
■ CHAPTER 8 ■

When Families Disagree: Family Conflict and Decisions

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*A society will be judged on how it treats those in the dawn of life,
those in the twilight of life, and those in the shadow of life.*

—Senator Hubert Humphrey

In the hospice community, we speak of cherishing the end of life as much as we cherish its beginning. Admittedly, it's a concept that appears to run counter to modern culture. Yet only a few generations ago, when death was a more conspicuous part of life, the thinking was different. Families were the primary providers of care for loved ones at the end of life. Life often ended where it began—at home. Like birth, death was a family affair. Today, birth is a widely celebrated event, with expectant fathers and their video cameras in the delivery room. However, we tend to distance ourselves from the natural death of a loved one, who is more likely to die in a care facility than at home. Despite the growth of the hospice movement in the United States in the past 30 years, more than 50% of Americans die in hospitals and long-term care facilities.

We know how to embrace birth, but our culture seems to have forgotten how to accept death. As a result, the dying process of a loved one is often a very difficult family experience that can test even the closest

relationships. Family caregivers provide more than 80% of all home care services, yet they receive no formal training or support in their roles. Like birth, death requires preparation, education, and support, as well as special attention to the needs of the family. Through hospice, we are leading the way in preparing families for the issues, concerns, and conflicts at the end of life.

Life today is much different from life a hundred years ago. In 1900, the average life expectancy was only 50 years and the infant mortality rate was very high. Thanks to improved sanitation, antibiotics, immunization programs, new therapies, and amazing technological advances, Americans can now expect to live into their 70s and 80s. The field of medicine has become infinitely more complex. One interesting result is that many people now feel as though death is optional or avoidable.

Health care's increasingly complex system has its own unique language and culture. It can be confusing for the most experienced, and often there are no clear or obvious answers. In this environment, patients and family members must not only try to make sense of it all, they must make difficult decisions based on the information they receive.

From the physicians' perspective, the core principles of medical ethics are "beneficence" and "nonmaleficence." Beneficence refers to their efforts to "benefit the sick," while nonmaleficence means to "do no harm" in the process. Physicians are trained to cure and may be troubled by the thought of a medical "failure." Many people think the health care system is not set up to deal with dying because it is designed to cure the sick. Patients and families obligated to choose a physician from a list imposed by a managed care plan may have no sense of connection or trust. Adding to the physician's conflict are more and more modern-world legal and ethical issues. According to a study reported in *JAMA* (2000), "one of the most difficult situations physicians face is how to handle conflicts with families over forgoing life-sustaining treatment. Physicians may feel their competence or judgment is not trusted and turn to legal or ethics consultants for help with what they feel is a wrong decision by the patient or the patient's proxy decision maker. Families may feel isolated, misunderstood, or abandoned and begin to doubt the healthcare team's commitment to the patient's well-being. As a result, there can be tension and disagreement between

physician and family, adding to the family's stress" (Goold, Williams, & Arnold, pp. 909-914).

According to some families, initially there must be a good communication link to the physician. Unfortunately, in one study, nearly one-quarter of family members surveyed believed that neither the patient nor the family was part of the discussion about end-of-life decisions (Hanson, Danis, & Garret, 1997). Good communication with patients early in the clinical course whenever possible assists in reducing conflicts. A nonconfrontational, sympathetic, and compassionate approach to family members and legal surrogates facing the immediate death of their loved ones leads to the best possible outcome. It is the duty of the physician and the health care providers to assure the patient and the family that they will not abandon the patient. Effective communication is the key to solving almost all ethical dilemmas when caring for the dying . . . patient (Krishna & Raffin, 1998).

CAUSES OF CONFLICT

Adding to families' difficulties is the increasing complexity of family life itself. Today's families may be spread out across the country, with no shared hometown. There are more children from previous marriages and new types of relationships. More and more legal issues confront physicians and families today. Furthermore, given that most people do not want to discuss the end of life until they must, it is no wonder that making any decisions on behalf of a dying loved one has become so overwhelming. Making decisions such as whether to maintain life support is difficult enough for an individual. The difficulty can readily be compounded when decisions must be made by "committee," or family.

