

# OHIO STATE JOURNAL ON DISPUTE RESOLUTION

VOLUME 23

2007

NUMBER 1

## **Introduction to the Symposium Issue on Alternative Dispute Resolution Strategies in End-of-Life Decisions**

CAROL B. LIEBMAN\*

### I. INTRODUCTION: A STORY

At about 8:30 p.m. on a spring evening approximately twenty-five years ago when I was living in Newton, Massachusetts, our telephone rang. It was the emergency judge on duty that week asking me to go to a nearby suburban hospital to represent a sixty-eight-year-old woman whom I'll call Mrs. P.<sup>1</sup> She had been hospitalized for heart failure and was refusing treatment, saying that she wanted to die with dignity.

Mrs. P and her husband had traveled to Boston from her home, a small town in New York about five hours away, to meet their newest grandchild. When I arrived at the hospital, the judge, her clerk, my client's husband, her ten-day-postpartum daughter, and the hospital attorney had already gathered. I was introduced to them and given a bit of background. I learned that the patient had been treated for congestive heart failure for some period of time before her trip to Boston and that she had also received treatment for psychiatric problems. Soon after her arrival in Boston, she took a turn for the worse and went to the hospital. It turned out she had forgotten to bring her heart medication with her, but did not tell anyone until she became weak and disoriented. Earlier in the day her vital signs had begun to worsen. She was refusing intramuscle injections of medication that had a high likelihood of saving her life and having her up and about in a short time. In addition, the nurses reported that she had been a difficult and demanding patient.

---

\* Clinical Professor, Columbia Law School. Thanks to Brandon Duke for his research assistance.

<sup>1</sup> I rely on memory for the details of this case.

According to the physicians, without treatment she was likely to die within the next twenty-four to forty-eight hours.

I was escorted to the Intensive Care Unit (ICU) and introduced to Mrs. P. She was lying in bed hooked up to various monitors and had had a catheter inserted after a series of bed wettings. She seemed alert but a bit uncomfortable because of the monitor leads and the catheter. I explained who I was, why I was there, and that there would soon be a hearing in front of a judge to decide whether the hospital would be allowed to give her the injections against her will. She reiterated her desire "to die with dignity."

While I was prepared to argue for my client's right to refuse treatment, I confess that it did not make sense to me. I wanted to be sure that she was making an informed decision, and, if truth be told, assumed that with full information she would decide to accept treatment. I asked the physician in charge of her care to meet with the two of us. When he arrived we sat down next to the bed. I asked him to explain to Mrs. P what was going on with her heart and what the injections would do to help her, stopping him to ask for clarification whenever he drifted into medical jargon.

The treatment was simple—injections several times a day would soon have her out of danger and out of the hospital. "And," I asked, "what would her life be like when she got home?" The physician replied that she would be able to participate in normal activities but with limits; for example, walking up a flight of stairs would be difficult and require that she stop and rest several times. Not great, but not so terrible that most people would want to die. Pressing on I asked what my client's prognosis was, expecting that the physician would say there was a good chance she would live for many years. Instead he answered that she might have six months to a year left. Suddenly my client's choice began to make more sense.

Once the physician left, I reviewed the decision to refuse treatment and its consequences—almost certain death within a few days—with my client. She remained adamant that she "want[ed] to die with dignity." I returned to the waiting room where another lawyer, asked by the judge to be available to be appointed guardian ad litem (GAL) for Mrs. P in view of her psychiatric history, had joined the crowd. I told them that Mrs. P was determined to refuse treatment.

We all moved to the ICU. The judge, the clerk, two other lawyers, Mrs. P's daughter and husband, the attending physician, and I formed a circle around Mrs. P's bed and, with curtains drawn to provide a bit of privacy from—or perhaps for—the other ICU patients, the hearing began.

As testimony was taken we all repeatedly stole glances at the various monitors, anxious about the impact of the legal proceeding on Mrs. P. There is no need to go into detail about the testimony. Everyone except my client

## END-OF-LIFE ISSUES SYMPOSIUM INTRODUCTION

argued that she should be ordered to accept life saving treatment. I argued my client's contrary position forcefully, feeling quite certain, whatever the governing legal principles were in theory, that she would lose since the proposed medical intervention was relatively minor and the benefits great. The judge issued a temporary order appointing a guardian ad litem with power to consent to medical care. The GAL then consented to Mrs. P's receiving the injections. A full hearing on the merits was scheduled for early the following week. (It never happened.)

