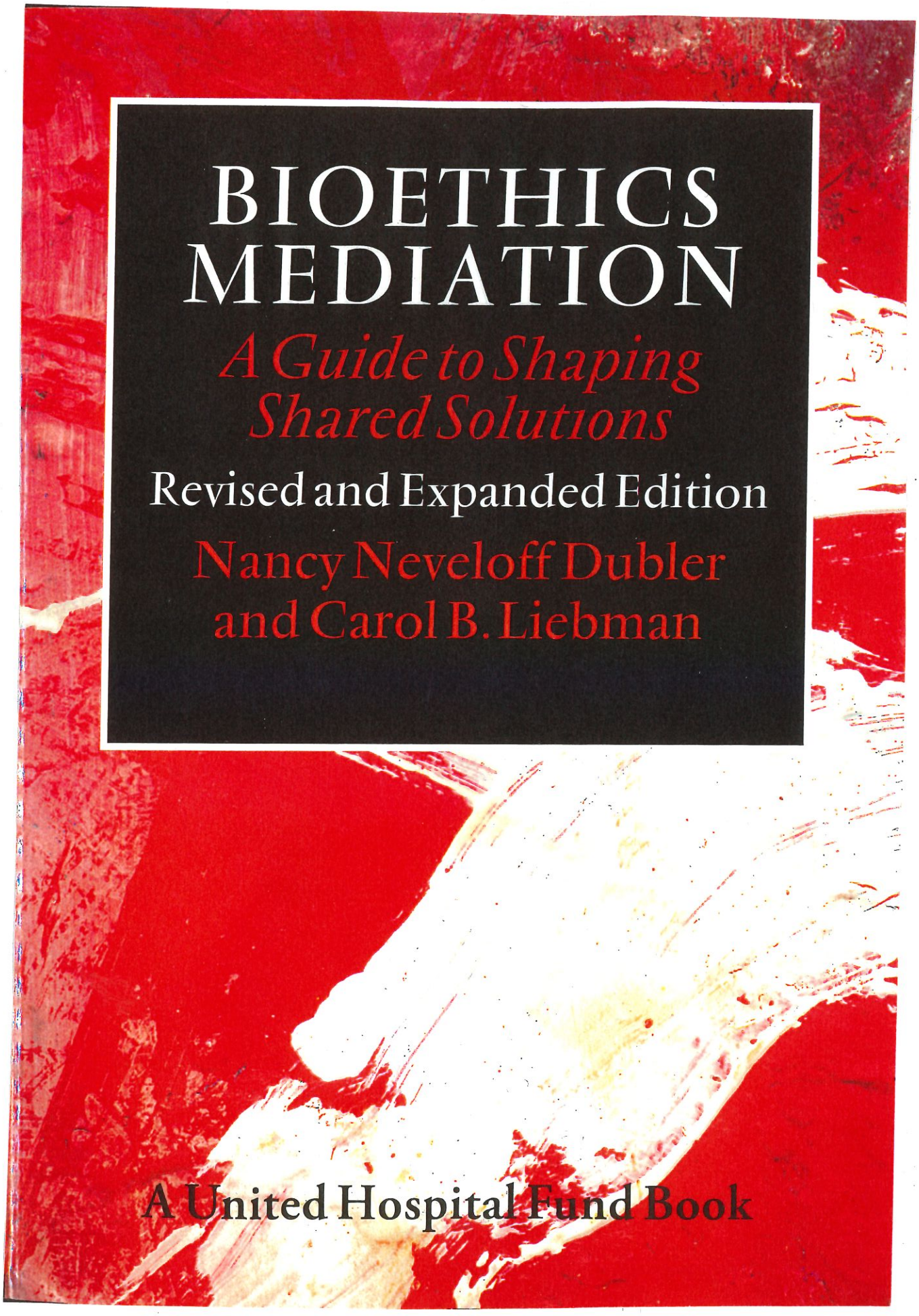
BIOETHICS MEDIATION
A Guide to Shaping Shared Solutions
Revised and Expanded Edition
Nancy Neveloff Dubler and Carol B. Liebman
A United Hospital Fund Book

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Why Mediation?

