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The end of the academic year 2002-2003 is upon us! This has been an excellent year at the Center. First, we have three PhD graduates this May, as follows. John Brehany, PhD, is the Director of Mission Services & Ethics for Mercy Medical Center in Sioux City, Iowa and his dissertation title is, *Germ Line Genetic Engineering: An Analysis of Principled Argumentation in Light of a Critical Theology of the Body*. John Paul Slosar, PhD, is the Director of Ethics at Ascension Health's national offices in St. Louis and his dissertation title is: *Teleology and Bioethics: An Aristotelian and Thomistic Approach to Mediating the Modern Moral Dichotomy in Health Care*. Kevin Valadares, PhD, is a tenure-track Assistant Professor of Health Services Administration at the University of Southern Indiana and his dissertation title is: *The Contribution of a Services-based Organizational Culture to Support the Operational Success of Health Care Institutions and its Affect on Charity Care*. With these three doctoral graduates our interdisciplinary degree program has now graduated seven PhD students - a very pleasing accomplishment. Second, this year the Center crossed the $1million threshold for external grants funding our scholarly research. Third, the Center opened two new faculty positions during the year, with Sandra Johnson, JD, LLM as Professor and Endowed Chair (specializing in health law and bioethics) and Ana Iltis, PhD as a tenure-track Assistant Professor (specializing in institutional review board ethics and organizational ethics in health care). Fourth, Griffin Trotter, MD, PhD has been promoted to the rank of Associate Professor with tenure at the Center - a very notable accomplishment for which we extend hearty congratulations. Finally, we have completed our admissions for next Fall and we hope to welcome five new students - more on that in a later issue of *Health Care Ethics USA*.

As usual, this issue of *Health Care Ethics USA* has three essays, each by senior doctoral student in our PhD program. The first essay is by Ann Suziedelis, "Cosmetic Surgery for Children with Down Syndrome: the Cruelest Cut of All?" Using case analysis the essay discusses the ethical dilemma entailed by surgical procedures undertaken solely for cosmetic reasons. The second essay is by Thomas Knoblach, "The Burden on Non-Professional Alzheimer's Caregivers." Again by case-type analysis the essay considers the need to respond to this widely experienced concern by a new ethical synthesis that addresses the complex intricacies of such care. The final essay is by Kevin Voss, "Conflict between Families and Providers: Avoiding Treatment Disputes." The essay explores the concerns raised by end-of-life treatment decisions that require an inordinate amount of time from the health care professional.

I hope you enjoy the essays and I look forward to receiving suggestions for topics that we might address in future issues.

Professor Gerard Magill, PhD
Executive Director & Department Chair
Center for Health Care Ethics
Cosmetic Surgery for Children With Down Syndrome: The Cruelest Cut of All?

Two television documentaries aired recently, featuring pediatric plastic surgeons and their small patients. The first involved "Lili," who suffered from a deep red, tumor-like hemangioma, the size of a hen's egg, which sat prominently on her cheek. It was successfully removed, and we saw her several months later, with only a faint scar where the growth had been. She was playing with other children, her now beautifully unspectacular face blending in among theirs.

The other story was about four-year-old "Jimmy," a boy with Down Syndrome, whose parents opted to alter his facial features surgically, so that he would look more 'normal'. (The word 'normal' is problematic, and it is used here in its most common sense, i.e., conforming to the average in a large group.) Jimmy, of course, already looked quite normal for a boy with Down Syndrome, so the actual goal of the surgery was to make him look more like a child without Down Syndrome. We were introduced to him as he played with friends, while his parents discussed the upcoming surgery. The procedure was performed (as was Lili's) under general anesthesia. It included resection of his tongue, lifting of the bridge of his nose, removal of fat from his neck, placement of implants in his cheekbones, and removal of the distinctive folds of his eyelids. He was also shown, some time later, playing happily with friends.

While there are other children with Down Syndrome or hemangiomas who undergo similar operations for therapeutic reasons, it is important to make clear that Lili's and Jimmy's were, from a physical perspective, purely cosmetic. Leaving aside surgical procedures undertaken to improve or restore a child's physical functioning, and considering only those carried out solely for cosmetic reasons, questions arise of whether they are ever ethically justifiable, and if Lili's and Jimmy's are ethically equivalent.