The hearing in the ICU took place late on a Thursday evening. I went to visit Mrs. P in the hospital on Saturday morning. She was out of the ICU, her new grandchild was lying on the bed next to her, she was quite happy to be alive, and she was willing to take her medications.

When I got home from the hearing early Friday morning, it took me some time to fall asleep. At 3:00 a.m. I awakened with a start, realizing for the first time how each of the players in this drama had failed Mrs. P. If we had been better communicators, or if a bioethics mediator had been called in instead of the hospital lawyer and then a judge, the stress of the hearing on Mrs. P, her family, and the health care professionals; Mrs. P's loss of autonomy; and the expenditure of judicial, medical, and legal resources could have been avoided. All of the players—including me—had brought their own values to Mrs. P's bedside, made assumptions, and argued for or against Mrs. P's no-injection position based on those values and assumptions. We failed to ask the sorts of questions that would be instinctive for a mediator—questions that would have explored what Mrs. P's true interests were and what she was trying to communicate when she took the no-injection position.

When I awakened in the middle of the night, what I suddenly realized (and confirmed during that hospital visit on Saturday) was that when Mrs. P said she wanted to die with dignity, she did not mean that she wanted to die. What she was trying to say was that she hated having a catheter—something imposed on her for the convenience of the staff which had tired of the frequent need to change the bedding—and that the leads to the monitors were irritating her skin, making her itchy and miserable.

Mrs. P's case was relatively simple compared to most end-of-life controversies, but it is a dramatic example of the way that poor communication can first produce conflict in the health care setting and then lead to escalation of that conflict.

## II. END-OF-LIFE ISSUES

In this essay I will first set out some cases that raise the kinds of issues that bioethicists wrestle with daily. Then I will describe a model of bioethics

mediation, developed by Nancy Dubler<sup>2</sup> and her colleagues in the bioethics service at Montefiore Medical Center, which promotes a kind of communication most likely to resolve end-of-life and other bioethics disputes.<sup>3</sup>

Mrs. P's case shows how poor communication can turn simple differences into a big and expensive conflict. Three other cases, two from recent news stories and one from my own practice, show the sorts of conflicts that arise at end-of-life.

At the end of December 2006, newspapers reported about the struggle of Italian poet Piergiorgio Welby to end his life.<sup>4</sup> Mr. Welby had suffered from muscular dystrophy for forty years and had been ventilator-dependent for nine years. He finally reached the point where he described continuing to live as "torture."<sup>5</sup> He was fully alert and wanted to end treatment; that is, he wanted to have his ventilator removed with death certain to follow. Eighty-nine days after Welby asked the President of Italy to allow him to die legally, a physician put him under sedation and removed the respirator, allowing him to die and provoking calls for the physician's arrest from some politicians.<sup>6</sup>

---

<sup>2</sup> Director of the Division of Bioethics, Department of Epidemiology and Population Health, Montefiore Medical Center and Professor of Epidemiology and Population Health at the Albert Einstein College of Medicine.

<sup>3</sup> In addition, for the past four years Chris Stern Hyman and I have been doing research on the ways that mediation skills can aid patient-physician communication after adverse medical events, that is, preventable harm resulting from error and system failure or harm as a bad outcome of appropriate care. Our focus has been on ways to enhance communication that can lead to fair, prompt resolution of legitimate claims; communication which can help heal the injured patient-physician relationship; and, in some ways most important, communication that can lead to enhanced patient safety. In fact, one of our key recommendations is that hospitals develop a consult team of communication experts who can help plan for, and, where appropriate, facilitate the sorts of difficult conversations that should—but too rarely do—follow adverse events. It has been interesting for me to see that in both of these efforts, figuring out ways to improve communication is key.

<sup>4</sup> See, e.g., Ian Fisher, *A Poet Crusades for the Right to Die His Way*, N.Y. TIMES, Dec. 20, 2006, at A4; Ian Fisher, *Italian Poet Dies with Help from a Doctor*, N.Y. TIMES, Dec. 22, 2006, at A3 [hereinafter Fisher, *Italian Poet Dies*]; Maria Sanminiatielli, *Italian Law Tangles Right-to-Die Case*, CHI. TRIB., Dec. 22, 2006, § 1 at 18; *World Briefing Europe: Italy: Church Funeral Denied in Right-to-Die Case*, N.Y. TIMES, Dec. 23, 2006, at A13; *World Briefing Europe: Italy: Setback for Man Who Wants Right to Die*, N.Y. TIMES, Dec. 21, 2006, at A16.