An approaching death often produces conflicts, as loved ones must come together to make decisions in a highly stressful setting that they have never before experienced. To understand the root causes of family disagreement, one must look at the individuals within the family. In some cases, the only thing that family members may have in common is DNA. Their belief systems, interests, lifestyles, experiences, and codes of ethics may all be different. Even in close-knit families, each person remains an individual with a unique perspective. Patient and family members react to the stress

of illness in different ways. They process their emotions and thoughts at different speeds. Various family members have different perspectives, perhaps feeling guilty, or trying to make decisions without fully understanding the complete context of the situation. Like victims and witnesses at the scene of an accident, each family member may see things completely differently, depending on their emotional state, their relationships with other family members, their age, and other factors. Further, everyone deals differently with his or her emotions. Family members may fall back on their own lifelong mechanisms for coping, such as avoidance or control. Emotional expression can depend on the temperament of the individual, family heritage, and gender.

UNIVERSAL ISSUES

Even with the best input and support from medical professionals, family members may find themselves at odds over virtually any issue associated with the care of a loved one. A hospice counselor worked with a mother and daughter who never came to an agreement on the husband/father's funeral arrangements. The counselor soon determined that the mother and daughter had spent a lifetime disagreeing on most everything.

In the case of one dying father, siblings complained to their counselor that their sister, the appointed trustee, refused to share information with them about the father's estate, the funeral arrangements, or any other matters. On behalf of the siblings, the counselor tried to talk with her, but she refused. The siblings all indicated that the sister had always been this way—she had no close family relationships. In fact, she hadn't even been around their father in 10 years.

Families may argue over where the patient should die. While many patients may express the desire to die in the comfort and familiarity of their own home, some family members do not want those kinds of memories. A spouse or sibling may want the patient moved to a hospice house or nursing home.

Family members often disagree on how to care for the surviving spouse. The adult children may argue over where the mother should live. A married couple, working full time in another city, may want the mother to move in with them, while other brothers and sisters may also try to persuade her to move in with them.

Perhaps the most common issue is settlement of the estate, which has been an issue as long as there have been estates.

Further, the more mundane aspects of daily living must also be addressed. Who will pay the bills? Who will feed the pets? Who will do the grocery shopping? Who will get the prescription medications filled? Who will do the chores around the house? In some cases, there is argument over which siblings are perceived as not doing their fair share. Those who are able to provide daily, hands-on assistance may resent family members who live farther away and aren't available to help. The reality that most hospice patients are older and seriously ill, yet are cared for by younger family members, produces difficult reversals in generational hierarchies. The daughter or daughter-in-law, who typically becomes a caregiver for her or her husband's parent, must adjust to new patterns. Long-standing unresolved conflicts may reappear under these stressful conditions and may lead to power struggles and other dysfunctional expressions.

Regardless of family dynamics and issues, it is well documented that most couples and families simply do not want to discuss death. But at the point where there is no avoiding the subject, patients often cannot participate in the conversation because they are too ill or sedated. Decision making falls to the surrogate or to unprepared family members, in consultation with the medical team, at perhaps the most emotionally difficult moment in their lives. Decisions of such import are emotionally stressful and are often a source of disagreement. Failure to resolve such disagreements may create conflict that compromises patient care, engenders guilt among family members, and creates dissatisfaction for health care professionals. However, the potential for strained communications is mitigated if clinicians provide timely clinical and prognostic information and offer the patient and family aggressive symptom control, a comfortable setting, and continuous psychosocial support. Effective communication includes sharing the burden of decision making with other family members. This shift from individual responsibility to patient-focused consensus often permits the family to understand, perhaps reluctantly and with great sadness, that intensive caring may involve letting go of life-sustaining interventions (Prendergast & Puntillo, 2002).

In the experience of one hospice caregiver, the best means of circumventing these problems are early referral to hospice and advance directives. Ideally, the patient should be admitted while still competent and capable of making and communicating decisions, and at that point, the patient's preferences should already be documented. This relieves the family of the stress of making decisions based on guesses and assumptions, and leaves less room for debate.