Principles

These two children clearly have physical and intellectual differences, but as human persons they also have much in common. For example, the principle of totality and integrity requires them to develop, use, care for, and preserve all of their natural physical and psychic functions. It directs us all to respect the gifts given to us by God, as well as those given to every other person, so that mutual dignity can be fostered within the human community. This dignity is neither variable nor subjective, for we are willed by God and imprinted with God's image. The dignity we possess stems not from our personal attributes - our beauty, our brains, our talents or skills - but from the persons we are as children of God. Further, we are not only sacred but social. We live in society, and each of us is called to consider every neighbor, without exception, as another self.

The reality of this human community is as critical to Lili and Jimmy (and as relevant to the issue of the operations they underwent) as it is to those who do not, quite literally, carry their afflictions on their faces. It makes clear our shared obligation to respect the dignity of all human persons - regardless of the burdens with which they were born or which they may acquire later in life. It invites us to consider the place of Jimmy and Lili, and of others like them, in the human community, and to seek the fundamental reason why cosmetic surgery was thought necessary for them.

Discussion

It is a sad reality that there are those who cannot get past the surface, and who tease and taunt, or perhaps dismiss altogether, those who are not sufficiently fair-of-face to satisfy their high bar of external beauty. Though we may not agree, it is not hard to understand that Jimmy's and Lili's parents sought to erase the triggers of prejudice by "fixing" their faces. Nevertheless, even if, for the sake of argument, we allow them this particular response to the shortcomings of others, ethical questions still remain. Practically, the results of the operations will be different for Lili and Jimmy, and this directs us
back to the original question: Are their cases ethically equivalent? To answer that, we must first consider whether they are medically and socially equivalent.

From a medical perspective, both children underwent invasive procedures performed on otherwise healthy bodies. Both operations carried physical risks, none of which was warranted in their cases by medical benefits. Both were performed for the sake of subjectively improving appearance, with the clear hope that that improvement would lead to better social acceptance and personal self-esteem. Both interventions were undertaken by parents who wanted their children to conform to standards of beauty and to an accepted concept of 'normal'. But one critical medical difference does exist: Surgery eradicated a pathology from Lili (the hemangioma), while it only tinkered with the outward signs of Jimmy's (his Down Syndrome). Thus, independent of any other factors (such as comparative risk) the cases are not medically equivalent.

From a social perspective, casual conversations about Jimmy and Lili evoke a gut instinct consensus that there is an essential difference between (a) removing a severely disfiguring (though not life-threatening nor even function-impairing) growth from the face of Lili, and (b) surgically altering Jimmy's Down Syndrome features. There is little doubt that the parents were well intentioned in seeking to remove Lili's hemangioma and to modify Jimmy's distinctive features; little doubt that it was truly the burden of those "scarlet letters" that they sought to remove. In that, their cases are similar.

Yet Lili (like most children who have hemangiomas removed) recovered from surgery with only a faint scar to remind her of the excised growth that had once dis-graced her face. Her parents are delighted, and Lili seems pleased. It is hard to imagine a down side to her experience, save for the risk and physical discomfort of the surgery and recovery. Subjectively, it is also hard to imagine that Lili might ever look back and regret that her parents made this choice for her. No studies could be found to rate the reactions of parents and strangers to the esthetic outcome of operations such as hers, but such studies do exist in regard to the surgery Jimmy underwent. A number of those show that while parents (such as Jimmy's) are pleased with the results, independent reviewers discern "no improvement in appearance." Other studies dispute the notion that the natural appearance of children with Down Syndrome has any negative effect on how they are perceived. Perhaps they are protected by the features that alert the world that they are coping with the realities of Down Syndrome. Perhaps those features invite understanding and acceptance instead of discrimination. And it is reasonable to surmise that those who would discriminate against Jimmy upon seeing the distinctive features of Down Syndrome, will now discriminate against him once its behavioral and intellectual aspects show themselves. We have to wonder if surgery eliminates or simply delays social disrespect by those so inclined. In any case, the surgical approaches to Lili's and Jimmy's problems are not socially equivalent.