<sup>5</sup> Fisher, *Italian Poet Dies*, supra note 4, at A3.

<sup>6</sup> *Id.*

## END-OF-LIFE ISSUES SYMPOSIUM INTRODUCTION

A second example comes from my own practice.<sup>7</sup> A forty-five-year-old man, Mr. R, had lived in a persistent vegetative state for ten years after falling on his way home one evening and striking his head. While he suffered severe brain damage, he was able to breathe on his own and was being fed through a tube. After ten years his wife wanted to end the tube feeding and allow him to die, saying that he was never going to recover and that as long as he lived she and her children would be trapped in a terrible limbo, unable to get on with their lives or live fully. Some of the staff of the skilled nursing facility, which had provided excellent care for Mr. R over the years, agreed with his wife that it was time to end treatment. Others were adamantly opposed. The facility administration insisted that Mrs. R obtain a court order allowing her to end the feeding.

The third case occurred in Boston at the end of 2006. Cho Fook Cheng, a seventy-two-year-old Chinese-American, was declared brain-dead following cardiac arrest.<sup>8</sup> His family wanted to continue treatment because, according to their religion, while the heart continues to beat, one's spirit lives.<sup>9</sup> The health care professionals thought that further treatment was futile and wanted to end medications and remove Mr. Cheng from the ventilator. The dispute ended up in court.<sup>10</sup> Ultimately the family agreed to end his medications which resulted in his heart's stopping.<sup>11</sup>

In two of these examples, the patients, Mrs. P and Mr. Welby, were conscious and appeared legally competent in the sense that they were aware of the nature of their proposed action and its consequences. One of them had a history of mental illness, one of them did not. Experts could argue that for each of them decisionmaking ability was impaired by physical disease. How should we measure competence in these situations?

Both Mrs. P and Mr. Welby were refusing treatment that could prolong life. In one case the treatment was relatively non-invasive: a few injections and then oral medication leading to a fairly decent quality of life for at least the next six months to a year. In the other case, the treatment was harsh, the quality of life described as brutal. Is the quality of life a relevant criterion? Does it matter whether the terrible quality is short-term or long-term? And if so, who decides what the acceptable length of suffering is?

---

<sup>7</sup> Again I rely on memory for the facts of this case.

<sup>8</sup> Megan Tench, *After Buddhist Dies, Legal Battle Continues: Kin, Hospital Split on When Death Occurs*, BOSTON GLOBE, Dec. 3, 2006, at A1.

<sup>9</sup> *Id.*

<sup>10</sup> *Id.*

<sup>11</sup> *Id.*

Both Mr. R and Mr. Cheng were unconscious. Neither of them had an advanced directive. Mr. R still had some minimal brain function, but given the current state of medical knowledge, no hope of recovery. He could have continued in a persistent vegetative state for many more years. Mr. R's family said "enough," while care-givers had mixed views of the propriety of his wife's request. Mr. Cheng was brain dead in a jurisdiction which recognized brain death as being "legally" dead. There was no hope of recovery and his body could have been expected to deteriorate in the days ahead.

Nonetheless, Mr. Cheng's family, driven by their Buddhist faith, was saying "carry on with treatment," which the physicians said was futile and waste of expensive resources. Should either Mr. R or Mr. Cheng's family have the right to make those choices? What criteria should we use to determine who can decide and what they can decide? When do we honor the religious and cultural beliefs of patients and families? How do we balance scientific knowledge and the teachings of faith?

Note that in three of the four cases—Mr. R, Mr. Cheng, and Mr. Welby—the families were in agreement about what should happen. Decisionmaking becomes much more difficult if family members are in conflict about whether to continue or end treatment or about what sorts of treatment should be provided. From whom should the health care providers accept directions in the absence of a living will or advanced directive and in the face of conflict among family members?

