

# Communication, Negotiation, and Mediation: Dealing with Conflict in End-of-Life Decisions

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**Abstract** / In recent years, it has become possible for the end of life to be a negotiated event, particularly in the intensive care unit. A multitude of often unidentified and poorly understood factors affect such negotiations. These include, family dynamics, ever-changing health care teams, inconsistent opinions about prognosis, and cultural differences between physicians, and patients and their families. When these factors converge, conflict may erupt. This article explores the nature, antecedents, and cost of such conflict. Arguments for the importance of balanced communication, negotiation, and mediation in end-of-life care are put forward.

**Résumé** / Au cours des dernières années, il est devenu possible de négocier les décisions de fin de vie dans les unités de soins intensifs. Une multitude de facteurs souvent non-identifiés ou incompris affectent de telles négociations. Mentionnons en particulier la dynamique familiale, le roulement du personnel dans les équipes de soins, la diversité des opinions sur le pronostic, et les différences culturelles entre les médecins, les patients et leurs familles. Lorsque ces facteurs convergent, on peut s'attendre à ce qu'il y ait des conflits. Cet article explore la nature, les antécédents et les coûts reliés à ces conflits. Ainsi on peut donc avancer certains arguments pour justifier l'importance qu'il y a à favoriser la communication, les négociations et même la médiation dans le contexte des soins de fin de vie.

## INTRODUCTION

When dealing with end-of-life decisions, health care professionals can face a variety of complex factors: family dynamics, varying beliefs about end-of-life decisions, ever-changing health care teams, inconsistent opinions about prognosis, and cultural differences between physicians, and patients and their families. When these factors converge, conflict may erupt. While rare, situations of conflict command an inordinate amount of the health care worker's time. Health care teams can begin to experience frustration, tension, caregiver burnout, and intra-team conflict due to the polarization of opinion (1). Families of patients begin to feel intense anxiety and

complications in the bereavement process. Prolonged disputes are extremely painful for both health care teams and families, and they may leave patients in pain or receiving unwanted treatment. Ultimately, resolving these conflicts is the responsibility of the health care professional. Understanding the importance of balanced communication, negotiation, and mediation will make this job much easier. This paper aims to enhance understanding of these issues.

Medical technology, despite its enormous advances, can often complicate the process of end-of-life decision making. Patients who are no longer cognizant may be sustained on life support. This means that negotiation often involves families, rather than the patients themselves. While advance directives or "living wills" may help guide families in making difficult decisions, these documents are rarely completed. Despite positive attitudes towards them, efforts to increase the rate of completed documents are only modestly successful (2-7).

Although we, as health care workers, can easily acknowledge the medical and ethical complexities of end-of-life decisions, we have barely begun to acknowledge their psychological and sociocultural complexities. In the past, several factors, including the absence of life-sustaining technology, a far shorter life expectancy, a higher child mortality rate, and a closer geographic proximity for many families, made death more frequently a home-based experience that had little to do with choice. Today, however, end-of-life decisions abound, and the stakes are high. These decisions involve life or death, views about the quality and meaning of life, high costs, moral principles, and legal rights (8). Not surprisingly, such decisions can generate intense emotions and increase the potential for conflict.

When patients or families refuse treatment, the ethical and legal foundations are clear. With the exception of some circumstances involving young children, such refusals must be respected,

based on the ethical principle of respect for autonomy, and on the legal doctrines of self-determination and informed consent. However, there is no widely accepted ethical and legal framework underlying the situation where patients or families request treatment which health care workers believe is inappropriate. This lack of social, legal, and ethical consensus regarding when to continue and when to terminate life-sustaining treatments further exacerbates the difficulties associated with end-of-life decisions. Debates about termination of treatment are potentially explosive, raising profound questions about the meaning and treatment of human life, and about who — if anyone — has the right to make such decisions.

