in the institution establishes trust among levels of institutional decision makers. If a case might be of concern to the Office of Legal Counsel or the Office of Risk Management, the chart note can be e-mailed to those offices after it is placed in the chart. The integrity of the process does not permit negotiating the content of chart notes. The effectiveness of the bioethics mediation service and awareness of its role as one among many institutional players argues for sharing the note when appropriate.

Be aware, however, that some situations may not be appropriate for clinical ethics consultation at all, depending on the issues and the prior determinations of administrators. If there has been a consultation on a case that was referred to mediation as a last-ditch effort, by which time the parties hate and distrust each other, the chart note must be written very carefully and with the full expectation that it will someday emerge in court.

Be especially aware of cases that involve very hostile family members or patients who are threatening to sue; of cases in which a suit has already been instituted; and of cases that involve special circumstances, such as wards of the state who are living in group homes as long-term mentally ill or congenitally retarded persons for whom special state rules regulate decisions about care. As a responsibility of the clinical ethics service, the bioethics mediator may be asked to attempt an intervention. In such cases, chart notes must be constructed with special attention to their possible later exposure in court.

The Chart Note

Clinical ethics consultation and bioethics mediation are not stand-alone interventions. They are part of the fabric of delivering clinical care to the patient. Clinical ethics consultation and bioethics mediation are clinical services that help the patient, family, and members of the medical team clarify, maximize, and evaluate ethical options and the benefits and burdens of these options. The bioethics mediator then communicates these discussions, the consensus reached, and the recommendations through a note that is placed in the patient's chart.

The clinical ethics consultation chart note, whether the product of mediation or not, communicates best with the entire medical team if it follows a standard template. Using a template helps readers recognize that this is a different sort of note, designed to convey an unusual kind of material. Over time, as members of the institution become accustomed to seeing ethics and mediation chart notes in patient records, use of a standard template also helps readers know where in the note to find specific information.

Clinical Ethics Consultation Bioethics Mediation • Chart Template

This checklist is for use when managing a clinical ethics consultation or bioethics mediation and as a template for constructing a bioethics mediation record of the intervention in a chart note. Its elements are designed to remind the consultant of the relevant issues in mediation or consultation and to serve as a tool to assess the adequacy of the draft note before it is placed in the chart.

Date of consultation

Name of consultant

A. Time and place of the consultation and participants

1. Note person requesting the consultation [for reasons that might emerge in the mediation, this fact might not be recorded in the chart]
2. If it was not the attending physician, inform that person and request involvement.
3. Involve critical care providers, the clinical team and specialists consulted.
4. Determine whether the patient is cognitively able to participate.
5. Conduct a face-to-face patient visit.
6. Contact, inform, and involve important family stakeholders.
7. Determine who is making decisions on the patient's behalf.

B. Relevant medical and social history

1. Present ethically relevant medical history.
2. Present ethically relevant social history.

C. Consult implementation

Discuss these issues:

- Was the consult largely mediation—that is, dispute resolution among care providers, family, or patient?
- Was the consult largely consultation—that is, clarification and analysis of relevant ethical principles and practices?
- Were there meetings/discussions with care providers only?
- Were there meetings/discussions with family only?
- Was there a joint meeting/discussion with care providers and family (or patient/proxy)?

D. Ethical problem

1. What was the ethical/mediation issue(s)?
2. Identify which of the following ethical issues most apply:
 - Advance directives
 - Allocation of scarce resources
 - Assent and consent
 - Benefit burden analysis in care options
 - Best interest standard
 - Brain death and reasonable accommodation
 - Confidentiality
 - Conscientious objection
 - Consent to and refusal of treatment
 - Cultural values and treatment
 - Dealing with the adolescent patient

- Decision-making capacity
- Decisions about artificial nutrition and hydration
- Decision making in the neonatal intensive care unit
- “Demanding families”
- DNR orders
- Doctrine of double effect
- Do not resuscitate and do not intubate
- End-of-life balance of acute and palliative care interventions
- Failure of the medical team to assume responsibility for difficult medical choices
- False choices
- Informed consent
- Medical futility
- Palliative care
- Religious values and treatment
- Sharing the burden of responsibility
- Signing out against medical advice
- Substituted judgment
- Therapeutic exception
- Truth telling
- Withdrawing and withholding treatment
- Other (describe)

E. Ethical Analysis

1. Integrate the relevant bioethical knowledge into the note.
2. Be certain that the chart note is sufficient for educational purposes.

F. Summary of Process

1. Give a clear description of the dynamic of the discussion.
2. Reflect the voice of the patient.
3. Record the voices of the family stakeholders.
4. State the positions of the care providers.
5. Document disagreement among health care team members and family members and the consensus reached in resolution.

G. Recommendations

1. State the consensus and recommendations clearly.
2. If consensus was not achieved, state the recommendation.

H. Style

Review for use of appropriate and neutral language.

A. Time and place of the consultation and list of participants.

This section locates the discussion. It sets the stage—cramped or spacious, orderly or somewhat chaotic. It may describe a meeting in an empty room in the Medical Intensive Care Unit with staff sitting on beds and on the windowsill. The conditions of the consultation and the participants emerge here.

This section identifies persons present at the consultation and provides their titles (house officer, hospitalist, patient’s attending, social worker for the patient, etc.). It also explains which important staff members were not present and why. If the patient’s attending physician, or others necessary to understanding the history and future possible courses of medical action, did not participate, the note should indicate whether or not they were contacted and why the meeting was held in their absence.

If possible, a bioethics mediation about care for a decisionally capable patient takes place with the patient present. If there is some reason to exclude the patient from the discussion, which would be odd indeed, the reason is noted in the chart (see Chapter 19). If the patient is able to participate but chooses not to attend, the note should record that she has been interviewed and should state her preferences clearly.

Respect for patients requires that the patient be encountered as part of the process. A clinical ethics consultant should never write a chart note, or even convene a discussion about a patient’s care, without having encountered the patient. Sometimes that means trying to rouse the patient and failing to do so. The attempt is what matters. If the patient is not alert, aware, and communicative, then the note should state that the patient was visited and give the consultant’s impression of that visit, supported by additional material in regard to decisional capacity.

B. Relevant medical and social history.

This is a more difficult section to write than one might think. Non-medical staff must be clear about what the sentinel medical issues are that correlate with the ethical questions. Before placing this section in the chart note, new consultants who are not medically trained find it wisest to prepare a draft of this section of the note for review by a medical person.

This section needs to indicate whether the medical history of the patient was clear and provide sufficient facts so that readers have a sense of the course and development of the illness or condition. Was it clear that there were, or were not, additional medical consultations that needed to be explored or facts that needed to be clarified? Were all at the meeting satisfied that the medical discussion explained the present status and possible future options for the patient?

This is an interesting section to construct, as the complexity of families is one of the givens of modern bioethical and literary life. As Leo Tolstoy famously observed in the opening line of *Anna Karenina*: “Happy families are all alike; every unhappy family is unhappy in its own way.”

This section needs to explore the patient and family history as they relate to the decisions that are looming.

C. Consult implementation.

This section describes the initial arc of discussion with the care providers, including what issues were raised, what disagreements surfaced, and what possible resolutions emerged. It should reflect the progress and process of the various meetings, telephone calls, e-mails, and other relevant interactions. It is often helpful for the chart note to include brief quotes; this textured language makes the discussion more authentic and vivid. The note should attempt to capture the tone of the conversations and the voices of the patient, family, and care providers, especially if the patient is no longer able to participate in the discussion. The bioethics mediator should choose

carefully in order to capture and record the feeling, tenor, emotion, information, and dynamic of the meeting. This discussion helps direct readers' attention to the relevant ethical issues and how they should be resolved.

D. Ethical problem.

This section describes the ethical problems encountered in the consultation and, if possible, assigns them to categories. This is a critical section in the chart note and is the core of the consultant's obligation to educate. It should address the categories of bioethical problems that have been elucidated in bioethics and legal literature. Clinical ethics consultants should explain the contours of the problem, both in the mediation itself, where teaching is always appropriate, and in the chart note, where the same holds true for staff education (see "Typical Ethical Issues and Analysis" at the end of this chapter for categories and analytic discussion).

This section should not focus on the identification of principles—autonomy, beneficence, nonmaleficence, and distributive justice. These are perfectly good midlevel ethical principles that animate much of the philosophical discussion in foundational bioethics, but telling the staff that a problem is solved by a deontological or consequentialist analysis is not helpful. Nor is it helpful, in and of itself, to identify the ethical issues involved. Autonomy may be the platform for the discussion, but it needs more elaboration to be ethically useful to the staff, patient, family, and chart-note readers.

E. Ethical analysis.

This is a central feature of the chart note and draws on all a clinical ethics consultant's training. The paragraphs suggested in "Typical Ethical Issues and Analysis" at end of this chapter will be very useful in this regard, as they can provide a roadmap for the analysis. Ethical knowledge and mediation skills are what qualify the bioethics mediator for the role. This section needs to be clear but not extensive.