If the studies mentioned above are correct that only parents see significant change, then there is little justification for the risk and suffering of surgery imposed on Jimmy. If, on the other hand, they are wrong, and people do see significant change toward the goal of a 'normal' face, then those other studies that show little correlation between DS features and discrimination remain to argue against surgery. In the light of this conflicting research, and given that surgery does nothing to address the syndrome itself, it is difficult to justify ethically the risks and suffering visited on this child. He remains a person with Down Syndrome, with or without the surgery, and it seems perversely forced to force him to undergo the pain of surgery in an attempt to accommodate the subjective standards of persons who refused to respect him as he was. According to the principles discussed above, it is those persons who should have accommodated Jimmy, not vice versa.

Conclusion

Lili recovered from surgery looking normal. That is, she looks and behaves like the normal children who are now her full peers (i.e., intellectually, behaviorally, and esthetically), as they would have been from birth if she had never had the hemangioma. The growth thus seems to have been an incidental factor that kept her from assuming her ordered place in society, and with proper care for her well-being, removing it from her was ethically justifiable.

According to his parents, Jimmy recovered from surgery resembling children who do not have Down Syndrome. If they are correct, and the surgery succeeded in its goal, then he no longer resembles the children who had previously constituted his full peer group. Instead, he now looks like children without Down Syndrome, who are neither behaviorally nor intellectually his peers. He has, in effect, been left
with no peer group, and will never have one unless (and statistics indicate it is unlikely) a large number of children his age with Down Syndrome undergo the same cosmetic procedures. The surgery has left him a sort of "man without a country." If he is aware of this and is distressed by it, then the surgery is impossible to justify ethically. If he is not aware that he has no full peer group, and is therefore not distressed by that fact, then it is equally difficult to justify the surgical assault on his face. On the other hand, if the independent reviewers are correct that he still looks like a child with Down Syndrome, then the surgery failed in its goal of achieving a normal face for him, and yet again cannot be ethically justified. Whichever scenario exists, and acknowledging his parents' good intentions, one can only conclude that it would have been more ethical to leave his face untouched; to encourage him to grow in self-regard; and to set an example for others in respecting his human dignity. The onus to change should have been on others - not on Jimmy.

Ann K. Suziedelis, PhD (c)

6. "Hearing Parental Voices"

**Questions For Discussion**

1. A twenty-two year old Dutch woman with Down Syndrome recently requested, collected funds for, and received the same kind of surgery that was performed on Jimmy. She is a high achiever, and works as a teacher's aide. She said that her face made her "look stupid." Is her case ethically different from Jimmy's? Why?
2. One of the stars of the television show "Life Goes On," has Down Syndrome. Do you think the presence of persons with Down Syndrome on television has had a positive or negative impact on their perception in the community? What have you learned about persons with Down Syndrome from seeing them act on television?
3. How would you suggest changing the attitudes that lead parents to seek such surgery for their children with Down Syndrome?

**Suggested Readings**


The Burdens on Non-Professional Alzheimer's Caregivers

Marcie's day began early again. This mother of three was used to the tasks the hours before her held: preparing meals and supervising breakfast, lunch, and dinner; helping with bathing and dressing and toileting; protecting her charges from harm; dispensing medicine and encouragement and guidance; trying to figure out incoherent demands for help; paying the bills, going shopping, doing the laundry; arranging for a schedule of activities; fighting traffic and putting in eight hours at work. She had done this for years and was good at the balancing act.

But lately it was getting harder to get up in the morning. Her appetite was gone and she had dropped out of the book club, aerobics, and making it to her children's games. She felt more and more isolated from her friends and unappreciated for her efforts. Her children had grown distant, her relationship with Don her husband strained. The one person she could count on was her mother, Agnes - Agnes was always there. Well ... always there in body, but not in mind. It was for Agnes that she was both daughter and yet parent all over again. Agnes has Alzheimer's disease (AD), and somehow, despite all the promises of Marcie's brothers, Marcie was the sole caregiver for Agnes. She had not asked for this role, and she was feeling increasingly trapped. She loved her mom, but with shame, she caught herself wishing her mother would die - or she herself would die - and end this hopeless mess that had become her life.