Moreover, substantial differences in age, culture, social class, and education often exist between physicians and families. What is known or valued by health care workers may be illusive or irrelevant to families. When differences exist, so too will perspectives on choices, creating a greater opportunity for conflict. Conflicting perspectives become increasingly obvious when major decisions must be made. Large health care teams with shifting and inconstant members, each trained in separate professions with separate working cultures, often fracture communication and make for an environment that is not conducive to balanced discussion and negotiation. Furthermore, all these factors occur within a climate of endless change that defines the contemporary health care system.

Given these various factors, it is not surprising that conflict in end-of-life decisions arises. Disagreements over end-of-life care will only become more common as the number of people receiving such treatment increases. It is, therefore, best to anticipate conflict, and develop mechanisms and policies to address it before it erupts. The most important task for health care workers is to focus on consistent and balanced communication and negotiation. If necessary, they should turn to mediation, which involves the resolution of disagreements by a knowledgeable and neutral third party.

### THE CASE OF MRS. S

Before examining the sources of conflict in greater depth, let us review a case that effectively illustrates the breakdown of communication in a situation of end-of-life decision making.

Mrs. S was a 75-year-old widow with breast cancer metastatic to bone. She was admitted to the intensive care unit (ICU) after a spinal fusion to relieve pain and prevent paraplegia. Postoperatively, she developed respiratory distress and pulmonary edema, and was intubated.

Through written communication, Mrs. S repeatedly indicated that she wished to "get off the machines" and return home as quickly as possible. She was consistently silent when asked what her wishes would be if this were not possible. All attempts to wean her from the ventilator were unsuccessful. In her second month in ICU, Mrs. S became increasingly confused and agitated. At times, she would panic when medical staff entered the room. She was frightened that someone would try to kill her while she slept.

Oncology assessment indicated that the cancer had now spread to the lungs, and metastases to the brain were suspected. Mrs. S's level of consciousness receded. Physicians approached Sandra, Mrs. S's daughter and only living family member, to question the amount of aggressive treatment her mother should receive. Sandra stated that her mother would want full and aggressive treatment, describing her mother as a "fighter" and a "survivor."

Several members of the health care team became increasingly upset with what was being referred to as Mrs. S's "pathetic quality of life." Each conversation between Sandra and the physicians became more adversarial. Sandra's position was, "You can't just give up on a person." The physicians' position was, "We are now only prolonging her dying, not her life." Mrs. S's skin began to break down and she started having small seizures. Many members of the health care team felt that discontinuation of treatment without family consent should be enacted. The situation had now been labeled "a major ethical problem."

Cases like this are uncommon, but they take a serious toll on everyone involved in resolving them. When a family's perception of appropriate treatment conflicts with that of the health care worker, the situation, if handled indelicately, can lead to a cycle of frustration, stress, and dismay for all parties.

### THE NATURE OF THE ICU

The ICU treats a substantial number of patients who will ultimately die. Although most ICUs have clear clinical goals and policies related to the treatment of patients, goals related to end-of-life decision making and the care of the dying are often absent.

Team members from various disciplines tend to hold differing and sometimes disparate views on end-of-life decisions and the care of the dying. This is especially true in teaching hospitals, which are known to have large health care teams with shifting members, each trained in separate professions with separate working cultures. These factors combine to fracture communication between health care workers even before they must communicate with patients and their families.

End-of-life decisions are often perceived as made through clinical judgement and ethical analysis. Yet, this does not account for more complex — and highly influential — factors at play in the ICU, including: team dynamics, institutional culture, research objectives, ethnic/religious background of physicians (9), and perceived costs and benefits. For health care workers, end-of-life decisions may illuminate differences between institutional practices, and personal or professional beliefs and values, creating further tension. A breakdown in communication often causes an impasse that is perceived as an either/or choice, and the opportunity to find creative solutions is diminished.