Or imagine other scenarios; for example, what should be done in a situation in which an elderly man agreed to risky heart surgery as his only hope for getting better but made it clear—repeatedly—that, should the surgery fail, he did not want heroic measures taken to keep him alive?<sup>12</sup> What if the surgery failed and his wife was insisting, contrary to his wishes, that everything possible be done to treat him? What if the patient is refusing care but is not capable of making that decision because of emotional or cognitive impairments? What if the physician is insisting on care that the family claims the patient would refuse if the patient were capable? And finally, who pays for expensive choices to continue treatment?

It is important to have default rules to guide physicians, patients, families, and health care facilities so that these wrenching decisions are based on principle rather than emotion or fear of litigation. As Professors Pope and Waldman argue, the lack of clear default rules can be a source of

---

<sup>12</sup> NANCY N. DUBLER & CAROL B. LIEBMAN, *BIOETHICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS* 3–5 (2004).

## END-OF-LIFE ISSUES SYMPOSIUM INTRODUCTION

conflict.<sup>13</sup> But default rules are the product of the legislative process, a process filled with compromise and consensus building with the consequence being that the consensus laws may not be in accord with the values and beliefs of an individual family, patient, or health care professional. My purpose in this essay, however, is not to analyze existing default rules or to propose alternatives. Other articles in this issue will do that. Instead, I argue that we need to be as concerned about the process as about the default rules and that a well-designed, communication-centered bioethics mediation process run by trained mediators will, in the vast majority of cases, provide a humane, caring, and principled resolution of these awesome end-of-life conflicts.

I do want to flag one issue for the default rule drafters. We know, in general, that only 5%–20% of patients have some sort of advanced directive.<sup>14</sup> Patients are often asked to sign advanced directives as part of the hospital admissions process (which, given most patients' high anxiety as they begin a hospitalization, may be the worst time to raise that issue). A few studies have found that the advanced directive signature rate can be increased with intense effort.<sup>15</sup> The generally low rates suggest that policymakers and legislatures are not doing a good job of writing laws about end-of-life decisionmaking that fit actual human behavior.

### III. MEDIATION MODEL

For the past thirteen years I have had the good fortune of working with Nancy Dubler, a bioethicist at Montefiore Hospital in the Bronx,<sup>16</sup> helping her develop a model of mediation to deal with bioethics conflicts. This is the label given to the kinds of cases I have discussed above involving end-of-life decisions, as well as to conflicts about treatment choices and resource

---

<sup>13</sup> Thaddeus M. Pope & Ellen A. Waldman, *Mediation at the End of Life: Getting Beyond the Limits of the Talking Cure*, 23 OHIO ST. J. ON DISP. RESOL. 143 (2007).

<sup>14</sup> Kristi L. Kirschner, *When Written Advance Directives Are Not Enough*, 21 CLINICS GERIATRIC MED. 193, 196 (2005); Louis J. Medvene et al., *Promoting Signing of Advance Directives in Faith Communities*, 18 J. GEN. INTERNAL MED. 914, 914 (2003); Steven H. Miles et al., *Advance End-of-Life Treatment Planning: A Research Review*, 156 ARCHIVES INTERNAL MED. 1062, 1063 (1996).

<sup>15</sup> See, e.g., Bernard J. Hammes & Brenda L. Rooney, *Death and End-of-Life Planning in One Midwestern Community*, 158 ARCHIVES INTERNAL MED. 383, 388–89 (1998); Medvene et al., *supra* note 14, at 917 (stating that "[p]rior to participation 83 (33%) had a directive; after completion 140 (56%) had a directive").

<sup>16</sup> See *supra* note 2.

allocation.<sup>17</sup> What Dubler has found is that conflicts get tagged as bioethics problems but are often, in the end, simply run-of-the-mill conflicts that result from communications breakdowns.<sup>18</sup>

The modern hospital and health care system is a perfect incubator for miscommunication and conflict. Physicians and other health care professionals work under impossible time pressures, often with too little sleep. They must explain complex information and deliver bad news to physically and emotionally vulnerable patients and their families. The care team is fragmented across shifts and specialties. Many physicians, nurses, and other providers are involved in the care of each patient and the numbers multiply in complicated cases. Multiple family members come and go from the bedside with each hearing from different members of the health care team and often hearing only part of the medical facts.<sup>19</sup>