THE CASE FOR ADVANCE DIRECTIVES

The highly publicized Schiavo case has resulted in years of legal battles among family members. The patient's husband, Michael Schiavo, maintains that the feeding tube sustaining his wife Terri should be removed so that she can be allowed to die after years in a persistent vegetative state following a heart attack. Meanwhile, Terri's parents continue to hold hope that she will recover. Michael claims that Terri would not want to be kept alive in this circumstance, although there is no confirming documentation.

In part because of the Schiavo case, there is growing interest in advance directives as a means of enabling families to avoid disputes over end-of-life care and to help patients protect their wishes and rights. "Advance directives" is a general term referring to an individual's instructions about future medical care in the event that the person becomes unable to communicate. Every state now has standards for how these documents should be prepared. A federal statute enacted in 1990 requires hospitals and other health care agencies to provide patients with general information about how their end-of-life issues can be handled. Many hospices, including Hope, have begun informational campaigns to raise community awareness about advance directives.

In matters of personal health, every competent adult has the legal right to choose or refuse medical treatment. However, when people are no longer able to make these decisions because of a mental or physical condition such as Alzheimer's disease, they are considered incapacitated. Advance directives can authorize the physician to provide, withhold, or withdraw life-prolonging procedures. They can also designate another individual to make medical decisions on the patient's behalf if necessary, and they can designate anatomical donations after death.

Some people make advance directives when they are diagnosed with a life-threatening illness. Others do it while they are in good health, sometimes as part of estate planning.

Advance directives should be considered equally important to patient and family. However, completed forms or checklists of desires and preferences cannot fully meet anyone's needs. It is not enough to have the individual's words on paper. It would be quite unrealistic to expect all possible decisions to be covered in black and white. Decisions may have to be made that cannot be guided by written statements. Therefore, it is imperative to know the real person from the inside, to know how he or she would think and feel in a given situation. In other words, open, ongoing communication among family members and medical professionals is key.

With or without advance directives and open communication, though, conflict can arise. The decision to withhold or withdraw life-sustaining treatment is now regularly considered at the end of life. Families are usually supportive advocates and concerned surrogate decision makers for patients, although they may also counter the wishes of the patient and disagree with the treatment team. Understanding the range of factors that can influence family responses helps in working with families at this critical juncture in an illness, and must include internal and external factors confronting the individual members and the family as a whole (Rothchild, 1994).

In a case cited by Jackson, Wilde, and Williams (2003), many physicians view family members as allies useful in resolving conflict between patient wishes and professional judgment, although they also find family members in conflict with one another when determining the course of care, even to the point of being directly opposed to the patient's stated wishes. In their case, an elderly woman who was admitted because of complications resulting from a bowel obstruction made very clear that she did not want surgery and requested no cardiopulmonary resuscitation. The medical team had conducted extensive counseling with the family, and the family was aware of her aversion to medical treatment. However, as her condition deteriorated during her hospital stay, some family members expressed a desire to pursue surgery. The disagreement became violent, resulting in arrests and threats of litigation. This presented an ethical

dilemma for the medical team. Should they continue to honor the wishes of the patient, in spite of some of the family members? Should they reduce the patient's sedation, on the chance she would be able to restate her wishes? Should they consult with a surgeon, or transfer the patient to another medical team or even another institution? Or, as a last resort, should they call for a meeting of the hospital's ethics committee? They opted to bring in a consulting surgeon, who explained that, given the patient's condition and the risks of surgery at that point, along with the patient's own wishes, he would not operate. The family members finally agreed to palliative intervention only.

To further complicate the advance directive process and potentially add to the pressure on families, some patients have indicated that they want their family's wishes to take precedence over their own previously stated wishes, in the belief that the family will do what is best (Sehgal, Galbraith, Chesney, Schoenfeld, & Lo, 1992). Patients may also assume that the family will be in a position to make decisions for them even if they have not prepared an advance directive. This is not always true. Depending on state law, the family may not be allowed to make decisions about life-sustaining treatments. Even in the states that do permit family decision making, treatment may continue if there is conflict among family members.

Although advance directives may not be fully adequate in some instances, they do offer an opportunity for open, healthy discussion among family members. Many hospices are now becoming more proactive in introducing families to advance directive planning.

HOSPICE CAN HELP

Hospice is at a unique point in the care of patient and family. Disagreements and emotional attitudes may have begun to form among family members during the hospital or nursing home stay or in years past, but when it is time for end-of-life care, they may feel the need for final resolution.