When differences in opinion on diagnosis and prognosis occur between members of health care teams, patients and their families can feel frightened and uncertain about the quality of care and the validity of decisions being made by health care workers. This kind of inconsistency and ambiguity only increases the potential for conflict.

#### FAMILY DYNAMICS AND FUNCTIONING

When a family is faced with the need to make decisions on behalf of their dying loved one, several factors can exacerbate conflict between family members, or between the family and the health care team. These include:

- the stress associated with these decisions
- a realignment of familial roles
- physical and emotional depletion.

Because negotiating death is a relatively new experience, there is a lack of clearly defined social and cultural norms, roles, and expectations related to a looming ICU death.

The admission of a loved one to the ICU may bring on a crisis situation in the best functioning of families. A crisis situation can be described as existing “when a person faces an obstacle which is, for a time, insurmountable through the utilization of customary methods of problem solving. A period of disorganization ensues, a period of upset, during which many different abortive attempts to a solution are made” (10). It is in this emotionally charged, fractured state of mind that many end-of-life decisions are approached. Families in crisis often have difficulty processing and retaining information (11–14). There are three factors that contribute to a family crisis: a family’s perception of the event, the availability (or lack) of supports, and family coping mechanisms (15). All these factors can be addressed to give support to families, reduce end-of-life conflict, and ease the pain of the experience.

First, a family’s perception of their loved one’s illness is well worth exploring in a gentle, humane, and supportive way. Often poorly understood, these perceptions reveal the profound beliefs that are rooted in a family’s history, relationships, religion, or culture. These can be impervious to medical definitions and realities. Second, supports can be built for a struggling family by encouraging them to contact friends, family, or religious leaders. On-site support can also be provided by hospital chaplains or social workers. Third, coping mechanisms are best assessed by considering:

- on a psychological level, what are the family’s coping abilities?
- on an interpersonal level, what type of relationship is being grieved and what amount of support is the family receiving?
- on a sociocultural level, is there a presence or an absence of death-related roles and rituals? (16)

The tension between holding onto and letting go of a dying loved one is enormous for any family, but can be overwhelming for a family with unreconciled conflict. The threatened loss of a loved one may open up painful or unresolved losses from the past, the exploration of which may be far more fruitful than negotiating the level of treatment of their loved ones. Pronounced hostility may well be a symptom of much deeper emotional conflicts and losses within a family (17). In such cases, blame and guilt can seriously compromise the acceptance of death. Family history is often a good indicator of potential conflict in end-of-life care.

Although striving to understand the patients’ and families’ experience of illness is highly important in communicating with families, qualified and committed support staff, such as psychiatrists or social workers, are best brought in as early as possible when cases warrant it. A family-systems approach — one which considers the effect of the illness upon the entire family, and how the threat of loss is perceived and handled within the family system — is useful in such cases (17).

#### THE INTERSECTION OF FAMILIES AND HEALTH CARE TEAMS

A family’s perception of the meaning and severity of an illness does not always correspond to a physician’s diagnosis and prognosis (18). A study done by Kelly (19) revealed that the concerns of families and the concerns of health care teams in end-of-life decisions were in bold contrast to each other. Health care workers fre-

quently described cases in terms of struggles based on professional authority, organizational jurisdiction, and communication. Patients and families were more likely to describe difficult personal, religious, or emotional aspects of their experience. Family interviews revealed deeply conflicted views of the situation, which went far beyond the clinical and ethical issues associated with the care of a patient in a persistent vegetative state.

For families, end-of-life decisions are not abstract philosophical questions or matters of clear-cut clinical judgement. On the contrary, they are painful emotional experiences that can generate profound revelations about mortality and family relationships. Rather than viewing families as an integral part of a patient's identity and life, health care literature often depicts families as extraneous to the care of the patient. Families are frequently described as being a help or hindrance, as supportive or difficult (20). Furthermore, the meaning of illness in the context of the family is rarely identified and is poorly understood by health care workers. This patient-centred perspective in health care may be rooted in the strong Western focus on patient autonomy and the sanctity of the physician-patient relationship (21).