The communication problems are heightened by the fact that many patients and their families distrust hospitals and physicians. They read news accounts about horrendous treatment errors or about the financial squeeze put on hospitals by insurers and government programs. In addition, there is a sense "on the street" (supported by research)<sup>20</sup> that people of color receive a lower quality of medical care. Finally, patients and their families have often been subjected by their physicians and the health care system to "micro insults" which add to their mistrust. Micro insults occur when, time after time, patients are made to wait for two or three hours to see a physician with no apology and no explanation; when hospitalized patients have to wait unreasonable (or at least unkind) lengths of time for help with a bed pan;

---

<sup>17</sup> Dubler's initial work linking bioethics consultants with mediation was done with Leonard Marcus, at the time Director of the Program for Health Care Negotiation and Conflict Resolution at the Harvard School of Public Health and David Matz, partner in The Mediation Group and Director of the Graduate Program in Dispute Resolution at the University of Massachusetts in Boston. For the book which grew out of that collaboration, see NANCY N. DUBLER & LEONARD J. MARCUS, *MEDIATING BIOETHICAL DISPUTES* (1994). For more on the history of the development of the mediation model discussed in this article, see DUBLER & LIEBMAN, *supra* note 12, at xvi–xvii.

<sup>18</sup> See generally DUBLER & LIEBMAN, *supra* note 12, at 69.

<sup>19</sup> A medical fact is "an interpretation of data at a particular moment that considers the patient in light of the overall history of the illness." DUBLER & LIEBMAN, *supra* note 12, at 50–51.

<sup>20</sup> See, e.g., Arnold M. Epstein & John Z. Ayanian, Editorial, *Racial Disparities in Medical Care*, 344 *NEW ENG. J. MED.* 1471, 1471 (2001); Kevin Fiscella et al., *Inequality in Quality: Addressing Socioeconomic, Racial, and Ethnic Disparities in Health Care*, 283 *JAMA* 2579, 2579–80 (2000).



## END-OF-LIFE ISSUES SYMPOSIUM INTRODUCTION

when it requires a twenty-four hour battle to obtain a palliative care consult; or when a patient is told "you failed your chemo."<sup>21</sup> These sorts of micro insults prime patients and their families to be suspicious and distrustful when things go wrong or when it is time to make the big decisions about end-of-life.

There are other reasons why communication in health care settings is so difficult. Modern medicine is filled with uncertainty and complexity; few physicians receive training in communication; and many members of the medical team are disinclined to talk about death, choosing instead to speak in euphemisms. Finally, patients and families often have unrealistic, but perhaps therapeutic, hopes for a good outcome.

Our mediation model provides a patient- and family-centered vehicle for reaching a caring, principled resolution of the conflicts which arise when patients, family members, and health care professionals face choices at end-of-life. By "principled resolution" we mean "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."<sup>22</sup> When bioethicists refer to ethical principles, they are talking about:

[A] set of ethical principles that support the therapeutic relationship and give rise to physician and caregiver obligations. These include patient autonomy (supporting and facilitating the capable patient's exercise of self-determination); beneficence (promoting the patient's best interest and well-being and protecting the patient from harm); nonmaleficence (avoiding doing harm to the patient); and distributive justice (allocating fairly the benefits and burdens related to health care delivery).<sup>23</sup>

Another characteristic of our model is that it provides a forum in which physicians, nurses, and social workers can share with family members<sup>24</sup> the awesome burden of deciding to end care. It is a model that recognizes that when addressing end-of-life cases there are two kinds of pain that need to be treated: the physical pain of the patient and the emotional pain of family members.

---

<sup>21</sup> Report to the Author by Marc Fleisher, experienced mediator, trainer, and partner in the Medical Mediation Group, LLC.

<sup>22</sup> DUBLER & LIEBMAN, *supra* note 12, at 11.

<sup>23</sup> *Id.* at 6.

<sup>24</sup> In this essay I often refer to "patients and family members." In fact, in most, though not all, bioethics conflicts the patient is unconscious and unable to participate in the discussion.

The goal of a bioethics mediation is to agree on a care plan with which families, physicians, nurses, and other health care professionals are comfortable. The process is usually run by a team of mediators, especially if there is a large number of participants. The mediators are bioethicists who have received extensive mediation training. Bioethics mediation is not a role for amateurs. Given the complexity of the issues and the often life-and-death stakes, the mediator needs to be well grounded in bioethics theory and practice and have participated in extensive, experiential mediation skills training.