Moreover, hospice has an ethical responsibility to assist. For hospice philosophy always has emphasized that the *family itself* is the unit of care. This infers a responsibility to assist the family even as they disagree, to

reach, if possible (and sometimes it may not be possible), a solution that does not render the family further asunder.

To best help the family, the hospice worker must continuously assess the family dynamics. When asked how they are feeling, hospice patients may express that they are feeling alone—even though family members are ever-present. How can this be? Family members may spend a great deal of time discussing the dying family member among themselves, excluding the dying loved one from the conversation. They may be gathered on one side of the room, speaking in whispers, while on the other side of the room, their loved one is alert and aware of the environment and the circumstances. Hospice workers have witnessed heated arguments within earshot of the patient. To rectify this situation, the social worker or chaplain may encourage them to include the dying family member in their conversations. They may ask the patient, “Is it okay if your family asks you questions about how you’re really doing, and asks your opinion on how to handle things for you?” Often the patient will say yes. Asking the patient for ideas and opinions makes his or her wishes known. This can give assurance that real human needs will be mutually understood and met by the family.

When family differences reach an impasse, there may be an opportunity for the professional caregiver to assist in an ethical, nonjudgmental way. Assertive, aggressive members of conflicted families may assume power over the patient’s care and conceal information. Less assertive family members may withhold their opinions. A member of the hospice care team may point out what he or she is observing, and ask each person to articulate their feelings in a group setting. At that point, the “talker” in the family is obliged to listen, and the passive listener has the floor. This can replace emotion with clearer thinking and promote more effective coping strategies. Open, ongoing communication within the family can help to alleviate the patient’s anxiety and depression.

All appropriate family members should be involved in the decision-making process with the physician and health care team. The same information should be given consistently to all adult family members. Reassuring a patient while giving bad news to his or her spouse or other family members will result in conflict.

The more information given, the greater the sense of control for the patient and family. Giving the patient and family an opportunity to maintain control restores a sense of hope, although the objects of the hope may change. Assistance with the cognitive aspects is one of several basic needs of the family of the dying patient, in order to make well-informed decisions, to have peace of mind, and to avoid conflict. Meeting the needs of the family reduces conflicts. These needs include being with the patient, helping the patient, knowing that the patient is comfortable, and being informed of the patient's condition. When these needs are met, family members will be in a much better position to find harmony, to cope, and to let go of a loved one.

Assisting the family in setting goals for care can reduce conflicts. Family members may request futile treatments as a means of conveying that (1) the loss of the patient is tantamount to losing part of themselves, (2) the patient should not be abandoned or devalued in any way, or (3) the patient is owed special obligations by virtue of the special relationship in which the family and the patient stand (Sehgal et al., 1992). Jecker and Schneiderman (1995) maintain that families can best express these important messages by caring for patients, rather than by making requests for futile interventions. Likewise, when life-sustaining measures are futile, health providers can best fulfill their professional obligations by ensuring patients' dignity and comfort, rather than by applying futile interventions. We can assist family members by helping them to identify what they *can* do to assist their loved one.

To aid patients and families in setting realistic goals and expectations, and to guide decision making, several versions of a patient's, or dying person's, bill of rights have been created. The bills recognize the patients' rights to make decisions regarding their treatment, care, and well-being and contain a number of common components, including the right to be comfortable and free of pain, the right to know the truth, the right to make and participate in decisions about care, and the right to express feelings and emotions.

Ironically, in comforting the patient and family by honoring their rights and meeting their needs, including the right to know the truth, the right to participate in decisions, and the right to be informed, we confront

them with potentially uncomfortable choices about life and death. The goal of health care workers is not to take an active role in making choices or resolving family disagreements, but to promote the best interests of patient and family throughout the dying process while upholding respect for the patient's and family's values.