Unfortunately, the professional and institutional influences on an ICU are unknown to families, just as aspects of family functioning and deeply rooted belief systems are virtually unknown to health care teams. For health care providers, end-of-life decision making is largely based on the concept of medical futility and the perceived value of continued treatment (1). Cases in which health care workers believe that further treatment is inappropriate are referred to as "futile." Futility cases can be marked by polarization of the views of the health care providers, and of the patients and their families. Although uncommon, these conflicts can lead to a complete breakdown in the physician-patient/family relationships.

The futility label is drawn from medical factors and outcomes. Among the leading definitions is that provided by Schneiderman, Jecker, and Jonsen: "when physicians conclude that, in the last 100 cases, a medical treatment has been useless," (quantitative futility) or "if a treatment merely preserves permanent unconsciousness or cannot end dependence on intensive medical care" (qualitative futility) (21,22). In the 1990s, the primary focus concerning such cases was to define "futility" in hopes that the right definition would clarify the most difficult and conflicted situations. However, declaring "futility"

is rarely useful in end-of-life conflict, as no broadly accepted definition has been established. In any event, a clear definition would do little to deal with a family's fears and beliefs.

More recent research has focused on the process of communication to address "futility" cases (23). This is probably a more realistic direction, given that these cases often involve fundamental differences in values between providers, and patients or families (24).

When conflict arises in the ICU, the locus of this conflict is often affective rather than cognitive, and it is deeply rooted in beliefs, not always rational or logical, that hold profound meaning for families. In the vast majority of serious conflicts I have seen, families did not believe that their loved one would recover (although health care staff often assumed they did). Rather, they were expressing a lack of readiness for their loved one's death, or a reluctance for their loved one to die under these circumstances.

## CULTURE AND END-OF-LIFE DECISIONS

Attitudes toward end-of-life care may be highly influenced by cultural perspectives that are rarely acknowledged (25). Cultures are maps of meaning through which people understand the world and interpret the things around them. When patients and health care workers have different cultural backgrounds, they frequently follow different "maps," which can hinder effective communication. For example, health care workers may expect patients to hold a biomedical perspective of illness, be future-oriented, be willing to work on therapeutic goals, and value direct communication about their condition, regardless of its severity (26).

Culture is a strong determinant of people's views of the very nature and meaning of illness and death (27), of how much health — or end-of-life decisions — can or should be controlled (28), of how bad news should be communicated (29), and of how decisions, including end-of-life decisions, should be made.

When weighing decisions about end-of-life care, it is important to consider that Western and non-Western cultures hold sharply divergent views about autonomy. Autonomy is generally a Western concept, reflecting a belief in the importance, uniqueness, dignity, and sovereignty of each person, and the sanctity of each individual life. Accordingly, every person is entitled to self-determination. This stands in sharp contrast to non-Western cultures, in which interdependence is often valued over independence (26). Profound social and moral meaning rests in these interrelations.

Western health care teams may therefore assume that the person experiencing the illness is the best person to make health care decisions. However, many non-Western cultures vest in the family or community the right to receive and disclose information, and to organize and make decisions about patient care. Applying the concept of autonomy cross-culturally will, therefore, mean accepting each person's terms of reference for their definition of self. Specifically, we should respect the autonomy of patients and families by incorporating their cultural values and beliefs into the decision-making process.

The most effective way to address cultural differences in end-of-life decision making is through open and balanced communication. When health care workers are uncertain about how a patient or family perceives a situation, it is best simply to ask. Frequently, differences can be easily negotiated. Many people now living in Western cultures already hold blended views of culture, illness, and death. The mere acknowledgement of such differences will usually lead to improved communication.