The following case was presented at Medicine Grand Rounds at a major urban teaching hospital.

The Angry Family Acting against the Best Interest of the Patient: Clarence Corning's Case

Clarence Corning was an eighty-six-year-old male with respiratory distress. He was hospitalized for a stroke that had occurred on the right side of his brain. He was initially on the neurology service and then transferred to the acute rehabilitation service, where he had a feeding tube placed; the medical team also began treatment for pneumonia in his left lung.

On the twenty-seventh day of the patient's hospitalization he had an acute event with desaturation, tachypnea, and decreased mental status and was transferred from the rehabilitation service to the Medical Intensive Care Unit, where he was promptly intubated for acute respiratory failure secondary to aspiration pneumonia.

The patient's hospital course was then quite troubling. He was intubated and treated for hospital-acquired pneumonia with broad-spectrum antibiotics. On hospital day (HD) #36 he was extubated. He was transferred to a step-down unit on HD #39. On HD #41 the patient spiked a temperature again and was restarted on broad-spectrum antibiotics. On HD #44 he was reintubated for recurrent aspiration pneumonia. On the same day the patient also was started on hemodialysis for renal failure. On HD #48 the patient underwent an elective tracheotomy.

When Mr. Corning entered the hospital, he had experienced some atrial fibrillation and hypertension. He had no history of drug or alcohol abuse or use of tobacco. His relationships with his family were warm and supportive. The medications he was taking included Warfarin, Reglan, Enalapril, Escitalopram, folic acid, and Albuterol/Atrovent.

On multiple occasions, communication with and decision making by the family had been difficult and possibly detrimental to the patient's best interests. For example:

- A Shiley hemodialysis catheter was placed for emergent hemodialysis. The patient became febrile ten days later but for over thirty-six hours the family refused to allow his catheter tube to be changed. In this interim, the patient had a positive blood culture for staphylococcal infection.
- The patient had been dialysis dependent since initiation and required permanent access. The family refused to allow permacath placement until twenty-two days later.
- The patient had recently become hypotensive and febrile and had a positive blood culture for gram-negative rods. The family at first did not allow the resident to order appropriate antibiotic coverage and was still refusing replacement of the permacath.
- There had been many instances of the family's arguing with the house staff and nurse practitioners involved in the care of the patient regarding routine orders and patient management.

Mr. Corning remained in the hospital. Though he was now on a tracheostomy collar, he continued to have nosocomial infections and recurrent bouts of sepsis. The decision makers for the patient were his son and daughter, who were joint health care proxies.

This case was presented at grand rounds in medicine at a major urban teaching hospital that does not have an active CEC service using mediation as its intervention for conflict. This is an example of a festering conflict that angered and incapacitated the medical staff and, one could imagine, infuriated and depressed the family. The resident in charge of the case admitted, when asked, that no one had actually told the family that Mr. Corning was dying. This large elephant at the dinner table was visible to all but mentioned by none.

Had the authors of this book been able, they would have

1. convened all of the care team for a meeting;
2. confirmed that, by all medical parameters, as far as could be determined, this patient's chances for recovery were very slim to nonexistent;
3. arranged a conference with some representatives of the team and the family; and
4. followed STADA:

- **Sat** with all in one room
- Begun by asking: "**Tell** me about Dad"
- **Admired** the family for loving their dad so much
- **Discussed** the diagnosis and the prognosis by (a) engaging in a process of generating options, and (b) engaging the family in a discussion about their values and goals and how to match those with the articulated options for care
- **Asked** what the family thinks Dad would want and what would be in his best interest (see Chapter 5 for a discussion of STADA)

Everything that could have gone wrong in this case did. A man quite vital before his stroke was now quietly slipping into death, and no more interventions could prevent his demise. No one on staff had told the family that they were sorry for the infections that some patients acquire. They need to say this even though quality improvement measures insist that these infections are not inevitable but are avoidable with greater care and checklists of preventives. No one had engaged the family in mourning this terrible outcome. Silence had become the rule, as administrators had advised the medical team that the family might take legal action.