Principles

Healthcare ethics evolved as a set of methodologies to consider and suggest resolution to difficult biomedical cases and to address emerging trends in the rapidly-changing world of health care. Since health is a broad human reality, concepts and principles from a variety of disciplines are brought to bear: philosophy, theology, medicine, law, sociology, psychology, and others. The dialogue has been fruitful in many ways: leading to protections for human research subjects; accepting appropriate limits on life-sustaining technologies; pointing to inequities in access, cost, and quality of healthcare for different populations; the need for ethical conduct by healthcare organizations and not just individual clinicians; calling attention to the social determinants of health; creating space and a vocabulary for public discussion on issues affecting the future of health like genetics, cloning, and stem cell research.

However, such cutting-edge, limit-testing cases and abstract principles do not exhaust the meaning of healthcare ethics. Ethical issues arise in the everyday situations of people like Marcie, whose plight is shared by several million of her fellow Americans: being the primary caregiver for a demented adult with a terminal neurodegenerative disease. But until Agnes faces end-of-life decisions, enters a nursing home, or develops some other complications, Marcie's struggles to meet the needs of her mother, her family, and her own self-care will most likely remain largely outside the consideration of healthcare providers, ethics committees, legislators, and ethicists. In this essay, I do not attempt to apply one or even several ethical principles to "resolve" the state of affairs in which Marcie finds herself; it is too complex for that. Instead, I merely suggest that this real and growing life problem in our midst challenges us to respond, both conceptually and practically, with a new ethical synthesis that can capture and respond to the intricacies of the situation of Marcie and millions like her.

Agnes, in the middle stages of AD, has lost her abilities to create short term memories or learn new information, access long-term memories reliably, make rational judgments, understand and supply her own needs, even in the activities of daily living. Her sweet disposition has lately become alternately combative and tearful; days and nights are confused; her paranoid fears that seem absurd to Marcie are frighteningly real to Agnes. To a culture that prizes intelligence, dialogue, and productivity, Agnes has nothing to offer. Living in a society where autonomy is a primary value, Agnes is a misfit. She has lost her autonomy; and much of her daughter's autonomy has gone with it. Not for nothing is the family caregiver called a secondary victim of Alzheimer's.

Discussion
Already in 1982, Elaine Brody pointed out that the burdens on non-professional caregivers are enormous; and while there has been sporadic attention to this phenomenon, studies have been largely anecdotal, limited by methodological problems and small samples. There are currently two to four million AD patients in the U.S., a number expected to swell to fourteen to sixteen million by 2050 as the population ages. At present, about eighty percent of these patients are cared for at home, by family members - eight or nine times out of ten, by women (primarily wives or adult daughters). Half of these women are, like Marcie, in their fifties or perhaps sixties, "sandwiched" between responsibilities of caring for a demented parent and for husband and children, often trying to hold a job as well (though like most, Marcie will eventually quit her job to provide 24-hour a day care that seems like a "36-hour day"). The other half are wives whose husbands of thirty and forty and fifty years have become strangers. Each of them faces multiple, simultaneous stressors, aspects of a debilitating trilogy: high demands, low control, and poor social support.

There are physical burdens of constant caregiving, dealing with wandering, sleep disturbances, bizarre or repetitive behaviors, and helping with bathing and toileting, all for a person who cannot seem to appreciate or cooperate reliably with her efforts. There are financial pressures - Agnes' small savings are gone, and she and Don are paying over $12,000 a year for Agnes' care with no reimbursements from insurance or government programs. There are intrafamily conflicts - the one time Marcie mentioned "nursing home" her brothers reacted strongly against the idea, yet they always have excuses about why they cannot take Agnes for a week or even a day, and Marcie has given up asking. Marcie knows that she herself would feel guilty about placing her mother in a facility and "abandoning" her. Her own children avoid being home with Grandma as much as possible. There is social isolation - Marcie can't leave Agnes alone, and Agnes will not accept care from anyone else. Her contacts with her friends have disappeared. She is experiencing multiple losses, but there is no social ritual or recognition for her in her mother's slow death as there might be if she had cancer. And the losses will go on and on; Agnes will never get better, only worse.