F. Summary of process.

This section follows closely on the ethical analysis section and describes the process of dissection and disaggregation of issues, discussion, and consensus building. Conversely, it describes unmanageable conflict that can't be ameliorated by the consultation process.

This section describes the discussions that took place among the staff and between staff members, patient, and family in order to help those staff readers who were not present to understand how the decision evolved. The more the narrative relays the developing dynamic of the conversation, highlighting its nuances, the better the readers understand what happened. If there were shifting positions, describing these will help readers understand how the decision turned out and why.

G. Recommendations.

This is an extremely important and very complex section to create. This is not a medical note that will suggest a medical intervention, although carrying out the ethical recommendations may require some medical follow-up. This is a recommendation that should emerge from the case discussion and analysis of the chart note and must reflect the categories of a principled resolution.

The recommendations section for a complex case might read:

Case summary: This is a difficult case of a medically complex patient, with COPD and a below-the-knee amputation, whose ability to remain at home and be safe is in question. However, despite some deficits, with the support of her son, all concluded that it was worth the attempt at one more discharge to home. Neither the patient nor her son wants her discharged to a nursing home. The patient has sufficient capacity to assess her situation and to opt for some level of risk in her setting to meet her needs for independence and autonomy. This is an example of

“supported autonomy,” which depends in large measure on the ongoing involvement and caring interventions of her son. However, as these remain in place, it seems not to endanger the patient more than her capacity to assume risk would support.

Recommendation: This patient, with some cognitive deficits and complex medical conditions, has sufficient “supported autonomy” to be discharged to her home with the supervision and support of her son. Both the patient and the son are aware that the complexity of care may determine that this discharge plan is not possible. However, both the patient and the son value independence and privacy and opt for this choice now, even though it was not the preferred staff plan.

This wording would have been more helpful to readers than that of the recommendation actually written in the case:

Recommendation: There is no reason at the present time to push for nursing home placement. Neither the patient nor her son wants it and we have a discharge plan that may work. We have K’s cooperation. The big question is how the patient will respond.

The suggested recommendation is also far better than the sort often seen that states:

Recommendation: Psychiatry should assess her capacity one more time. The pulmonary service should be asked to assess the oxygen machine in the home to determine whether or not it is working at peak capacity. Home care should assess her for services.

A clinical ethics consultation or a bioethics mediation is focused on decision-making dynamics and power of choice, maximizing options and choosing from among them. It is not a medical consultation that provides medical direction; it is an ethical consultation that provides guidance in decision making. It should therefore couch its recommendations in the language and form of ethics and not as a set of medical directives. An ethics consultation, whether explanatory, didactic, analytic, or meditative, should provide a set of recommendations that utilize and reflect ethical concepts and language. Ethics should beget ethics.

H. Style.

The language of the chart note should be precise, careful, respectful, and nonjudgmental. Slang should be avoided in favor of more formal medical, ethical, or sociological language. Avoid abbreviations and all derogatory terms. For instance, labeling a patient a “lolfof”—a little old lady found on the floor—does not advance her dignity. The chart note should model the sort of language and presentation that should be the goal for medical communication. The following are several particularly comprehensive examples.

Chart Note Example #1

The following chart note was written after a mediation with only staff present. It involved a fifty-seven-year-old male admitted from a nursing home after being found unresponsive. He had multiple medical problems and a clear lack of the decisional capacity that would permit him to choose among medical options. As described in the chart note, he was consenting to and refusing care on an inconsistent basis. The staff was deeply divided as to whether he should be coerced, cajoled, or tricked into undergoing certain tests, with the oncologist arguing for the most aggressive plan and the nursing team more willing to accept the consequences of no further tests and treatment. There had been heated exchanges between and among these groups and various members of the house staff in discussions peppered with charges of unethical behavior. It was at this point that the bioethics mediator was called. After a discussion of several hours, the team reached consensus, which was the basis for the recommendation in the chart note.

Clinical Ethics Consultation/Bioethics Mediation

Patient: GH MR# 000000

Time and place of consultation and participants: AB, MD internist and attending of record, CD, MD consult liaison psychiatry attending, EF, MD psychiatry resident, GH, Ethics, IJ, Ethics, KL MD Ethics. Location of consultation: Hospital 6B. The patient was interviewed in his hospital room. Discussion followed in the nurses' workroom on the unit.

Consult was requested because the patient, who appears not to have decisional capacity, is refusing recommended medical care. But he is consistent and clear in his position, although that position may not be responsive to the issues at stake. The staff was conflicted on how to proceed.

Relevant Medical and Social History: Mr. GH is a fifty-seven-year-old man who lives in XX Care Center nursing home. He has lived there for about five years. He has a history of psychiatric illness, homelessness, and substance abuse. Additional medical history includes diabetes and hypertension. Prior to living in the nursing home, he did not seek regular medical care. In the nursing home, his diabetes is managed with insulin but remains poorly controlled. He is treated with antipsychotic medications in doses used for the treatment of schizophrenia. Mr. GH was admitted to the hospital in [date]. In the nursing home he was described as being found pulse-less, received CPR, and was revived. Throughout the hospitalization, he has been clinically stable, without evidence of cardiac illness. He has intermittently refused blood draws. As part of the workup for a possible syncopal spell or cardiac arrest, a chest CT with contrast was done to rule out pulmonary embolus [PE]. There was no PE, but a speculated lung nodule was found, highly suspicious for lung cancer. To further evaluate his cardiac status, the cardiology team has recommended cardiac catheterization. To further evaluate the lung nodule, the pulmonary team has recommended a bronchoscopy and biopsy of the nodule. Mr. GH has refused both tests.

Mr. GH states he has parents in a western state as well as a brother and sister there. He has provided no contact information. The nursing home records have no contact information for friends or family.

Consult implementation: I first interviewed Mr. GH in his hospital room. He knows that he is in the hospital because he passed out and that there might have been something wrong with his heart or lungs. He remembered having the CT scan and did remember that it had showed something that might be cancer in the lung. He remembers that more tests would be needed. He does not wholly believe that there is a tumor in the lung, stating a few times, "I never had that before." I told him again about the bronchoscopy that would be necessary to definitively diagnose cancer and he said a few times,

"I don't want that." When asked why, he said, "I never had that before." He seemed upset by giving a piece of his body in the form of a biopsy. He said, "There must be a better way to do that." When asked if he would want to know if he had cancer, he did not answer directly or definitively. I asked if his brother and sister were people he would confide in about this kind of medical problem. He said yes, and that they would tell him to have the tests, but that he didn't want to. He stated his plan is to go home to the nursing home and come back to the hospital if he gets sick. He declined an offer to view the CT scan to see the tumor. I explained that the bronchoscopy was needed to try to see if he had cancer, and that if he had cancer, it could kill him, and that his doctors wanted to prevent that. He does not believe that he could have cancer or die from it. When asked what he is giving up by not having the recommended tests, he said he was not giving up anything. He does not understand that at the point he develops symptoms it could be too late to cure. When offered the option of trying the test, but stopping if he didn't like it, he said no, he didn't want to start.

Ethical problem and ethical analysis: Mr. GH is a patient who does not understand, or more precisely avoids, the nature of the medical problem he is facing. He does not understand the risks and benefits of the plan for workup his doctors have recommended. He does not have the capacity

to provide informed refusal. He has nobody that can act on his behalf as a surrogate decision maker who might argue with him or contest his decision.

However, his prior very clear and distinct pattern is to avoid medical care; some call this a “sedimented life preference” that is a strong pattern of behavior that is independent of understanding particulars of any situation. He has a hernia causing an enlarged scrotum that is the size of a small watermelon that he has never allowed to be fixed. In the hospital at this admission he has consistently stated that he does not want invasive procedures, but has tolerated a noninvasive test. This consistency over time in his refusal of medical care could be viewed as adding up to a statement of who he is and how he approaches life even without confronting the reality that we as caregivers encounter. Honoring these consistently stated preferences may honor the patient’s steady conviction but may not be in the patient’s best interest.

Some might argue that this is a moment to employ the “best interest standard”:

This standard requires an objective assessment of the relative burdens of benefits of available treatment options. Since this standard is employed when there is no knowledge of a particular patient’s prior wishes or inferred wishes, it is primarily an impersonal standard. In the absence of such particularized knowledge, the best interest standard considers what would be most likely to benefit or promote the well-being of a hypothetical reasonable patient in the same circumstances as those of the patient. Any additional information specific to the particular patient being treated might also contribute to an assessment of what is in his or her best interest [drawn from “Typical Ethical Issues and Analysis” at the end of this chapter].

However, this patient has a consistent pattern of choice that would contest the use of the best interest standard.