The role of the bioethics mediator has much in common with that of "classical mediators."<sup>25</sup> She empowers participants to engage in the discussion and decisionmaking; works to level the playing field for families faced with disparities of power, knowledge, and emotional reserves; facilitates the exchange of information within the health care team and between the team and the family; and helps all participants identify and evaluate options. She also needs to be sensitive to and work with cultural and religious values.

The tasks of empowering patients and families and leveling the playing field are especially challenging in bioethics conflicts.<sup>26</sup> Patients and families are often overwhelmed by the hospital setting. They must deal with a shifting array of medical experts and with complex and uncertain medical information in a setting in which they have little or no control over the basics of daily life and where everyone seems rushed. If the prognosis is grim, patients and family members may be sad, frightened, or angry. The illness itself may interfere with the patient's perceptions and judgment. As a result, patients and families may feel they are powerless and silenced and that their values, concerns, and interests are being ignored. In mediation, information can be shared with and explained to patients and families, and decisionmaking can be slowed<sup>27</sup> so that the patient and family members can be full participants whose values and concerns are heard and respected.

---

<sup>25</sup> For a discussion of ways bioethics and classical mediations differ, see DUBLER & LIEBMAN, *supra* note 12, at 21–31.

<sup>26</sup> For more on the role of bioethics mediation in leveling the playing field, see *id.* at 11–12, 25–26.

<sup>27</sup> While decisionmaking is slowed in bioethics mediations, it is important to be aware that time pressures are ever present in the hospital setting, that it can be difficult to get all the relevant parties in one room at the same time, and that it can be just as difficult to keep them there as their beepers go off and they respond to urgent needs of their patients.

## END-OF-LIFE ISSUES SYMPOSIUM INTRODUCTION

The bioethics mediator facilitates exchange of information so that patients and family members learn exactly what is happening to them or to their loved ones. In addition, hospital leaders and health care providers may learn about miscommunicated or ignored information which contributed to the dispute. Many times the conflicts among patients, family members, and medical staff develop because of fragmented communication. Members of the medical team may have differing views of the medical issues and communicate those disparate views to the patient or to family members without working through their differences within the team.

When this sort of communication breakdown occurs, it is neither surprising that various family members have differing views of their loved one's condition and of the likely prognosis, nor surprising that these differing views lead to conflict within the family or between the family and the care providers regarding how to manage the life or the death of the patient.

### IV. THE BIOETHICS MEDIATION PROCESS<sup>28</sup>

In our model, the mediation process begins when the bioethicist is contacted about the case. The contact can come from a physician, nurse, social worker, any other member of the care team, or, less frequently, from a patient or family member. Once the bioethicist is contacted, she identifies the parties to the conflict (most bioethics conflicts have more than two sides) and may look at the patient's chart. She typically convenes a meeting of the health care team (which, in a teaching hospital, may include attending physicians, house staff, fellows, residents, medical students, nurses, social workers, and consultants) to discuss the patient's medical history, current status, likely prognosis, and any competing recommendations from team members about treatment.

In this meeting, the bioethics mediator's goal is to identify and attempt to resolve conflicts among the members of the medical team, learn about the relationship of the staff to the patient and the family, and hear about family dynamics which may be having an impact on (or even be the source of) the conflict. At times, simply bringing together all the members of the care team to hear each others' perspectives and thrash out their differences can lead to an agreement on both the likely course of the illness and on recommendations that can then be communicated to the patient or family. When disagreements among members of the medical team are eliminated (and the reasons for the previous differences and the new unified view explained), the conflict with the family may also disappear. When the team

---

<sup>28</sup> See DUBLER & LIEBMAN, *supra* note 12, at 45-83.

members continue to differ, the bioethics mediator helps them decide how to present their differences to the patient or family. The final task in the medical team meeting is to decide who should meet with the family. It is important to include those with expertise, information, and good relationships with the patient and family without having the group grow so large that the family is overwhelmed with white coats. We think of these initial activities as part of the assessment and preparation stage.<sup>29</sup> The bioethics mediator is likely, at some point during the assessment and preparation stage, to stop by the patient's bedside to introduce herself and to explain that she will be having a preliminary meeting with the medical team and will then be meeting with the patient or family.