Aiding the family and assisting in the resolution of conflict at the end of life is rarely an easy task for hospice counselors, who may be faced with their own ethical dilemmas. Obligated to protect the client, the counselor may not be able to share personal information with other family members—not unlike a priest hearing a confession. In one instance, a family member told a counselor that the client could become “dangerous.” Should the counselor take action or not? Ethical ramifications accompany either choice. If the counselor believes the client is in danger, professional ethics and some state laws require the counselor to take action to protect the client. The counselor is even permitted to violate confidentiality in order to ensure the welfare of the client. However, in doing so, the counselor risks violating the client's right to autonomy and self-direction. One way out of an ethical dilemma such as this is for the counselor to encourage the family member who has knowledge of the problem to take charge of the situation and report to the appropriate authorities. The counselor is then free to remain a staunch advocate for the client.

In hospice care, counseling and therapy can play an important role in conflict resolution before death.

Expressive therapy can be one way to put a family at ease. In one instance, while creating a video about Hope Hospice, we filmed a distraught family that had begun to work together on a collage to celebrate the life of the husband/father, who was actively dying. Each family member was selecting photos and pictures clipped from magazines, sharing memories as they worked. On the tape, you can actually see smiles begin to appear on their faces. The atmosphere became visibly relaxed as they collaborated. Such a review of things enjoyed and loved, such as people, places, events, and experiences, can bring genuine comfort and relief to patient and family.

Spiritual support may be helpful for some family members, but this requires thorough exploration from the outset of care and could prove to

be problematic. In the study reported by Abbott, Sago, Breen, Abernathy, and Tulsky (2001), 48% of family members spontaneously mentioned faith or spirituality as a significant and reassuring aspect of their hospital stay. However, when family members are of different faiths or when some are nonbelievers, the provision of spiritual care as a means of comforting and unifying the family can become complex. It is not the responsibility of health care providers to resolve religious differences, but rather to assess and provide spiritual support as desired by the patient and family. In a study of members of 48 families of patients previously hospitalized in the intensive care unit (ICU) who had been considered for withdrawal or withholding of life-sustaining treatment, many of the families perceived conflict during end-of-life treatment discussions in the ICU. Conflicts centered on communication and staff behavior. Families identified pastoral care and prior discussion of treatment preferences as sources of psychosocial support during these discussions. Families sought comfort in the identification and contact of a “doctor-in-charge.”

While social workers, counselors, and chaplains aid patients and families with “anticipatory grief,” they may at the same time serve as neutral arbiters of family disagreements. Somewhat surprisingly, one senior counselor claims a “75 to 80% success rate.” However, this does not always mean that the conflict has been fully resolved. For example, it may mean helping an ostracized family member to live with the situation. It may mean helping family members to understand that a particular problem can never be worked out, and it’s okay to let it go. Emotional support and counseling can help to unite the family members and give them confidence to assume the challenges of patient care. Caregivers need to reassure patients and their families that care, compassion, and concern will always be available to them and that they will not be abandoned.

When a loved one is dying, the challenge for family members is to find a sense of hope. Even in the face of disagreements, they may still encounter an opportunity to bond and reaffirm their love for one another as they share in the celebration of the life of the dying loved one. Family conflict and disagreement over end-of-life issues can actually be beneficial if they lead to honest, open discussion. However, some decisions may forever be

questioned. Closure can be elusive. As the husband of a hospice patient told us, there can be no fairy-tale endings.

In our experience at hospice, we have found that families have two basic expectations for peace of mind: (1) In the curative stage, they need assurance that the medical team did everything possible to try to make the patient well again, and (2) in the palliative care stage, they need assurance that the hospice care team did everything possible to enable the patient to be completely comforted. Fulfilling these expectations can certainly help to circumvent conflict.

The end of life is not an easy time for families, but we can make it less difficult. I see hospice as a model for identifying and perfecting the best methods of helping people through these times. Hospices can easily and competently care for more patients and their families in need of good end-of-life care. By popular demand, birth has become an intimate family time that is a celebration of life. As a nation, we must recognize that no one is more vulnerable and in need of well-informed, harmonious family support than a person at the end of life.

Because of the demographic diversity in southwest Florida, Hope Hospice cares for people from throughout the United States, from every economic level, from an array of cultures and religious backgrounds. Our goal must be to establish best practices that provide communication throughout the experience and to identify them as soon as possible and begin interventions. Hospice can be a lab of the future, leading the way in successfully addressing family issues associated with the end of life. ■

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