This patient is not “decisionally capable,” as he does not understand that his life might be saved by proceeding now and may not be if he waits until he is symptomatic. Decisional capacity requires the components that follow that this patient does not possess:

Capacity refers to the patient’s ability to perform a set of cognitive tasks, including:

- Understanding and processing information about diagnosis, prognosis, and treatment options
- Weighing the relative benefits, burdens, and risks of the therapeutic options
- Applying a set of values to the analysis
- Arriving at a decision that is consistent over time
- Communicating the decision [drawn from “Typical Ethical Issues and Analysis” at the end of this chapter].

Some might argue that he should not be allowed to choose a potentially harmful plan of care if he does not understand the harm. He has told the care team that he likes his life in the nursing home and he has given no indication he is ready to die. Additionally, Mr. GH did not indicate that he would not want to know if he had cancer. He did leave also a door open when he said, “There must be a better way to do that,” which I took to mean that he might be willing to undergo further noninvasive tests that did not involve taking tissue.

Options: The team debated the following options about which there was, at the outset, no consensus:

1. The oncology physician argued that we should be proceeding with bronchoscopy with “administrative consent.” However, the patient would need to provide assent to even begin the procedure or be sedated at the very outset. Advantages—a definitive diagnosis could be made according to the recommended care plan, which may allow a definitive treatment, i.e., surgery, to

be done. Disadvantages—going against the patient’s stated wishes, uncertain that Mr. GH would go along with follow-up care (blood draws, etc.) which might be required to minimize the risks of bronchoscopy/ surgery. Even more invasive procedures would be required to fully realize advantages of this diagnostic test.

2. The nurses caring for the patient argued for discharging the patient to the nursing home without further workup and revisit when/if Mr. GH agrees to invasive tests or develops symptoms. Advantages: honoring Mr. GH’s stated wishes. Disadvantages: missed opportunity to provide for Mr. GH care that optimizes his chance of healthy survival. Because it has been difficult to contact the MD at the nursing home, continuity of care is not ensured. A plan for treatment/palliation of symptoms when they arise would need to be in place.

3. The house staff argued for pursuit of further noninvasive tests if would add additional information, such as a PET scan to evaluate for metastatic disease and a stress test to evaluate for high-risk coronary artery disease. The presence of either might alter the plan of care. Advantages: Because Mr. GH has a history of getting accustomed to things and allowing them more over time (insulin, medication), this plan may get more information for him and give some time for him to understand he may have cancer and assent to the workup. Medical conditions (metastases, severe cardiac disease) that would decrease his chance of having a favorable outcome with surgery or chemo could be uncovered and added to the risk/benefit analysis. There is a small possibility that Mr. GH could have a cancer that is curable by surgery and that he could medically tolerate that surgery well. Disadvantages: continued hospitalization. Mr. GH prefers to go to the nursing home.

Recommendation based on consensus: The team agreed that this is a patient with strong life themes who is inconsistent in his acceptance or refusal of care. He consistently refuses what he considers to be invasive tests. He has agreed to noninvasive testing. It is not clear how he evaluates these. As PET scanning and stress testing might offer useful data that could be incorporated into the plan, and as these might be acceptable to the patient, it is suggested that these be performed, if possible with the assent of the patient.

Pursuing this sort of interim plan requires that the care team and the clinical ethics consultant agree to reconvene when more information is available to recalibrate the risks and benefits of further invasive procedures for Mr. GH. A follow-up meeting will take place.

Chart Note Example #2

The chart note that follows was written for a case in which the staff was caring for patient who was dying and unable to acknowledge her terminal breast cancer. Her inability to participate in planning for her best care had pitted the surgical service against the palliative care service in terms of who had the responsibility and authority to manage her care. The stress caused by her case was heightened because she arrived at the hospital on the Wednesday before Thanksgiving. In this case the bioethics mediator met with the patient alone, the patient and her husband (who was also in denial), and the surgical service and the palliative care service both separately and together to try to figure out how to care for this patient.

November 26, 20XX

A, B. Time and place of the consultation and participants; relevant medical and social history: This consultation took place on the surgical service. This case involved a fifty-four-year-old woman with recurrent breast cancer who had put off treatment until the lesion had developed into an open and foul-smelling wound. She had been married less than a year before and she was committed to keeping her “secret”—the fact that she was dying—to herself. Her husband was committed to the same process of secrecy. The resident team on the surgical service where the

patient was placed was uncomfortable with the non-discussion of the fact that the patient was dying.

The consult was called by the surgical resident who was in charge of the patient's care, although it had been determined by the surgical attending that there was no possible surgical intervention in this case. The patient had been admitted to the hospital from the Emergency Department and when it was observed that there was bleeding from the tumor, she was admitted to surgery. At the time of the consultation, the patient was receiving dressing changes, transfusions for blood loss, and radiation, all of which were palliative. Each time the dressings were changed there was extensive bleeding. Diagnostic tests had indicated widespread metastases to the brain, spine, bones, liver, and pancreas.

Despite the diagnosis and prognosis, in conversations with the husband, he requested that the tone of talk with the patient be "upbeat." Part of the problem was that this consultation was the Wednesday before Thanksgiving and the patient's primary oncologist was not available. The mediator met first with the care team, then with the husband alone, then with the wife-patient alone, and then with the couple together, followed by the staff again. Taking her cue from the patient and her husband separately and together precluded any open and honest discussion of the fact that the patient was dying. The staff accepted this state of affairs but remained uncomfortable.

C. Conduct of the consultation: The mediator was stymied in her inclination to get all the parties together. The shared commitment to the "secret" made open discussion impossible. As a result this mediation was done almost exclusively by independent caucuses, the substance of which was relayed to the parties as appropriate. The mediator continued to return to the patient, which resulted in the second note in this case.

D. Ethical problem and analysis: The first issue presented is whether a patient with this degree of denial is capable of making health care decisions.

Determining whether a patient has the capacity to make medical decisions is often a key ingredient of a clinical ethics consultation. Decisional capacity is not a legal determination (this is called "competence") but a clinical one that can be made by any member of the health care team who is familiar with the patient and has interacted with him or her over a more or less extended period of time. Capacity refers to the patient's ability to perform a set of cognitive tasks, including:

- Understanding and processing information about diagnosis, prognosis, and treatment options
- Weighing the relative benefits, burdens, and risks of the therapeutic options
- Applying a set of values to the analysis
- Arriving at a decision that is consistent over time
- Communicating the decision

Having capacity enables an individual to make decisions; it does not obligate him or her to do so, and in fact a person with decisional capacity may waive the right to make decisions or confer this right on others [drawn from "Typical Ethical Issues and Analysis" at the end of this chapter].

In this case the patient is in denial (or is acting as if she is), as is her husband, although a conversation alone with him after the consult indicates that he knows that she is dying.

That does not mean that she cannot choose among options for care that are presented by her care team. In this case the most appropriate staff would be the palliative care team. However, the title

of the team might be disturbing to the patient, and thus a palliative care consultation should be arranged without being labeled as such.

Recommendation: This case involves a dying woman who is comfortable continuing all palliative care interventions despite the fact that it prolongs and extends her dying process. She wants every moment of life that can be hers.

Radiation, blood transfusions, and dressing changes, which might be uncomfortable to some patients in her condition, comport with her stance on her condition and her non-acceptance of her dying status. As such her choice is to die slowly and in the hospital rather than, perhaps, more quickly at home on hospice, an option that her denial makes unavailable to her.

The team needs to be assured that this is an extreme case of denial but one that warrants our ethical support as the choice of a capable patient.

One exception to the above would be in the case of a blood shortage in the hospital at which time the blood service would have to decide if blood would be available for palliative purposes for this patient and for all others with comparable need.

While this case was not a classic example of a bioethics mediation, since the patient, her husband, and the medical team never met as a group, mediation techniques were critical to its resolution. There is a hook of a bioethics issue, that of the capacity or lack thereof on the part of the patient. But, more important is the plight of staff, patient, and family caught in the grasp of hard decisions with no real choices. (The following second note in the case was added two days later.)

I have met with the patient and she stated clearly that she wants her husband to make decisions about her care. This idea—called delegated autonomy—is within permissible ethical analyses. This patient does not want to hear about her impending death. We cannot force her to engage with us. Dr. O—[the head of the palliative care team] and I have discussed this case, met together with the patient, and agreed that oblique communication, not direct, is likely to continue. This is a capacitated patient who wants (has chosen) to be passive. She cannot and will not confront her dying. We will need to support her comfort without her clearly accepting or refusing interventions. Her husband is beginning to meet with the team and discuss the options that are presented. He is sad but is adjusting to the situation and to the needs of his wife.

Typical Ethical Issues and Analysis

These mini-discussions of important ethical concepts were written largely by Jeffrey Blustein, who was part of the faculty on the Clinic Ethics Credentialing Project and is now professor of philosophy and Zitrin Professor of Bioethics, City College of New York. The paragraphs track the list of ethical issues listed under “D. Ethical problem” in the bioethics mediation chart template.