Consider in contrast a case in which mediation was used.

The Isolated Wife Adjusting to Loss: Edward Davidoff's Case

Edward Davidoff, an eighty-two-year-old man, was admitted to the cardiac service with chest pain. Diagnostic tests revealed the need for quadruple bypass surgery to open four occluded vessels. He was a poor candidate for surgery, however, because he had chronic uncontrolled diabetes with moderate-to-severe compromise of his peripheral vascular system. Unfortunately, there were no other choices if he wanted to live, which he did, and surgery was performed.

After the surgery, Mr. Davidoff did not recover and developed various infections, necessitating his return to surgery for the removal of infected muscle and bone. A bioethics consultation was requested after the second surgery, at which time he was ventilator dependent with an open chest wound that would not heal. Mr. Davidoff's wife was desperate about her husband's condition and determined that he should recover. She was unable to assimilate the nuanced, and not very clear, discussion by the care team, who used euphemisms to indicate that Mr. Davidoff was dying. No one in the cardiac team had been blunt about the prognosis, and Mrs. Davidoff used this oblique discourse to reinforce her unrealistic expectations about her husband's recovery. Completely alone and desperately lonely, she had moved her chair out into the hall and sat there waiting to waylay any staff member with a connection to the care of her husband. She responded to any specific discussion about care options by choosing the most invasive (why that option had been presented was the first question the bioethics mediator asked the cardiac team), which she equated with the best chance of insuring her husband's survival. She was never told directly that his survival would be unprecedented, and so it is not surprising that she continued to demand that everything be done. This demand led to the request for a CE consultation.

The consult was called by the nursing supervisor, who had been spending increasing time with Mrs. Davidoff. In keeping with the usual procedure of the service, the bioethics mediator met first with the care team—the cardiothoracic surgeon, the vascular surgeon, the first- and second-year residents, the surgical fellows, the primary nurse, and the nursing supervisor. They discussed the case and explored the history of Mr. Davidoff's care and the prognosis, concurring that Mr. Davidoff was unlikely to survive the night. No one had yet communicated this prognosis to Mrs. Davidoff. Moreover, Mr. Davidoff had clearly stated to various

members of the care team that if the surgery failed, he did "not want to be kept alive on machines."

The team felt that it had an obligation to the oft-expressed wishes of the patient but also to the anticipatory grieving of the wife. The team members did not think that Mrs. Davidoff could decide to remove her husband from the ventilator, although they felt this removal was probably what Mr. Davidoff would have wanted. Furthermore, they felt that a do-not-resuscitate (DNR) order was needed to prevent a terrible death if Mr. Davidoff went into cardiac arrest. The open chest wound precluded any effective resuscitation effort.

Before ending the care team discussion, the mediator asked which members of the large team wanted to be part of the discussion with the patient's wife; confronting her with the entire group would be intimidating. It was agreed that the cardiothoracic surgeon, one of the surgical fellows, one of the residents, and the primary nurse would meet with her. The mediator next asked who should lead the discussion. She explained that she was a stranger to the patient's wife and would introduce herself and explain her role but that she need not lead the discussion unless that was the wish of the team members. They asked her to lead the discussion.

The primary nurse then invited Mrs. Davidoff to join this smaller team. The mediator introduced herself and explained her role. "Sometimes when members of the care team and members of the family disagree about a plan of care," she said, "I am invited to join the discussion. My role is not to make the decision but rather to explore the various options—first with the care team, and later with the team and the family—to see whether all can reach a consensus about the best care plan for the patient. I am sort of a mediator but I am an employee of the hospital. I have spoken with the care team and they seem to think that your husband is dying."

"You mean like in a year or six months?" Mrs. Davidoff asked.