When handling end-of-life decisions, it is important to consider the following questions:

- Do patients value individuality and personal choice, or do they focus more on family and collective choices?
- Do they value open communication, or do they tend to draw cues from the context of the situation?
- Do they believe a person can and should influence their health or their death?
- Do they believe in a Western, scientific view of illness, or do they hold an alternative culturally based view? Is this view blended with Western perspectives on illness?

Exploring these areas is an excellent means of eliciting patients'/families' personal and cultural understanding of illness.

### COMMUNICATION, NEGOTIATION AND MEDIATION

The most important task in the ICU is to focus on consistency, balanced communication, and negotiation. Although many people see communication in health care as a simple straightforward process, there are often substantial differences between information given and information received. As previously discussed, the hospital environment is not conducive to balanced communication and negotiation.

Hospitals and their staff hold a good deal of power in our society. They may not be con-

scious of this, because their power is rarely openly identified (30). This power creates an innate imbalance in communication and negotiation. Health care teams often hold disparate opinions and beliefs related to patient care and end-of-life decision making. To exacerbate this problem, families' feelings of anxiety, fear, and denial often prevent them from absorbing important information (31).

The first step in end-of-life decision making is to understand the perspective of the patient and family, including their beliefs about the cause, treatment, and outcome of the illness. Support staff with a spiritual or psychosocial mandate can be very helpful at this stage. As simple as it may sound, the mere act of having a family explain their understanding of illness and what it means to them can often ameliorate conflict and misunderstanding. The next step is to negotiate a treatment plan that is acceptable to both the patient and family, and the health care team. In many cases, simply acknowledging each other's perspective can lead to improved communication. The most effective way to deal with differences is through open and balanced communication. This clinical situation is perhaps best conceptualized as a negotiation.

In the event of a complete breakdown between the health care team and family, mediation is a useful tool (32-38). It promotes good health care by creating a forum that fosters respect for family perspectives, while allowing for a comprehensive examination of the medical, ethical, and legal elements of a situation. Mediation can also create an environment in which multidisciplinary teams can learn to integrate the psychosocial, cultural, ethical, legal, and medical concerns in a case. While mediation can be beneficial, health care professionals should strive to achieve balanced communication before the need for outside consultation arises. The current necessity for mediation largely reflects a failure within our existing systems.

Furthermore, it is the author's experience that many models of mediation have evolved in the context of law or business, and are based on the application of logic and negotiation. Their effectiveness and impartiality to the complexities of end-of-life care have, therefore, not been well tested. The family facing end-of-life decisions is often mired in an emotionally charged state. End-of-life decisions may represent the last chance for a loved one to resolve a complex and poorly understood emotional relationship with the critically ill patient. It is essential that mediators have the knowledge, skill, and empathy to explore this difficult terrain.

## THE CASE OF MRS. S EVALUATED

Having reviewed the variety of factors that may intersect to create conflict in end-of-life decisions, let us revisit the case of Mrs. S to understand what got lost in the communication process. A series of one-to-one interviews with Sandra, Mrs. S's only family member, revealed the following:

### Family History

Mrs. S was a Dutch Roman Catholic who married shortly after the German invasion of The Netherlands. Her husband was Jewish, yet living under the pretence of being Roman Catholic due to the new laws imposed by the Third Reich. Mr. and Mrs. S were planning to leave Holland for Switzerland as soon as they could save enough money for their passage. The Nazis, however, discovered their true identity and arrested Mrs. S in her workplace. Mr. S escaped minutes before his attempted arrest. Mrs. S was sent to a concentration camp, where she struggled for life until the war ended and she was liberated. Mr. S went into hiding and eventually made safe passage to England. They were reunited after the war and emigrated to Canada. This history helps to illuminate Sandra's view of her mother as a "fighter" and a "survivor", who would struggle for life against all odds.