Advance directives. All patients who are capable of making decision have the right to execute an advance directive to ensure that their wishes will be followed if they become incapacitated. Advance directives may be oral or written.

There are basically two types, living wills and proxy or health care agent appointments. A living will is a document that explains what the patient would want if in the future she could no longer discuss the decision and provide contemporaneous informed consent. Living wills are value neutral and could be used to prospectively request or refuse care. Most living wills, however, are structured to refuse interventions like surgery, ventilators, and antibiotics. Health care proxy appointments give the person appointed general ability to make decisions for the patient based on the standards of what the patient has said she would want (explicit directive), what one could surmise she would want from her behavior and pattern of life (substituted judgment), and absent both of these, what is in her best interest. Health care proxy appointments are generally more

flexible and more responsive to the nuances of medical conditions than are living wills. Proxy appointments permit the team with the proxy to begin an intervention, to assess its success, and then to continue or withdraw it as the condition of the patient requires. Living wills are less flexible and tend not to reflect the nuance of patient wishes: “I do not want a ventilator” does not generally mean that the patient would not want a few days of supported breathing if the result is likely to be effective and then would let the patient continue unassisted. Living wills tend to make absolute rather than nuanced statements, and as such are less appropriate to the art of medicine.

Allocation of scarce resources. A condition of scarcity occurs when demand exceeds supply, and medical examples include intensive care resources and transplantable organs. An important distinction is between scarce and expensive resources. Ventricular devices are currently extremely expensive resources, but they are widely available. By contrast, hearts for transplant are expensive as well as scarce. Scarce resources are generally also expensive, but the converse does not hold. Another distinction is between natural scarcity and created or artificial scarcity. For example, ICU beds are an expensive resource that is made into a scarce resource by an organizational decision limiting the number of beds. If the institutional budget permitted ICU expansion, more beds could be made available. In contrast, solid organs, such as hearts, are from the outset a scarce resource because of their finite supply, and the scarcity cannot be eliminated entirely. When the scarcity is a created or artificial one, an appropriate question to ask is what it would take to eliminate the scarcity and at what cost to other programs meeting other needs. Sometimes, because the cost would be ethically prohibitive, the scarcity must be accepted as the least bad arrangement.

Scarce resources are those that cannot meet the needs of all who could benefit from them, and therefore some way of setting priorities among the recipients must be devised. Because not everyone who could benefit can receive the resource, some will have to go without, and this may mean some will have to die. Because of the stakes involved, decisions regarding allocation of scarce resources must be based on sound medical and ethical criteria. Ethically, a system of allocating scarce resources must be both fair and designed to benefit the greatest number of patients. In the case of ICU care, priorities are established and patients with a greater likelihood of benefiting from ICU care are given preference over those who are less likely to benefit from care in that setting. Generally accepted medical criteria exclude patients who won't benefit from critical care because it would be physiologically futile, or they are in a persistent vegetative state or are brain dead. Criteria that are considered ethically unacceptable include ability to pay and social worth.

Assent and consent. Effective informed consent provides ethical as well as legal authorization for the physician to treat. Consent contrasts with assent. The latter, a notion with particular relevance in pediatrics, reflects the patient's agreement with a treatment plan, rather than authorization of it. Only when the conditions of informational disclosure, understanding, and voluntariness have been met in the context of decisional capacity can the patient's consent or refusal be considered truly informed.

Though young children cannot provide truly informed consent to treatment, they can, depending on the circumstances, assent to it, at least in the sense that they do not actively oppose it. Assent in this context is important because it facilitates treatment that is deemed to be in the child's best interest. It may be difficult or not practically impossible to treat a child who is unwilling to cooperate with the plan of care. As the child matures and becomes an adult, he may be able not merely to assent but to provide legally and ethically valid consent. Among incapacitated adults, assent also has value. Though an adult patient may lack the capacity to consent to dialysis, for example, long-term treatment is likely to be unsustainable if the patient persists in actively opposing it.

Best interest standard. Frequently treatment decisions must be made for patients who lack capacity and cannot decide for themselves. These may be persons who were formerly but are no longer capable of making decisions, or individuals, like newborns or severely retarded persons, who never had the opportunity to form values or preferences. The standards for health care decisions for patients who lack capacity give preference to the patient's voice as the central and most widely accepted source of authority. In some cases, the decision maker may rely on the prior stated wishes of the patient or, if these are not known or were never articulated, the inferred wishes of the patient. But when neither is possible, the decision maker must rely on a best interest standard. This standard requires an objective assessment of the relative burdens of benefits of available treatment options.

Because this standard is employed when there is no knowledge of a particular patient's prior wishes or inferred wishes, it is primarily an impersonal standard. In the absence of such particularized knowledge, the best interest standard considers what would be most likely to benefit or promote the well-being of a hypothetical reasonable patient in the same circumstances as those of the patient. Any additional information specific to the particular patient being treated might also contribute to an assessment of what is in his or her best interest.

In assessing best interest, both the outcome and the probability of achieving this outcome for different treatment options should be considered. In the clinical setting, the best interest standard would consider mitigating pain and suffering, prolonging life, restoring and enhancing comfort, and maximizing the potential for independent functioning. In all cases where this standard is invoked, best interest should be determined as far as possible from the perspective of the patient, not that of the decision maker. A life that may be unacceptable to the decision maker may be acceptable to the patient, and it is the latter standpoint that the decision maker should adopt.

Brain death and reasonable accommodation. According to traditional criteria of death, death is the irreversible cessation of heartbeat and respiration. However, with the advent of heart transplants in the late 1960s, it became necessary to supplement this definition with a neurological definition that allowed the timely retrieval of usable organs for transplantation. The first well-accepted definition of brain death was the product of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, which issued its report in 1968. The committee defined brain death as the irreversible cessation of total brain function. The Uniform Determination of Death Act, adopted in 1980 by the National Conference of Commissioners on Uniform State Laws, expanded the definition of death to include both cessation of circulatory and respiratory function and brain death. Brain death should not be confused with other neurological conditions, such as permanent vegetative state or minimally conscious state.

Though the nature of death has been a question with which philosophers and theologians have wrestled for millennia, there is widespread consensus that, medically speaking, a brain-dead patient is dead, period. The qualifier brain can be confusing to families because it suggests that only one organ of the patient is dead, so many clinicians prefer to use the expression dead rather than brain dead.

Patients who are brain dead might have their organs maintained on a ventilator for some period of time, awaiting organ retrieval, and families often have difficulty accepting that the patient is truly dead when looking at a body that is warm and healthy colored, has a heartbeat, and appears to be breathing. It only adds to the family's confusion to say that the patient is brain dead but "is being kept alive" on a breathing machine, and such language should be avoided.

Because the definition of death raises deep ethical, religious, and philosophical issues, some patients and families—for example, some Orthodox Jews and Muslims—reject defining brain death as death. Their religious and ethical convictions should be respected to the extent of making

an effort at reasonable accommodation. Reasonable accommodation includes, for example, continuing ventilation, nutrition and hydration, and/or medications for a short, specified period of time. It does not mean that the now dead individual should continue to be treated as a patient. Since brain-dead patients can no longer benefit in any way from care, they should not remain in the ICU in particular, where resources are scarce and should be allocated to those who can benefit from them the most.

Confidentiality. Confidentiality is one of the bedrock ethical principles in health care. The principle of confidentiality has a number of bases. First, respect for persons underlies patients' right to control who has access to their health care information and requires that medical records and communications in the clinical setting be protected from unwarranted disclosure. Control of this information can be seen as a form of self-determination. Second, the effectiveness of the clinical relationship and the resulting quality of the health care provided depend on an atmosphere of trust between the patient and the physician, and this trust is facilitated by confidentiality. Without assurance of confidentiality, patients may be reluctant to provide all relevant information about their medical condition. Third, confidentiality protects patients from unauthorized disclosure of information that, if made public, may be personally embarrassing or damaging to them.

The principle of confidentiality governs other relations as well, including priest-penitent and lawyer-client, and various protections for the confidentiality of these relationships are established in the law. In recognition of the fact that most health care today is provided by teams of medical professionals, and consonant with the requirements of the Health Insurance Portability and Accountability Act, the principle of confidentiality does not preclude the free exchange of patient information within the team caring for the patient. In other ways as well, changes in health care delivery have altered the contours of the principle of confidentiality, allowing legal and government bureaucracies and third-party payers access to personal medical information.

The principle of confidentiality is not absolute. There are three exceptions: first, when the patient poses an imminent risk of serious harm to him- or herself; second, when the patient poses an imminent threat of serious harm to identifiable others (as argued in the 1976 case *Tarasoff v. Regents of the University of California*); third, when the patient poses an imminent threat of serious harm to society at large (the so-called public health exception, as in cases of reporting infectious diseases).