"No," the mediator answered, "maybe even today. They have not been able to remove the infection, which continues to spread, and they seem to think that there is not much more that they can do. They are also concerned about the fact that your husband told many of them that if he were in a state where he was on machines and where he was not expected to recover he would want to be permitted to die." She went on to explain the team's reasons for wanting to remove Mr. Davidoff from the ventilator and why they recommended a DNR order.

Mrs. Davidoff had no involved family and only a few friends, none of whom came with her to the hospital. Also, she was Jewish and it was the time of Rosh Hashanah, the Jewish New Year, when families often get together and when, by religious tradition, decisions about life and death are logged for the future year. For any person accustomed to this practice, it is a time when being alone would be particularly poignant. Mrs. Davidoff therefore requested the support of a rabbi and soon agreed that her husband would not want to live this way and that a supportive care plan was appropriate.

Bioethics conflicts range in difficulty from simple to extremely complex. This book emphasizes difficult cases to illustrate the range of issues involved in mediating complex disputes. But the majority of bioethics conflicts are similar to Mr. Davidoff's case and fall at the easier end of the spectrum.

In Mr. Davidoff 's case the fragmentation of the care team, the complexity of the prognosis, the disinclination of medical staff to talk about death, and the unrealistic hopes of his wife combined to produce a conflict about the best plan of care. Although cases like this one may raise bioethical issues, the skills that are called into play—helping those most concerned about the patient clarify the medical facts, explore the options, and develop solutions that reflect the patient's values and satisfy the family—are most often those associated with classical mediation. The distinctive character of CEC creates its own process, however, blending ethical principles and mediative skills into something unique. This unique process is the subject of this book.

Managing Conflict in the Contemporary Medical Context

Bioethics is about people: the lives and deaths of individual patients in the context of family, friends, significant others, and care providers, as well as the personalities, history, attitudes, feelings—including fears and a sense of guilt—and commitments of each person involved. In recent years, bioethics disputes have become more common. Both the patients' rights movement and the consumer movement have legitimized the place of the family and the patient in deliberations regarding medical matters. Patients are now considered customers in many hospitals, and aiming to please these consumers is one of the goals of various medical administrators. At the same time, awareness of the potential for conflict has grown as a result of the shifting structure of health care funding and delivery and will only increase as additional systems and measures are generated by the new health care reform. The growth of managed care and the shift from fee-for-service medicine (with its incentives for overtreatment) to capitated arrangements (with their incentives for undertreatment) have fueled growing mistrust among patients and their families, who perceive that the integrity of the care provided may be affected by factors external to the best interests of the patient. This shift has also led to increased tension between doctors and nurses, on the one hand, and, on the other, organizational administrators who seek to improve the profitability of the health care institution by increasing the productivity of health care providers and shortening the time patients spend in acute care institutions. Discharge planning has become, in many institutions, the only role for social workers, as time once available for warm and sympathetic support for families and patients has been squeezed out by demands for targeted careful arrangements for the patient to return home or go to some intermediate health care facility. As a result of these changes—and of the ever-increasing number of medical choices available—CEC has taken on a heightened profile, reflected in the developing professionalism of the field, the growth of graduate school programs, the increase in the number and quality of scholarly publications and academic programs that prepare professionals for the tasks of clinical bioethics, and the impact of national organizations.

Mediation

Mediation has long been used to resolve disputes. It is a private, voluntary, informal process in which an impartial third person facilitates a negotiation between people in conflict and helps them find solutions that meet their interests and needs. The current alternative dispute resolution movement began in the late 1960s and early 1970s with impetus from two very different sources. In many areas community action groups turned to mediation as a way to draw on local people and local values to resolve conflicts. The focus was on shaping outcomes that met community interests and that provided a higher-quality outcome than was likely to result from a formal process. At about the same time, courts began to look to mediation as a docket management tool, focusing on the opportunity for a more efficient and more economical resolution of cases rather than on ways in which mediation could enhance the quality of the resolution. Today mediators are routinely consulted in employment cases, special education cases, and civil cases ranging from the most complex to those in small-claims court. They are called on to help resolve family disputes (divorce, custody and visitation, parent-child, and estate cases), consumer disputes, environmental disputes, and labor-management disputes, as well as disputes within institutions as diverse as junior and senior high schools and the U.S. Postal Service. On the international level, mediators have been called on to help restore peace or avoid violent conflict.