But worst of all for Marcie, the research suggests, is the emotional burden - grief for Agnes' losses as well as her own; frustration; embarrassment; loss of her own privacy; feeling helpless and trapped into this role not of her choosing; anger at her family, her mother, herself; guilt at her selfishness in wishing the burden were gone or in taking a day for herself. Marcie is three times as likely to be depressed as others over fifty-five; and though her depression is acknowledged, it is rarely treated. Even if Agnes is institutionalized, Marcie's stress will not disappear if she is like most of her peers; she will continue to render care, advocate for her mother, and expend emotional energies at the nursing home.

Some outreach to family caregivers has been attempted, including things like support groups, respite services, home health care, and personal and family counseling. However, most caregivers do not make use of these services for a variety of reasons: feeling the need to do it themselves; thinking others should know their needs without having to ask; fear of imposing on others; the patient's rejection of other caregivers; the belief that no one else can give care as well; not knowing how to access services or finding attempts to access them too difficult; or the belief that no help is really needed.

Marcie, like many other caregivers, continues to accept this role - with more grace some days than others - for deeper reasons than duty, social utility, prudence, autonomy, or other abstract concepts could explain. Marcie doesn't know anything about an "ethics of care," but she does love her mother, and believes that what she is doing is the right thing, despite the sacrifices, the costs, the stresses, the burdens. She has found meaning in her role, and that allows her to cope with its demands. Somehow, through the impenetrable fog of her mother's mind, Marcie believes that Agnes understands, and her very dependence is the precise reason that Marcie's love takes the concrete form it has. If only, Marcie thinks, everyone could see it this way, acknowledge the value of what I am doing, and support me instead of turning away or making this harder.

**Conclusion**

Non-professional caregivers of persons with Alzheimer's disease render the vast majority of care for this population, and they experience a range of physical, psychological, and social burdens without adequate support or assistance. In the relatively limited research that has been done, these caregivers suggest that it is not so much the demands of the role as the lack of social support for their efforts that create the largest burden on them. How this broadly practiced pattern of sacrifice and service does - and ought to - fit into established concepts of healthcare ethics is not entirely clear. Systemic changes
are needed to provide financial assistance, needed auxiliary services, alternative care structures, and most of all, education, social support and recognition for this increasingly prevalent role of caring for the deeply forgetful in our midst who are among the very weakest and most dependent.

Fr. Thomas Knoblach, PhD (c)


Questions For Discussion

1. How might a concerned healthcare provider identify and assist non-professional caregivers in an era of rising costs and limited resources? Is such an outreach necessary?

2. What kinds of changes would need to take place in the current healthcare delivery system to assist non-professional caregivers?

Suggested Readings


See *Journal of Clinical Ethics* 9, 1 (1998) for detailed discussions of neglected ethical issues related to Alzheimer's disease and various ethical methodologies.
Conflict Between Families and Providers: Avoiding Treatment Disputes

Conflicts involving end-of-life treatment decisions can demand an inordinate amount of a health care professional's time. Providers desire to avoid conflict, for decisions must be made whether or not to continue treatment and, if so, which interventions to continue. Prolonged disputes can be emotionally unsettling for physicians and nurses and for patients and their families.

One can think of conflict over health care as an intersection in which four busy streets come together. Traffic planners take great care to add safeguards to help prevent accidents at intersections. They might upgrade traffic lights, add turning lanes, or decrease speed limits. Similarly, four "streets" intersect when end-of-life decisions must be made: the nature of health care, family dynamics and functioning, the interaction between families and health care teams, and the influence of culture on medical decisions. These four factors, akin to four converging streets in a city, lead to the intersection of conflict. If health care providers don't give proper regard to the intersection of these four elements, the result can be the administration of inappropriate treatments, caregiver burnout, dissatisfied patients and/or families, and legal action.

In first part of this essay, several ethical principles and concepts involved in end-of-life treatment disputes are described. Then, each of the four factors leading to the "intersection" of conflict is discussed. Finally, strategies are suggested for avoiding end-of-life treatment disputes. This paper specifically addresses conflict between providers and patients' families; however, much of the following could apply to conflicts with non-family surrogates as well.