Conscientious objection. Conscientious objection refers to a situation in which a physician or other caregiver opts out of participating in a plan of care or providing a particular medical service on moral or religious grounds. Most hospitals have policies permitting conscientious objection, as long as certain other conditions are met. Common examples include objection to honoring the decision of a patient or surrogate to forgo life-sustaining treatment or to institute a do-not-resuscitate order, and objection to assisting with or performing an abortion. The grounding in religious or moral principles is definitional of conscientious objection. Thus, objection to participating in withdrawal of life support because it reminds one of an unpleasant experience from one's past does not count as conscientious objection, however much we may sympathize with the clinician's reluctance. Similarly, treatment that the physician believes is detrimental to the patient's best interest is not the same as treatment to which a physician has a conscientious objection.

The rationale for honoring conscientious objection is that it respects and preserves the clinician's personal integrity. One's moral and religious convictions represent what one stands for on a deep level, and they constitute one's identity as a responsible individual accountable for one's actions. To violate them is to do damage to one's moral and religious identity; and to bar an individual

from engaging in conscientious objection is to put him or her in the position either of resigning or violating his or her conscience. It is unfair to health professionals to put them in this position.

At the same time, there are certain conditions that must be satisfied if conscientious objection is to be permitted. First, the clinician who conscientiously objects must notify the patient or surrogate, as well as his or her supervisor or superior, that religious or moral convictions prevent his or her participation. Second, the objecting clinician must make reasonable efforts to find another non-objecting clinician to take his or her place and to arrange transfer of the patient to that physician. Continuity of care should be maintained as far as possible, and non-abandonment remains an important ethical obligation. Third, if transfer of the patient cannot be arranged, the objecting health professional may have to provide the requested service, depending on the seriousness of the patient's medical condition and prognosis with or without the intervention.

Consent to and refusal of treatment. The flip side of a capable patient's right to consent to proposed treatment is the right to refuse proposed treatment. It is an established principle of law and ethics that a capable patient has the right to refuse any proposed medical treatment, even if its likely consequence is his or her death. Respecting the patient's refusal, like seeking the patient's consent, is an aspect of honoring the patient's right to autonomy.

Refusal of recommended treatment should initiate a discussion about the reasons for the refusal. The patient might not understand the nature of the treatment that is being proposed and its potential risks and benefits, may have certain fears relating to the treatment that can be addressed, or may have a treatable depression. Because of their profound implications, refusals of life-sustaining treatment in particular should receive heightened scrutiny. In general, in the case of treatment refusal, special attention should be given to the adequacy of the information presented and the quality of the explanation, possible language or cultural barriers to understanding, and the patient's capacity and appreciation of the consequences of forgoing treatment.

Cultural values and treatment. Patients and family members live in the real world of different cultures and in the sui generis world of their own making. There are documented differences among cultures that have profound differences on how they think about and make health care decisions. In Japan, for example, it is most unusual for a physician to talk with the actual patient about diagnosis and prognosis. In certain Native American cultures, language does not reflect reality but creates reality. For patients and family members steeped in these traditions, the Western medical commitment to open discussion of diagnosis, prognosis, alternative treatments, and risks and benefits of those treatments could be alarming and even harmful to the patient. There is always the possibility of a clash between the legal and ethical dictates of contemporary American medicine and the traditions and comfort zones of persons whose values and expectations are honed in a different culture.

In addition to the difference of cultural context, there is the matter of family conventions and arrangements, some of which may be conscious and chosen but many more of which are unconscious and accretions over time of frequent successful patterns of interaction. Some families leave all decisions to the paterfamilias, as the embodiment of power and authority. Others cede decision-making aegis to the mother or have a gradual evolution to the children. These patterns precede, and will likely dominate, the medical crisis. Understanding the family dynamic is important in establishing trust and opening up useful communication about options for care.

Dealing with the adolescent patient. Adolescence is a developmental stage that falls between childhood and adulthood and that shares properties of each. By the age of fourteen, the normal child demonstrates a capacity to reason, including the ability to understand the causes and effects of illness, that is both as good and as flawed as it will be in adulthood. However, the capacity to reason is not the only ingredient of decisional capacity, and adolescent capacity may be deficient

in other respects. Other factors include personal values, biological and emotional maturity, life experience, and appreciation of the long-term consequences of one's actions. Moreover, the capacity of adolescents to make autonomous decisions is enormously varied because it is tied to the development of a sense of identity and to the adoption of a more or less stable set of values. As the adolescent matures, she acquires an increasing ability to assume control of and responsibility for her own decisions, and correspondingly, a greater weight should be given to her values and wishes. All these factors make ethical decision making for adolescents very complex.

Adolescent decisions are typically the product of less experience and more volatile emotions than are adult decisions, and compared with those of adults, the decisions of adolescents reflect immature self-image, unrealistic appraisal of risks and consequences, and susceptibility to peer pressure. However, the decision-making capacity of some adolescents is not impaired in these ways, especially older adolescents or those who have lived with chronic illness for much of their lives. While the law makes categorical distinctions between adults and minors based on somewhat rigid and arbitrary standards, ethically a more individualized assessment of adolescent decisional capacity is required. The factors to be considered include the adolescent's emotional maturity, her ability to solve problems and consider alternatives, and her experience with illness and loss.

Decision-making capacity. Determining whether a patient has the capacity to make medical decisions is often a key ingredient of a clinical ethics consultation. Decisional capacity is not a legal determination (this is called competence) but a clinical one that can be made by any member of the health care team who is familiar with the patient and has interacted with him or her over a more or less extended period of time. Capacity refers to the patient's ability to perform a set of cognitive tasks, including:

- Understanding and processing information about diagnosis, prognosis, and treatment options
- Weighing the relative benefits, burdens, and risks of the therapeutic options
- Applying a set of values to the analysis
- Arriving at a decision that is consistent over time
- Communicating the decision

Having capacity enables an individual to make decisions; it does not obligate him or her to do so, and in fact a person with decisional capacity may waive the right to make decisions or confer this right on others.

It is an established principle of law and ethics that adults who have the capacity to make their own medical decisions should be permitted to do so. Not to give them the opportunity to make their own decisions is a violation of their right to autonomy.

Decisional capacity is decision specific, that is, it varies according to the complexity and seriousness of the decision at hand: more complex and more weighty decisions require a greater degree of decisional capacity than do less complex and less serious ones. The appointment of a health care agent, for example, requires only a fairly low level of decisional capacity, whereas deciding whether to have a complicated surgical procedure requires considerably more. In addition, decisional capacity is not always clear-cut or necessarily constant. In some cases, there may be no definite answer to whether the patient has the capacity to make a particular decision. And depending on their age, cognitive abilities, clinical condition, and treatment regimen, patients may exhibit fluctuating capacity. For example, elderly patients often exhibit greater alertness, clearer reasoning, and better communication earlier in the day. Drug interactions can also cause a temporary loss of capacity.

Decisions about artificial hydration and nutrition. The issue of withdrawing artificial hydration and nutrition frequently arises for patients who have permanently lost consciousness; it is also considered for patients who are irreversibly and terminally ill and do not tolerate the procedure well. Ethical concerns about forgoing artificial hydration and nutrition often take the form of worries that we will be “starving” the patient if he or she is not fed or hydrated. However, existing medical opinion suggests that patients who have permanently lost consciousness do not experience pain or discomfort following the withdrawal of artificial hydration and nutrition. Less information is available about the experience of patients in the end stage of the dying process, but available information here too suggests that these patients appear to experience little if any discomfort when routine comfort measures are provided. In fact, provision of artificial hydration and nutrition can in some instances actually increase the patient’s discomfort and cause numerous complications, including pulmonary edema, nausea, and mental confusion.

Ethical debate about artificial hydration and nutrition has centered on whether these measures should be distinguished from other treatments on medical or clinical grounds. On one side, some argue that artificial hydration and nutrition constitute basic care rather than medical treatment, hence that artificial hydration and nutrition should almost always be provided. Also, some commentators argue that forgoing artificial hydration and nutrition intentionally causes death—unlike, say, the forgoing of ventilatory support—and is tantamount to killing. On the other side of the debate are those who argue that artificial hydration and nutrition should not be distinguished from other medical treatments. They are not universal needs for all persons but interventions in response to an underlying disease and condition. In addition, it has been argued that forgoing artificial hydration and nutrition is crucially different from intentional and active killing. The view that artificial hydration and nutrition are not to be distinguished from other medical treatments is reflected in statements by the AMA’s Council on Ethical and Judicial Affairs and recent court decisions.

Decision making in the neonatal intensive care unit. Decision making in the NICU involves three parties—caregivers, parents, and the state, in its role as *parens patriae*, or protector of the vulnerable. In this setting, parents have a great deal of authority to make decisions on behalf of their newborns, including, in some circumstances, the right to terminate life-sustaining care. Our society’s deference to parental decisions rests on respect for family integrity, the presumption that parents act in their child’s best interests, and the need to have a designated authority to make such decisions.