The "formal" bioethics mediation discussion begins in much the same way as classical mediation. The bioethics mediator or, if the case is medically complex or involves large numbers of participants, the co-mediators explain their roles, what will happen during the mediation, and the goals of the process. She also makes sure that any participants who have not met do so and that everyone is clear about the roles of all the others.

Then, unlike classical mediation, the discussion begins with one of the physicians stating the medical facts.<sup>30</sup> In our model, a presentation of medical facts involves providing data about the current status of the patient, not any single physician or family member's interpretation of the facts or prediction of the likely prognosis. There are several reasons for beginning with the medical facts. The first is to ensure that all participants are working from a common set of data, even though there may be differing views about the significance of the medical facts. Second, starting with the medical facts avoids having families embarrassed by committing to a position based on erroneous understanding and their becoming entrenched in a view that is difficult to alter without losing face. It is important that the mediator limit the discussion during the presentation of medical facts, intervening to avoid allowing the presenter to mix recommendations and predictions into the presentation. At times the bioethics mediator may need explicitly to instruct the speaker to defer that part of the discussion. After the presentation of the medical facts, the mediator needs to make a judgment about who should speak next. At times it will be the family's turn. In other situations the mediator may want to involve other members of the care team to add

---

<sup>29</sup> DUBLER & LIEBMAN, *supra* note 12, at 49–58.

<sup>30</sup> For a discussion of what constitutes a medical fact, see *id.* at 50–51. See also *supra* note 19 and accompanying text.

## END-OF-LIFE ISSUES SYMPOSIUM INTRODUCTION

information, especially information that the mediator thinks will be helpful for the patient or family.

When the patient or the family speaks, it is important that the mediator ensures that their values, interests, and perspectives are heard and honored. She does this by frequent summaries<sup>31</sup> and by open-ended questions.<sup>32</sup> As in classical mediation, the bioethics mediator listens for underlying interests, tries to separate the conflict into manageable and discussable pieces, and helps the parties generate and evaluate options. The mediator and the mediation process provide support for the patient and family members, ensuring that their expertise about their own or, if the patient is not present, their loved one's preferences and needs are respected. When the patient is not able to participate in the mediation, the mediator will ask the family members to introduce their loved one, asking them to tell the other participants what their loved one was like before becoming ill. When family members disagree about treatment decisions, the mediator will try to advance the process in a way that minimizes damage to their relationships.<sup>33</sup>

Ultimately the bioethics mediator will need to ensure that any consensus agreement can be justified as a principled resolution, compatible with bioethics norms and the legal rights of patients and families. Once an agreement is reached, the resolution is recorded in the patient's chart so that all of those involved in the patient's care, not just those participating in the bioethics mediation, are aware of the outcome.<sup>34</sup>

As discussed below, the norm-enforcing responsibility of the bioethics mediator to ensure that any agreement is in accord with bioethical principles and legal requirements is one of the ways that bioethics mediation differs from classical mediation. Other differences include:

- The bioethics mediator is generally employed by the hospital.
- The bioethics mediator and members of treatment team are repeat players.

---

<sup>31</sup> For more on summarizing in mediation, see *id.* at 87–89.

<sup>32</sup> For a discussion of forms of questions mediators should ask and other purposes of questioning, see *id.* at 90–91.

<sup>33</sup> Nancy N. Dubler, Montefiore Med. Ctr. & Albert Einstein Coll. of Med., *Mediation and Health Care: Resolving Bioethics and Other Disputes*, Lecture Before Saltman Center for Conflict Resolution at the William S. Boyd School of Law at University of Nevada Las Vegas (Nov. 15, 2006).

<sup>34</sup> DUBLER & LIEBMAN, *supra* note 12, at 41, 77–80.

- The bioethics mediator provides information, enforces norms, and ensures that resolutions fall within medical "best practice" guidelines.
- Deciding not to reach a resolution is not an option.
- The playing field is usually uneven for patients and their families.
- Confidentiality is limited to information not relevant to patient care.
- Time is of the essence.
- Bioethics mediations involve life-and-death issues.
- Facts play a different role.
- The person with the greatest stake in the dispute, the patient, is often not at the table.
- There may be a sequence of separate, prior meetings in addition to the group mediation.
- Bioethics mediations are almost always multiparty events.
- The parties usually do not sign an agreement to mediate.
- The physical setting may not be in the mediator's control.
- Bioethics mediators are often involved in following up on the implementation of the agreement.
- All participants in a bioethics mediation have a common interest in the wellbeing of the patient.<sup>35</sup>

Each of these differences is discussed in our book. In this essay, I want to highlight several of them.