The mediator works with the parties, helping them identify their goals and priorities, generate and explore options, and exchange information that may be necessary for formulating a solution. Unlike a judge or arbitrator, the mediator is not interested in acquiring information in order to determine what happened and who is to blame, nor does a mediator decide who is right and who is wrong or impose solutions on the parties. In mediation the historical facts are important only insofar as they help the mediator and the parties understand how each party experienced the event that brought them to mediation. The mediator is interested in learning each party's view of what happened in order to better understand the issues that should be addressed, not to determine whose version of the facts is correct. Another way to conceptualize the difference between mediation and adjudication is to think of mediation as a process that allows the discovery of the version or interpretation of reality that can accommodate the coinciding and conflicting interests and needs of the participating parties.

Mediation is based on three core principles: party autonomy, informed decision making, and confidentiality. Mediators are optimists. They believe most people enmeshed in a conflict have the ability, given the proper setting and access to necessary information, to consider options and select resolutions that meet their needs.

Confidentiality allows the parties to speak freely, without fear that what they say during the mediation will have repercussions in a subsequent proceeding. In the health care context, however, confidentiality is limited. The health care team shares all medically necessary information (see Chapter 2).

Introducing a mediator into a dispute does not change the fact that the participants are essentially involved in a negotiation process. A large part of the mediator's value lies in serving as a guide and coach, helping the disputants move from position-based to interest-based negotiation, encouraging them to discover solutions in which value is not left on the table and each realizes as many of his or her goals as possible, focusing the parties on interests, discovering differences in preferences, and helping them generate options.

Mediation in Health Care Settings

In the hospital setting, where health care providers, faced with intense demands on their time, are called on to explain complex information and deliver bad news to physically and emotionally vulnerable patients and their families, and where large numbers of physicians, nurses, and other providers interact with one another and with the patient, it is not surprising that communication breaks down and disputes arise. Mediation is now used in a variety of medical settings to deal with disputes between residents and staff in nursing homes, disputes over Medicare reimbursement, and quality-of-care complaints involving Medicare and Medicaid, and to resolve medical malpractice claims (Hyman et al. 2010; Hyman and Schechter 2006) and bioethics disputes, most notably by Montefiore Medical Center in its pioneering program. Mediation tools are also being used to aid in disclosure of adverse medical events (Boothman et al. 2009; Liebman and Hyman 2004; Shapiro 2008). Bioethics mediation combines the clinical substance and perspective of clinical ethics consultation with the tools of the mediation process, using the techniques of mediation and dispute resolution in order to

- identify the parties to the conflict (although disagreements between family and care providers are common, most conflicts have more than two sides);
- understand the stated (presented) and latent interests of the participants;
- level the playing field to minimize disparities of power, knowledge, skill, and experience (to the degree possible) that separate medical professional, patient, and family;
- help the parties define their interests;
- help maximize options for a resolution of the conflict;
- search for common ground or areas of consensus;
- ensure that the consensus can be justified as a principled resolution, compatible with the principles of bioethics and the legal rights of patients and families;
- craft a chart note that makes the consensus accessible to all members of the medical team on all shifts and explains the bioethics issues at stake;

- track implementation of the agreement; and
- conduct follow-up.

Bioethics mediation in the acute care setting can serve many ends. It may, under certain circumstances, enhance the autonomy of the patient, support the shared values of patient and family, or make clear and strengthen the agreed-upon principles of health care provision. Sometimes it results in the implementation of a commonly shared plan. Whatever the end result, the fundamental goal of mediating bioethics disputes is to maximize the likelihood that a principled resolution will be reached in a way that is comfortable for all parties.