Specifically, three ethical rules of thumb guide decision making in the NICU:

1. If the parents are making decisions that are medically indicated and clearly in their child’s best interest, their decision should be supported.
2. If the parents are making decisions that are not medically indicated and not in the child’s best interest, their decision should be resisted.
3. If it is unclear whether the parents’ decision is in the child’s best interest, or if there is legitimate disagreement about this, the parents’ decision should be respected.

Conceptions of benefit and harm may be defined differently by caregivers and parents, creating conflicts in the NICU over how or even whether to treat their sick newborns. These conflicts may reflect different conceptions of what constitutes an acceptable quality of life for the child. In addition, prognostic uncertainty complicates decision making. Often conflicts between parents and caregivers can be resolved as the child’s condition and prognosis become clearer, parents are given time to absorb bad news, and parents receive the emotional support of the team. Part of this emotional support is dispelling the notion that they are monsters because they have decided to terminate life-support for their critically ill newborn.

“Demanding families.” Health professionals sometimes find themselves confronting families that they describe as “demanding,” “difficult,” or “unreasonable.” It is important for good patient care to uncover and deal with the source of these problems. Families may demand treatments that clinicians judge to be therapeutically inappropriate or otherwise not indicated, such as dialysis for a patient who is actively dying; or families may refuse treatments that are clearly medically indicated, such as a lifesaving blood transfusion for a young child. Another possibility is that uncorrected proof, all rights reserved families may try to micromanage care for their loved ones. However, although family members often provide consent for recommended treatment, there are ethical limits to what they may demand or refuse, and these limits are set by existing standards of care. Though members of the health care team may feel intimidated by demanding families, there is no ethical obligation to provide treatment simply because the family wants it. Boundaries also have to be set by the health care team to prevent intrusive and obstructive interference by family members in the care their loved ones receive.

Demands for treatment should trigger a discussion with families that explores their understanding of the patient’s medical condition and prognosis, the specifics of their demands, and their hopes and expectations for the patient. A mediation approach, which seeks to level the playing field and provides a forum for all interested parties to voice their concerns and raise questions, is often helpful in these circumstances. Families may demand that “everything” be done without having an understanding of what “everything” encompasses or that everything reasonable and medically indicated is already being done. Carefully probing their concerns may reveal fears and misconceptions that can be addressed. In the end, however, if no consensus can be reached between family and caregivers, it is the ethical obligation of health professionals to adhere to the standards of practice in medicine.

DNR orders. An order stating that a patient should not be resuscitated (“do not resuscitate,” or DNR) means that in the event of cardiac or respiratory arrest, resuscitation efforts will not be initiated. The resuscitation team will not be called emergently, according to the institutional code, to the bedside to administer stimulating medications, to insert a breathing tube, to pound on the chest, and most invasively to open the chest and engage in cardiac massage.

It is now appreciated that certain patients with complex medical problems and multiple organ failure will not survive the resuscitation itself; it is even more unlikely that they will survive until they can be discharged. Thus an unwitnessed cardiac or respiratory arrest in a frail elderly patient will almost certainly result in death. DNR orders are now an accepted practice in ICUs, and their use follows basic ethical and scientific guidelines.

Patients who are decisionally capable are often asked to choose whether they want resuscitation. If a dying patient, with relevant data presented, chooses this intervention, it should normally be honored. For incapacitated patients, the family is often approached for direction. In these circumstances it is imperative that the medical team know the data on survival and be ready to bear the burden of suggesting either that resuscitation would be helpful or that it would only prolong the process of dying. Family members should be shielded from being primary deciders, as they will often struggle to avoid responsibility and deny complicity. Many family members, weighing the risks and benefits and choosing a DNR order, feel as if they have signed the patient’s death warrant. It is thus critical for the staff to bear the burden of the decision without disempowering the family who for emotional or social reasons must insist on resuscitation. In these discussions, staff must emphasize that the patient will not be medically or emotionally abandoned if the order is written but rather will be saved an intervention that would extend and complicate the dying process.

The **doctrine of double effect.** The doctrine of double effect was formulated in response to the recognition that an act may have both a good and a bad effect. According to this doctrine, the

permissibility of an action depends largely on whether the bad effect is intended or is merely foreseen and permitted to happen. In addition, it must also be the case that the act is not wrong in itself; the good effect is the result of the intentional act, not the result of the bad or harmful effect; and the benefits of the good effect outweigh the foreseen but unintended bad effect. The doctrine of double effect has been used to support adequate palliation of symptoms, especially at the end of life. The doctrine recognizes that, while the administration of sufficient opioids to manage pain at the end of life may risk depressing respirations enough to hasten death, the clinical and ethical mandate to relieve suffering is paramount.

The physician's intent is not to kill but rather to alleviate pain, although he foresees that death is possible, perhaps even likely. Also, giving drugs to relieve pain is not wrong in itself, and the good effect—the relief of pain—is produced directly by the administration of the drug, not by the patient's death. Finally, when a patient is terminally ill and suffering, the desirability of relieving pain sufficiently compensates for the shortening of his or her life.

The doctrine of double effect is recognized as a valid ethical principle by professional medical associations, as well as by state and federal courts of law, including the Supreme Court in the 1997 physician-assisted suicide cases. However, the doctrine also has its critics. They argue that the doctrine is often difficult to apply because it is not always easy to know whether a result is intended or merely foreseen, or whether it is brought about by the bad effect (e.g., the patient's death) or by the morally neutral action (e.g., administration of pain killers). Whatever the final verdict about the difficulty of its application, the doctrine is an important part of the practice of end-of-life care, and it would be unwise to abandon it. To do so would risk equating pain relief that has the effect of causing death with pain medication administered in order to cause death, and this would have a detrimental impact on the quality of patient care near the end of life.

End-of-life balance of acute and palliative interventions. As a patient nears the end of life, or experiences pain and suffering that can be alleviated, the balance between acute interventions and palliative interventions will likely shift.

The shift requires involving the patient, and the family if the patient desires, in a discussion of the obligations of medicine to address the needs of the patient, in pursuit of greater health and well-being, or to address the symptoms of the patient in need of comfort. These are not incompatible goals; however, the balance will likely shift as the patient becomes less likely to return to a prior stage of function and the discomfort, both physical and emotional, or the illness advances.

In this gradual shift to a different sort of intervention, it is critical to assure the patient and loved ones that the patient is not being abandoned but is being offered those interventions that are best suited to present needs. The shift does not entail withdrawing or withholding acute care interventions but rather providing those interventions designed to address the advancing prognosis and symptoms of the patient.

Failure of the medical team to assume responsibility for difficult choices. Medicine is not magic. It cannot prevent a patient who is in the process of dying, after all appropriate interventions have been offered, from that ultimate end of the human condition. Much of religion and philosophy is addressed to the existential crisis of life, which is always death. However, medical staff can—and should, when possible—shield the patient and the family from the feeling or the notion that they are in any way complicit in this death. Thus it is important for the team to be clear and precise about how the inevitability of death limits and changes the options for care. As with the later section “False choices,” it is important for the team to assume the responsibility of stating that the treatment will not be of benefit and that they do not recommend it. This course is far preferable ethically and practically to offering a treatment and leaving it to the family to reject the offer—and to feel responsible for the inevitable negative outcome.

False choices. The suggestion is sometimes made that the full disclosure necessary for informed consent requires that the physician offer patients and families all possible treatment options for their consideration. However, this is an incorrect interpretation of what informed consent requires, because some care decisions do not require and should not impose the burden of patient or family consent. These are cases of false choice, in which patients and families are asked to reject interventions that have no clinical indication and that can provide no real benefit. Presenting patients and families with false choices actually diminishes rather than enhances the exercise of their autonomy, and abdicates the professional's responsibility to exercise clinical judgment and to guide patients and families in ways that make clinical sense.

When reversal of or improvement in the patient's condition is no longer possible, it is inappropriate for physicians to present care options in a way that suggests otherwise. Interventions that are physiologically futile (see the later section "Medical futility") or outside the standards of medical practice should not be proposed. When specific treatments, such as dialysis, antibiotics, or vasopressors, are no longer effective, it is disingenuous to present them to patients and families as if they were real options, and unfair to burden them with a choice that is not theirs to make. This is not an instance of medical paternalism that disempowers patients and families. Rather, it involves physicians assuming responsibility for making the judgments that only physicians can make, and leaving patients and families with choices that fall within the realm of the medically possible. In this way, physicians support rather than usurp the genuine health decision-making authority of patients and families.

Informed consent. Informed consent is a process of communication between physician and patient characterized by mutual participation, respect for the autonomy of the patient, and shared decision making. Informed consent is not a perfunctory discussion or a signature on a document. The legal doctrine of informed consent, out of which the ethical principle developed, was initially based on the law of battery, holding that any unconsented-to touching constituted an unlawful act. The signal case establishing the principle of informed consent in medicine was *Canterbury v. Spence*, 464 F.2d 772 (D.C. 1969), which held that the physician is obligated to provide sufficient information about a procedure's risk so that a reasonable patient can make an informed decision. All health care procedures and treatments require the informed consent of the patient or an authorized representative.