The bioethics mediator is a norm-enforcer charged with ensuring that the care options are based on respect for the interests and rights of the patients and families and in accord with ethical and legal principles. She may need to educate both health care professionals and family members about ethical norms (an unusual role for mediators—at least in theory), and she may have a role monitoring implementation of any agreement. She may also be responsible for bringing issues with institutional policy implications to the attention of the hospital's leadership. This explicit educating and norm-enforcing role of the bioethics mediator differs from the way that many classical mediators would describe their roles. Many mediators would thus question how educating and enforcing norms squares with the principles of neutrality and impartiality. While the subject of the mediator as norm-

---

<sup>35</sup> *Id.* at 21–22.

## END-OF-LIFE ISSUES SYMPOSIUM INTRODUCTION

enforcer is beyond the scope of this essay, it is worth noting that in many settings mediators have a norm-enforcing role; for example, they must report child abuse or, in court-annexed custody and visitation mediations, be concerned about the best interest of the child.

Many mediators wonder whether outsiders, rather than hospital employees, could perform as bioethics mediators. This was my view in the first years of my work with Nancy Dubler. But as my understanding of the complex culture of modern hospitals grew, I came to agree that at this stage in the development of the field, insiders—the limits on their neutrality notwithstanding—are more likely to be able to advance the use of mediation. Hospitals are complex, sometimes Byzantine institutions which in many ways function as a closed society whose citizens are unlikely to trust outsiders. In addition, bioethics conflicts often arise in the moment and require immediate attention with no time to find an outside mediator with free time.<sup>36</sup>

### V. WHEN BIOETHICS MEDIATION IS NOT THE ANSWER

As in other types of conflict, mediation is not always the solution to bioethics conflicts.<sup>37</sup> As in classical mediations, it may turn out that the patient or designated decisionmaker lacks the mental capacity to make choices. Sometimes the patient or family members may need the health care team to take on a large part of the decisionmaking burden because they lack "the emotional strength to take responsibility for facing difficult facts or making hard choices."<sup>38</sup> In addition, the family history may have produced a set of dysfunctional dynamics that make it impossible for them to work together toward agreement.<sup>39</sup> On some sad occasions such as the Terri Schiavo case,<sup>40</sup> outsiders with their own agendas have a stake in escalating the conflict and attracting publicity for their views. In many cases, even when the bioethics mediation fails, participation in the process may have

---

<sup>36</sup> I am aware of one instance in which the chair of the Bioethics Committee at a New York City hospital brought in a team of outside mediators to mediate a complex dispute. Conversation with Chris Stern Hyman, July 2002.

<sup>37</sup> DUBLER & LIEBMAN, *supra* note 12, at 12–13.

<sup>38</sup> *Id.* at 13.

<sup>39</sup> For an example of the difficulties involved in a case where bad family dynamics existed, see *id.* at 109–15.

<sup>40</sup> See generally Joan Didion, *The Case of Theresa Schiavo*, N.Y. REV. BOOKS, June 9, 2005, available at <http://www.nybooks.com/articles/18050> (last visited Sept. 29, 2007); Sheryl G. Stolberg, *The Dangers of Political Theater*, N.Y. TIMES, Mar. 27, 2005, at 43.

helped the parties gain a better understanding of each other's perspectives and of available treatment options, as well as greater clarity about their own goals and values.<sup>41</sup>

## VI. CONCLUSION

As we said in our book, "[a]s long as disparate values exist within families and between patients, families, and the health care system, conflicts are inevitable. And if conflicts are inevitable, strategies for managing them are required—both morally and practically."<sup>42</sup> The great value of mediation is that it is a process that can help the patient and, when involved, the family to amplify their values and interests in the face of the complex and intimidating health care system; honor the professional values and knowledge of those who give care; and share the burden of making complicated and awesome choices.

---

<sup>41</sup> DUBLER & LIEBMAN, *supra* note 12, at 13.

<sup>42</sup> *Id.* at 8.