A key component of bioethics mediation is the neutral turf created by the presence of a person who is not a member of the health care team and who has not participated in the interventions that have gone awry or the discussions that have broken down. Unlike the classical mediator, who is assumed to be impartial and connected to neither party, the bioethics mediator will likely be an employee of the health care institution that is the site of the dispute. Nonetheless, the bioethics mediator brings a distinct set of concerns and skills to the meetings with providers, patients, and family and must be impartial to the situation at hand.

One important reason for a bioethics mediation is to level the playing field by giving patients and families opportunities to be heard. Frequently, in the context of modern medical facilities, patients' or their family's voices are muted, if not lost, and their ability to vindicate the patient's interests is overpowered. The power imbalance in a hospital setting comes from many sources: the greater knowledge and expertise of the treatment team compared to that of most patients, the highly technical and unfamiliar physical setting, and the imperfectly aligned interests of the patient and the treatment team members.

The physical and emotional stress of serious illness also contributes to an uneven playing field. Patients in hospitals are often very sick; cognition, understanding, and judgment are all affected by illness. Some patients regress when ill and become dependent. Others simply withdraw. Also, families are under moderate to extraordinary stress depending on the health status of the patient and on the trajectory of illness—whether the patient is improving or deteriorating. A family's ability to cope with hard decisions depends on long-established patterns. Families with a tradition of pulling together and supporting each other do better than families with histories of discord. Dysfunctional families rarely improve under stress.

Families under stress are also at a disadvantage in medical settings because they have a bad collective reputation among health care professionals (Dubler 1999; esp. Powell 1999). They are regarded as disruptive, hard to manage, and at odds with staff, although there are almost no hard data to support these opinions or prejudices.

Often families feel that no one has really listened to them or taken their wishes and concerns into consideration. They may not believe that they are viewed as an active and integral part of the decision-making process by the medical staff. Sometimes the very fact that they are able to express themselves in an environment where they feel their views are respected can be more meaningful than reaching the

solution they had first advocated. If families feel they have been heard, they may be more open when listening to the concerns of the medical staff and more willing to work with them to find the most satisfactory treatment options for the patient.

One of the greatest advantages of using the mediation process in bioethics disputes is that the process is flexible. The general structure of mediation can be adapted and altered to fit the needs of the participants. But the starting point is always the same: respect for the patient, the family, and the care providers and an impartial stance regarding what the outcome should be in any particular case.

In bioethics mediation, the process is a key part of the product. Opening up the decision for scrutiny by a larger, medically sophisticated group and to the input of interested parties who have relevant information and relevant value considerations is of itself a step ahead in the ethical process. It is much harder to take any action that skirts ethical norms when many people are alerted to the problem and are watching the outcome. In this sense, bioethics mediation is of value because it permits a problem to be characterized and analyzed by a greater number of trained professionals, thereby collecting experience and facilitating multidisciplinary discussion. This process also makes it less likely that the bioethics consultant will be co-opted by the more powerful players in the medical center. Clinical ethics consultation, when effected through the process of mediation, is collaborative, open, and transparent. The bias of this book is that collaborative processes are, by their very nature, superior to secret, hidden, authoritarian, and private decision making that emerges only as a progress note or a consultant script in the medical chart. The openness inherent in mediation is one of its chief strengths.

Principled Resolutions

A principled resolution is a plan that falls within clearly accepted ethical principles, legal stipulations, and moral rules defined by ethical discourse, legislatures, and courts and that facilitates a clear plan for future intervention. For a principled resolution to have an impact in the real world of shifting staff, it must be described in a note in the medical chart that explains the logic, describes the ethical dilemma, and details the components of the agreement.

We developed the idea of the principled resolution in 2005 when we were first struggling with the stringent limits imposed by law on medical providers and institutions, contrasted with the powerful decision-making authority permitted individual patients and families in medical situations, in light of the power imbalances that infuse the operations of the modern hospital and medical center. A principled resolution reflected the deep and thorough support in the law and in societal norms for decisions of patients and families, especially when these decisions contest the juggernaut of modern, institutionalized medical care. A principled resolution reflects the strength of a mediative process that incorporates legal norms and ethical conventions and intuitions and uses both of these as support for forging a consensus in a crisis.