Informed consent has a number of requirements. There are disclosure requirements: the physician must disclose information about the proposed diagnostic or therapeutic intervention, the purpose of the intervention, the consequences of nontreatment, and alternatives to the proposed intervention; and the physician should make a recommendation about how the patient might consider the benefits and burdens of the intervention. There is also a requirement that the consent be voluntary, that it not be coerced, or forced, or unduly influenced. However, this does not preclude providing a recommendation and support to the patient. Independent decision making is not the same as isolated decision making.

There are a number of exceptions to the consent requirement: emergency care; the so-called therapeutic exception in which disclosure of information is reasonably believed to present a substantial risk of immediate, direct, and significant harm to the patient; and waiver of consent by the patient.

Medical futility. The term medically futile is commonly used quite broadly and loosely to describe treatments that are felt not to benefit the patient because he or she has a very poor prognosis. For example, dialysis for a patient with terminal cancer may be said to be medically futile. However, the term futile should be used with great care and may in fact be unhelpful to the process of resolving conflicts in patient care. Some physicians use futile narrowly, considering treatments futile if they would be physiologically ineffective or would fail to postpone death for

any significant period of time. Some physicians adopt a broader understanding of the term to refer to treatment that cannot improve the patient's prognosis, comfort, well-being, or general state of health. Following this approach, a treatment might be seen as futile if it does not offer what the physician considers to be an acceptable quality of life.

Debates about medical futility are not just about labels. How we define futility has important practical consequences for how conflicts in patient care are addressed and resolved. Underlying different definitions of futility are different assumptions about the balance that should be struck between the authority of patients and families, on the one hand, and the authority of physicians, on the other. The term futility commonly functions as a trump card, permitting the physician to discontinue or not initiate treatment, and it is appropriately used in this way when it has a narrow physiological sense. Physicians currently have no duty to provide treatment that is futile in the narrow sense, even if patients, families, or both request it. But it is not appropriately used as a unilateral physician trump card when it reflects judgments about acceptable quality of life or broader notions of patient well-being. In general, the term futile should be avoided except in the very narrow circumstances of physiological futility.

The danger of using too expansive a notion of medical futility is that it will preempt communication and conversation between the physician and the patient.

In this time of soaring medical costs and proliferating technology, it should not be surprising that an intense debate has arisen over the notion of medical futility, a concept that is as old as medicine itself. Should doctors be doing all the things they are doing—in particular, should they be attempting treatments that have little likelihood of achieving the goals of medicine? What are the goals of medicine? Can we agree when medical treatment fails to achieve such goals? What should the physician do and not do under such circumstances? Exploring these issues has forced us to revisit the doctor-patient relationship and the relationship of the medical profession to society in a most fundamental way.

Some argue that medical futility cannot be meaningfully defined, even calling for the term to be expunged from the medical lexicon. Spokespersons for various ethnic and religious groups raise the challenge: What right does medicine have to set its own professional standards over our values? In response, law professor George Annas argues that it is up to medicine, like any profession, to propose its standards of practice, which society can accept, modify, or reject. Other professions, when subjected to outside pressures, stand up for their professional standards. For example, the teaching profession consistently has resisted demands to teach creationism as a science, on the grounds of professional standards, even in communities where it is a majority belief. And within the medical profession itself surgeons make futility decisions every day simply by refusing requests to operate on a patient they deem “inoperable.”

As Edmund Pellegrino, chairman of the President's Council on Bioethics, points out:

Those who call for the abandonment of the concept have no substitute to offer. They persist in making decisions with, more or less, covert definitions. The common sense notion that a time does come for all of us when death or disability exceeds our medical powers cannot be denied. This means that some operative way of making a decision when “enough is enough” is necessary. It is a mark of our mortality that we shall die. For each of us some determination of futility by any other name will become a reality. Some working definition therefore must be recognized by which the criterion of futility can be judged. or family regarding difficult matters, such as withdrawal or withholding of life-sustaining treatment.

Lawrence Schneiderman, a colleague in bioethics who takes a very different approach to this issue than we do, offered the analysis that follows, which we include at this point in the spirit of open and frank disclosure of scholarly oppositions. We use this material with his permission.

Today, more and more hospitals are writing futility policies, recognizing it as an inescapable necessity. These policies, like all health care institutional policies, attempt to bridge the gap between the cultures of medicine and the law—physicians trying to say legal things, lawyers trying to say medical things. Health care providers tend to seek specific and descriptive definitions of futile treatments, while lawyers and judges seek to put in place procedures that protect vulnerable patients. Definitions and processes are both essential, even when pursuing a “case-by-case” analysis. Without this grounding, end-of-life outcomes run the risk of being determined less by medical circumstances and justifiable standards and more by nonmedical factors, including rhetorical skills and economics.

Will all hospitals agree on the same definition and process? No. Is unanimity necessary to establish a professional standard of practice? Not at all, given that the law does not demand unanimous agreement among professionals regarding issues that are matters of professional judgment. Rather it allows for a “respectable minority,” namely hospitals that would continue to provide life-prolonging treatments that the majority of hospitals regard as futile. These hospitals, however, should consider the obligations and actions associated with their position. Specifically, are these hospitals willing to accept the transfer of such a patient? If so, disputes over end-of-life treatments could be resolved without requiring hospitals to go to court.

It is worth noting that the word futility derives from *futilis*, a religious vessel that had a wide top and a narrow bottom. This peculiar shape caused the vessel to tip over easily when filled, which made it of no practical use for anything other than ceremonial occasions in ancient Greece. The root of the term reminds us that words have a mythical power as well as a literal meaning. Is it not possible that unrealistic expectations and unreasonable demands for futile treatments, such as a family’s insistence on attempting cardiopulmonary resuscitation in a cancer patient with barely hours to live, may represent deep ritualistic needs to express love and devotion? CPR, the only intervention that requires no informed consent, has become almost a religious ceremony in today’s television age. Indeed, it is not too extreme to point out that in the past when patients sought a miracle they went to church and prayed to God. Today they come to the hospital and demand it of the physician. It is important to emphasize, therefore, that physicians are not and have never been capable of or obligated to produce a miracle. And comfort care measures are much better ways to express love and devotion.

Palliative care. Providing comfort, especially at the end of life, is not a new concept or a departure from the traditional responsibilities of the caring professions. However, its importance has been overshadowed by the tremendous advances medicine has made in recent years in curing disease and forestalling death. The discipline of palliative care has successfully cast the light once again on the notion that relieving pain and suffering is central to the complete and authentic practice of medicine. Its defining philosophy is that cure and comfort are consistent objectives that may assume greater or lesser prominence, depending on the patient’s condition, prognosis, wishes, and values. When the potential exists for significant improvement, the plan of care tends to emphasize aggressive curative measures supplemented by comfort measures. As the likelihood of cure fades and the patient approaches the end of life, the goal of care ought to shift, and aggressive palliation should become the primary focus. Aggressive palliation refers to the provision of therapeutic interventions, including narcotic medications and surgery, to relieve pain and manage other symptoms effectively. When curative measures are no longer possible, the message to patients and families should not be, “There is nothing more we can do,” but rather, “There is a great deal we can do to keep the patient comfortable and allow for a dignified death.”

The relief of pain is both a professional obligation and a moral imperative, clinically as well as ethically mandated. Before the advent of palliative care as a medical sub-speciality, it was frequently noted that patients’ pain was often not adequately appreciated or managed and that many patients died in pain. With greater understanding of pain and of how to assess and treat it,

and an enhanced appreciation of the importance of this long-overlooked aspect of patient care, this situation has begun to change in significant ways.

Religious values and treatment. There is broad-based consensus in our society that adults who have the capacity to make their own decisions have the right to consent to and refuse medical treatment, even if that refusal leads to their death. This right is endorsed in the bioethics literature, as well as by federal and state courts of law, including the famous New Jersey case *In re Quinlan* in 1976, the first right-to-die case to achieve national prominence, and the U.S. Supreme Court decision in *Cruzan v. Director, Missouri Department of Health* in 1990. The right to refuse unwanted treatment is not predicated on any specific reasons that the patient has for refusing. As long as the decision can be construed as a more or less rational or reasonable one, the obligation to respect it applies. In particular, the refusal of treatment may be based on religious objections, such as the objection of a Jehovah's Witness to receiving blood transfusions. A person's religious faith embodies some of his most cherished values and deepest commitments, and respecting them is part of respecting patient autonomy.