Sandra reported that her parents had a "close but crazy marriage". She stated that, as a child, she often felt frightened by the emotional intensity between them. Sandra described her mother as a vibrant woman with a strong zest for life, yet she suffered from severe bouts of clinical depression. The war was never spoken of in their home, yet it had shaped the lives of this family. Mrs. S reportedly feared illness, took many measures to safeguard her health, and avoided doctors. Both of Sandra's parents were highly observant of the Jewish faith and had a strong regard for the "sanctity of life." Sandra described her father as a passive "worrying man". Sandra herself was married with two children under five years of age. She was now facing marital problems and beginning to question why she had married such an emotionally erratic man. She was in therapy and exploring just how much her parents' past had influenced her life.

### Physicians' Perception of the Situation

Mrs. S's admission to the ICU was questioned from the outset. Three of five ICU staff physicians felt that, in light of Mrs. S's seriously impaired lung capacity and metastatic cancer, ICU admission was not realistic. At the first family

conference, the physician on duty felt it was very important that Sandra — as the only family member — be made aware of the severity of Mrs. S's situation and of the strong likelihood that treatment would be unsuccessful. He felt it would be unfair to give her unrealistic hope. This physician's communication to Sandra was specific as to interventions, and he strongly and repeatedly highlighted the probable futility of each. Sandra had prepared a list of questions that generally fell within two categories, the first relating to her mother's comfort and care, the second relating to the possibility of more accurate diagnostic procedures. Communication between the two parties broke down quickly and ended in disagreement and silence. Following the conference, Sandra was described to the team as "difficult" and "unrealistic". Subsequent meetings were strained and increasingly brief, with physicians repeatedly stressing the growing futility of treatment. Physicians spoke of the frustration of dealing with a person "who just doesn't understand" and "wasn't listening". Sandra repeated her alarm at the thought of "just giving up".

### Sandra's Perception of the Situation

Sandra felt the physicians had been grudging about her mother's ICU admission from the outset. She stated that her mother had commented on this attitude several times following her admission. Sandra also stated that, although she was told the first conference would be an opportunity for her to ask questions, her questions were twice interrupted. She felt the real agenda "was for the staff doctor to stress that treatment should not be given". Sandra left the meeting with a mounting fear that her mother would covertly be "under-treated".

Sandra described the physician at the first conference as "cold". She found his approach "depressing". She was also very upset that he had twice referred to her mother as "him". Sandra saw this as a sign of extreme disinterest in the "human side of all this". The physician, who was Chinese, later stated that he regretted the mistake, which he had made because gender distinction is not used in the third person in Chinese, and he was "a little nervous" because the meeting wasn't going well.

This case highlights the interface of fractured communication, conflicting family and physician perspectives, and the profound effect of family history, functioning, and cultural/religious values on end-of-life decisions. Mrs. S's religious beliefs in the sanctity of life together with the trauma of the war greatly affected both

her and her daughter's perspectives on end-of-life decisions. These decisions opened up painful and unresolved issues for Sandra, which had a greater influence on her decision making than did the notions of medical outcomes or futility definitions. Although this case was framed as an ethical dilemma requiring an "either/or" decision, the locus of the conflict was rooted in inconsistency, miscommunication, and profound events which transpired more than 55 years ago. It highlights the depth and complexity of end-of-life decisions.

## CONCLUSIONS

As the breadth of scientific and medical knowledge grows, the clinical and ethical complexities of end-of-life decisions increase. Difficulties in family functioning may be amplified by medical complexity, poor communication, or discrepancies between caregiver reports — all of which contribute to conflict in end-of-life care. Although most of us see ourselves as good communicators, we all have room for improvement. Health care training in cross-cultural differences, team building, communication, and negotiation would greatly enhance our ability to avoid or decrease conflict. The availability of support staff and mediators trained in family therapy is essential. We can further reduce conflict in end-of-life care by focusing on improving our working systems and on understanding the perspectives of patients and their families, and by continually striving for balanced and open communication at all stages of the caregiving process. It is essential that we create policies, procedures, and a framework for improving team functioning, communication, and dealing with potential conflict.

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