Principles

Several makes and models of cars head toward a busy intersection. Similarly, end-of-life treatment disputes involve clashes between various principles and concepts. An example of such a clash occurs between patient autonomy and provider autonomy. Medical decision-making in the United States has placed great value on the principle of respect for patient autonomy. Western medicine grants patients the basic right to say what happens to their own bodies, but problems arise when an incompetent patient has not designated a surrogate and state laws do not clarify who the decision-maker should be. Even if a surrogate is known, family members may disagree about the proper course of action among themselves. When a patient demands treatment with an ineffective drug that is outside the bounds of standard care (e.g., use of an antibiotic to treat a cold), respect for provider autonomy gives the physician the legitimate right to refuse; however, ethical boundaries become murky when families insist on inappropriate treatments. For example, a family might demand that an antibiotic be prescribed to treat pneumonia in a comatose patient who has terminal metastatic liver cancer. In this situation, the patient's interests and wishes (ostensibly represented by the family) and professional authority and judgment may conflict. In addition to autonomy issues, there also may be different understandings of what is good for the patient and hence what constitutes beneficence. The family's desire to do what it thinks best for the patient may conflict with the provider's sense of appropriate and inappropriate care.

Families of patients are often involved in end-of-life decisions because patients want them to be. A public opinion poll showed that 30% of respondents wanted their families to make medical decisions should they lose the ability to make decisions of their own. Fifty-three percent wanted their families to decide in concert with their physicians. Therefore, adding these two statistics together, a notable 83% want families involved in making decisions if they are unable to. Many physicians willingly seek family consent because they do not want to make important end-of-life decisions alone. However, health care literature often depicts families as extraneous to the care of the patient. A persistent tendency is evident to equate families with trouble. The patient-centered perspective in health care may be rooted in the Western focus on patient autonomy and the sanctity of the physician-patient relationship. Thus, the high value that most patients place on the importance of the family being involved in treatment
decisions can conflict with the traditional emphasis on patient autonomy.

The concept of medical futility can be viewed as conflicting with the principle of the sanctity of human life. Schneiderman, Jecker, and Jonsen have defined medical futility in two ways: "when physicians conclude that in the last 100 cases, a medical treatment has been useless" (quantitative), or "if a treatment merely preserves permanent unconsciousness or ... fails to end total dependence on intensive medical care" (qualitative). However, some families might feel that medical futility is an excuse used by the health care team to devalue the life of a patient so that treatment can be stopped. For some family members, futility may imply an uncaring or indolent attitude, whereas the medical team, in reality, highly values life and desires to provide the best care for a patient. On the other hand, providers may be suspicious when individuals openly assert strong pro-life views because estranged family members have been known to use sanctity-of-life arguments to inappropriately prolong the life of patients so that reconciliation might take place. Therefore, misconceptions on the part of families and on the part of providers can lead to a clash between medical futility and sanctity-of-life arguments.

Discussion

The first street, or factor, involved in the dynamic of provider treatment disputes with families is the nature of health care itself. In order for families to exercise their responsibility to make treatment decisions, they must have access to understandable information about the patient's condition. Unfortunately, obscure medical terminology can complicate the decision-making process. Most people have little medical training, and even the simplest medical term can cause confusion. Large health care teams, with shifting or changing members each trained in separate professions and specialties, also can fracture communication between providers and families. A hospital may easily have different physicians on duty from week to weekend, or even from one day to the next. Each brings differing experiences and expertise to the case. Sometimes sincere differences in opinions in diagnosis and treatment occur between physicians. A nurse may insist a treatment is beneficial which a physician thinks is futile, or vice versa. These inconsistencies and ambiguities increase the potential for conflict.

The second street leading to the conflict intersection is the perplexity of family dynamics and functioning. Several causes contribute to the potential for conflict between family members, or between the family and the health care team. For example, family members are placed under extreme stress when making medical decisions. Sometimes the family may have to rely on advice given by a younger family member who has medical training, rather than on advice from established family leaders. Several family members might have had to travel great distances to the bedside and are lacking adequate rest. For some family members, the threatened loss of a loved one may open up unhealed wounds from the past. Taking all this into account, families in crisis often have difficulty processing and retaining information therefore contributing to the potential for conflict.