A principled resolution defines the boundaries of the acceptable spectrum of

outcomes from which the decision makers may choose. Bioethics conflict is almost always about the "proper" or "appropriate" plan for future care. The parties generally include the attending physician, other members of the health care team, and an advocate for the patient. This advocate can be a family member or friend. Sometimes the patient is alone without family, such as an "unbefriended elderly" (Karp and Wood 2004) patient. But the patient may be a younger, isolated, and perhaps mentally ill person. The reason that the mediation is largely with nonpatient advocates is that capacitated adult patients have the legal right to choose to accept or reject medical alternatives even if their decisions are judged to be wrong by others. Thus bioethics mediation often addresses situations in which the adult patient is alleged to be incapacitated, is clearly incapacitated, or is a minor or otherwise legally compromised.

Identifying Issues, Interests, and Feelings

The mediator must keep in mind, while listening to the parties, that people in conflict are likely to present their stories in the form of threats and generalities (as Margaret Shaw suggested in a mediation training program at Tsinghua University in Beijing in 2000), taking positions about how they want the problem solved and then digging in and defending those positions. Often the positions that parties take do not address all the issues and fall far short of satisfying their interests. Thus, when all the parties have spoken, the mediator provides an initial summary of the

information, reframing it in terms of the issues, interests, and feelings rather than simply repeating parties' positions. The mediator's task is to probe deeply enough to identify the underlying interests of the parties and the issues that must be resolved in order to satisfy those interests.

Parties to disputes often assume that the rules and principles that apply will inexorably lead to a single conclusion. But the parties may possess incomplete information; in addition, the medical facts, especially the prognosis, and an accurate medical and psychosocial history are often difficult to uncover. Thus, for example, a patient's refusal of care may be based on his relative penury, his lack of trust in the provider, or his misunderstanding of the risks and benefits of the proposed intervention. Only knowledge of the context and investigation of the actual circumstances—both the issues and the interests—can produce a fair and just result in an individual case.

Issues are the concrete things—behavior, allocation of resources, or future action—that must be dealt with in order to solve the problem. *Interests* are the concerns or needs of the parties that are threatened by failure to resolve the issues and that must be satisfied if the solution is to be workable. Interests tend to be substantive, psychological, or procedural. Substantive interests might involve goods, time, money, or other resources. Psychological interests typically involve respect, safety, and face-saving—how parties feel about what they experienced. Procedural interests focus on being heard and feeling a decision was made fairly (Menkel-Meadow 2001).

Once the mediator has identified the issues and interests and summarized them to be sure that nothing has been omitted, he or she then sets the agenda for the discussion by proposing which issues to discuss and in what order. Classic mediation might address, for example, the case of a complaint about noise from the apartment upstairs that escalated into a screaming match the next morning in front of the neighbors; the issues are the sounds coming from the upstairs apartment and the ways the neighbors communicate. The interests of the downstairs neighbor may be getting enough sleep, having quiet when her children are doing their homework, and being treated with respect by her neighbor. The upstairs neighbor's interests might include being able to live as she chooses when in her apartment, having her children able to play without fear of the downstairs neighbor, and also being treated with respect. In bioethics cases, issues are likely to include the number and intensity of interventions and the desire of the family to ensure the comfort of the patient.

How does the mediator decide what to attend to and what to ignore? The mediator is constantly trying to clarify what is important to the participants. People do not always list issues in order of importance; in fact, they often bury the most important information because they feel it is sensitive, they fear it will not be credited, or they do not realize its significance. So if they list four issues that are important to them, the fourth may be the issue to which they give highest priority. The mediator should be aware of this possibility when determining how best to assist the parties. This knowledge may also help the mediator assess what represents useful information.