The right to refuse treatment based on one's religious convictions does not include the right to refuse treatment for one's child, especially lifesaving treatment, based on those convictions. Ethically, parents may martyr themselves to their religion, but not their children who are too young to have autonomously adopted religious beliefs. Further, most states do not allow individuals who have a religious objection to brain death to reject this definition of death (the only exception is New Jersey). What is called for in such cases is "reasonable accommodation," and this does not include giving patients and their families the right to define death as they choose. Finally, the rights of physicians may impose some constraints on the exercise of religious choice by patients. For example, some anesthesiologists may refuse to participate in surgery on Jehovah's Witness patients if they cannot use blood as needed.

Sharing the burden of responsibility. It is sometimes assumed that respect for patient autonomy means providing patients and families with full information about available treatment options along with their risks and benefits, and then stepping back and allowing them to make their own decision. However, in most cases, such a view of patient autonomy amounts to truth dumping. It overlooks the very real vulnerabilities that are part of the experience of illness and disability, and the need of patients and families for professional guidance in making sound health care decisions. Patients and families depend on such guidance, and depriving them of the benefit of clinical judgment, advice, and support, relying solely on the provision of full information, can be seen as a form of abandonment. Instead, physicians should be encouraged to clearly recommend what they believe to be the most appropriate therapeutic course and to discuss with patients and families their reasons for recommending it.

Physicians often avoid giving advice, recommendations, and guidance out of the fear that they amount to the imposition of unjustified physician paternalism. But unjustified paternalism means violating another person's right to freedom of choice, whereas advice and guidance can augment freedom of choice rather than curtail it. Recommending should not be confused with imposing; assisting the exercise of autonomy should not be confused with usurping the exercise of autonomy. When physicians share the burden of decision making with patients and families and take some responsibility for guiding them in ways that make best clinical sense, they actually enhance the capacity of patients and families to make autonomous decisions.

Signing out against medical advice. Patients who choose to leave the hospital prematurely and against the advice of their physician represent a common and challenging dilemma. These patients who sign out against medical advice are at risk because they have a higher rate of readmission. Finding a balance between attempting to protect patients from making unwise medical decisions and permitting patients to fully exercise their autonomy is challenging. This

issue is particularly important because patients facing illness are in a higher-risk state both medically and emotionally. Physicians relying too heavily on their patients' right to self-determination without a careful and thorough evaluation of their decisions may be abandoning patients when they are particularly vulnerable. Framed in terms of ethical principles, this problem is characterized by the tension between beneficence for patients and respecting patients' autonomy.

Describing the patient's medical decision as "unwise" in these types of dilemmas assumes the priority of health concerns over all others. Indeed, health and longevity are only two of many values patients routinely take into account in making decisions about their life. Using a nonjudgmental approach to patients' decisions can collect clearer information about their motivations for leaving the hospital before an appropriate discharge. Better information about patients' motivating behavior allows physicians to target their counseling more appropriately and potentially negotiate a discharge at a more medically appropriate time. For example, when the clinician is able to determine that the patient wants to leave the hospital because she feels pressure to return promptly to work, he can attempt to reduce that burden by focusing on that issue (advocating on the patient's behalf to her employer), rather than on the conflict over discharge.

Discussion with the patient can maximize the possibility that patients who choose to sign out against medical advice are receiving the best possible care. An informed decision means that patients have arrived at their decision by consultation with their provider, not under duress or coercion, and by understanding and appreciating its risks, benefits, and alternatives. Part of this process requires a capacity evaluation of the patient's decision to discharge herself from the hospital.

Substituted judgment. The standards of proxy decision making for incapacitated patients place particular emphasis on respecting the wishes and values of the patient when he or she had capacity. Often, however, the prior wishes of the patient are not known or were never expressed; in such cases, proxies should consider whether a substituted judgment standard applies. A term originally borrowed from law, a substituted judgment is a decision by others based on the formerly capacitated patient's inferred wishes. The question for the clinical ethical consultant to ask here is: "Knowing what you know about this patient's values, behavior, and decision history, what do you think she would decide in this situation?" It may also be helpful to pose the question this way: "Suppose that the patient were sitting here now, capable of making decisions, listening to this conversation and knowing his medical condition and prognosis. What do you think he would tell us to do for him?"

Since patients often have not given much thought to what they would or would not want if they became critically or terminally ill, or they have not discussed these matters with others, substituted judgment is frequently a useful approach to decision making for incapacitated patients. Persons who know the patient well and are familiar with his values and beliefs, such as close friends or family members, are in the best position to make substituted judgments. It is particularly important in discussions with them to stress that, as far as possible, they should try to make decisions based on what they believe the patient would want, not what they would want for the patient.

Therapeutic exception. Informed consent, including disclosure of information, is generally a requirement of ethical patient care. However, the requirement is not absolute and without exception. In very rare circumstances, physicians may believe that the disclosure of information about diagnoses or prognoses will cause clinically unstable patients to suffer immediate, direct, and significant harm. In these cases, potentially harmful information may be withheld from patients, even if the patient is judged to otherwise have the capacity to make medical decisions.

The rationale for the exception is that disclosure of information is designed to support and facilitate autonomous decision making. When disclosure of information is likely to result in immediate, direct, and significant harm, autonomous decision making is not enhanced but threatened.

Even if information is justifiably withheld on therapeutic exception grounds, once the patient's clinical condition permits disclosure, the disclosure must take place. The therapeutic exception is not a license to withhold information indefinitely, regardless of any change in the patient's medical condition. Further, withholding information on grounds of therapeutic exception must be based on strong evidence that the patient will or is likely to suffer harm from the disclosure. Conjecture that the patient may suffer harm, or that the harm may be significant, is not ethically sufficient, given the strong presumption in favor of truth telling and informed consent. In this connection, it is particularly important for clinicians to determine whether withholding information is really for the benefit of the patient, or for their own comfort or the comfort of the family. Breaking bad news is difficult, and it is understandable that clinicians may be reluctant to disclose an unwelcome diagnosis or prognosis to the patient or may defer to a family's request that their loved one not be informed. However, this cannot serve to justify withholding clinical information from an otherwise capacitated patient. To preserve the basis of trust in the doctor-patient relationship, information should be withheld from capacitated patients only in the narrowly described circumstances of the therapeutic exception.

Truth telling. Collaborative decision making and informed consent depend on the reasonable disclosure of necessary or material medical information. Patients and their authorized surrogates are ethically and legally entitled to information that enables them to understand the likely course of the medical condition, evaluate the therapeutic options, and make choices consistent with the patient's goals and values. The ethical basis of the principle of truth telling is twofold. First, disclosure reflects respect for the patient's right of self-determination. Patients or their surrogates cannot make autonomous decisions if they are denied information relevant to those decisions. Second, patients are normally the best judges of what is in their best interest, and they may not be able to protect those interests if material information is withheld from them.

The principle of truth telling does not permit physicians and other health professionals to bludgeon the patient with the truth. Truth must normally be told, but it should be told when the patient is ready to hear it and in a manner that the patient is able to assimilate. If a patient has clearly indicated that he or she is not ready to receive the truth, the truth is not required, at least for the time being. Also, the truth may be withheld if disclosing it would cause immediate, direct, and significant harm, although this occurs only rarely. Withholding truth is not the same as lying, however, and lying is more difficult to justify ethically. Bad news is always difficult to hear, but sadness at such times is normal, and avoiding causing

sadness should not be used as an excuse for withholding information. Indeed, truth telling can be therapeutic, in that it dispels the complicity of silence that often surrounds discussion of such matters.

There are cultural differences with respect to truth telling. In some cultural groups, telling the truth to the patient is not a moral requirement and may even be frowned upon. In these circumstances, clinicians should ask the patient how much she wants to know about her medical condition, how much she wants to be involved in decision making about her care, and if there is someone else she would prefer to have making decisions.

Withdrawing and withholding treatment. Health care professionals often distinguish between withdrawing and withholding treatment; as a result, they are sometimes willing to honor decisions by patients or families not to start treatment, but will not allow them to refuse treatment once it has begun. Studies have shown that for clinicians there is a significant emotional difference

between withholding and withdrawing treatment: in general, withdrawing is felt to be more emotionally difficult. This may be due in part to the belief that withholding treatment is an omission, whereas withdrawing treatment is a positive action and hence more culpable. Some regard withholding as letting nature take its course, and withdrawing as killing.

Over the past decades, however, consensus has emerged that there is no moral distinction between withholding and withdrawing treatment. Whether treatment is stopped or never initiated, all relevant moral factors are the same, including the health professional's duty to respect the patient's wishes, the consequences, the intentions, the cause of death, and the potential for abuse. Indeed, if there is any distinction to be drawn at all between withdrawing and withholding, it may favor the former, for withdrawal may occur after a therapy has been tried and found ineffective or unacceptable to the patient. The law also does not distinguish between withholding and withdrawing treatment. When one is legally permissible, so is the other.

It is important to understand that withholding and withdrawing treatment are morally and legally equivalent, for this may facilitate good patient care. If withholding is believed to be morally or legally permissible, but withdrawing is believed not to be, then physicians may elect not to start treatment and patients may suffer.