Problems caused by the interaction of families with health care teams are the third street. Some providers may be wary of involvement of family members in health care decisions because families might seem to interfere with traditional physician-patient relationships. Providers might cast a wary eye at certain family members, thinking that they might lobby for treatment decisions based on their own best interests rather than that of the patient. Even though physicians might believe that a certain family is committed to doing the right thing for a patient, the question remains open whether or not family members always know how to do the right thing for a patient. On the other hand, families may view the health care team as outsiders who do not really know what their loved ones would have really wanted. This potential for an atmosphere of uneasiness between providers and families could lead to conflict over medical decisions.

The fourth and final street leading to conflict is the influence of culture on medical decision-making. Culture is a strong determinant of people's views of the very nature and meaning of suffering, illness, and death. Illness may have a spiritual meaning for some. For example, in the Christian tradition, suffering can be given a constructive meaning by relating it to the cross of Christ. In non-Western cultures, interdependence might be more highly valued than individual autonomy. Cultural differences and language barriers can often cause simple communication errors. Bowman relates a situation describing why a female family member felt that an ICU physician's attitude toward her mother was "cold." She became upset because he twice referred to her mother as "him." The physician, who was from China, later confessed to others that he was nervous. The third person singular personal pronoun in Chinese has no gender distinction. So when he became nervous because the meeting wasn't going well, the physician defaulted back to this characteristic of his native tongue and called the mother
Just as traffic lights, sand-filled barrels, and seat belts are used to prevent or minimize the effects of accidents, so there are various strategies for minimizing or handling treatment disputes at the intersection of the four "streets." Rather than speaking of futility when discussing the appropriateness of a medical treatment, physicians might want to explain the idea that when benefits outweigh burdens of treatment, treatment may be appropriate, but otherwise not. Providers should not hesitate to explore a family's perception of their loved one's illness. They could enable the family to share their feelings about the patient. The team might encourage the family to contact friends, other family members, or religious leaders such as pastors, priests, or rabbis. Chaplains or social workers can provide additional on-site support. Providers may strive to foster and assess family coping mechanisms on a psychological level (e.g., unresolved issues), on an interpersonal level (e.g., support), and on a sociocultural level (e.g., deathbed rituals).

There are several hazards the health care team might want to avoid when interacting with a patient's family. Having a patient-centered perspective and not viewing the family as an integral part of a patient's identity and life raises an attitude of mistrust for the provider by the family. Members of the health care team also need to avoid being impatient and giving the impression they are not approachable. A provider should seldom give unexpected news by phone, for there is too much potential for miscommunication without personal contact. Because medical practice consists of many procedures, physicians might be tempted to view a family meeting, in which withholding or withdrawing treatments will be discussed, as just "one more thing to do." Rather, it's advisable to present treatment decisions to families as just one aspect of an overall plan of care. When speaking with patients or their families, it is wise to avoid certain words and phrases that may become stumbling blocks during the discourse.

The word "futile" is a technical term in medicine, but to families it might imply that a patient is not worth the effort of comprehensive care. A phrase like "it's time we talk about pulling back" can insinuate abandonment, or describing CPR as "doing everything" may suggest that, if a do-not-resuscitate order is written, the medical team is doing nothing. Rather, physicians could open a family meeting by reinforcing the goal of appropriate health care with these words: "We can hope for the best, but we also need to plan for the worst."

**Conclusion**

Difficulties in family functioning can be amplified by medical complexity, poor communication, or discrepancies between caregiver statements. Accurate communication is vital between families and providers when end-of-life treatment decisions are being made. Providers must remind themselves to give frequent updates to families in simple language. Patience is vital; families often need time to understand and accept the situation. Providers should affirm that they will never abandon the patient. Health care training in cross-cultural differences, team building, communication, and conflict resolution would help. Health care organizations need to improve policies and procedures for improving team functioning, facilitating communication, and dealing with potential conflict.

Kevin E. Voss, M.Div., D.V.M.


**Questions For Discussion**
1. Which ethical principles or concepts often clash when a conflict arises between providers and a patient's family?

2. What four factors contribute to the potential for conflict between families of patients and providers of end-of-life care? How have you experienced these factors in your personal or professional life?

3. What support systems or personnel from within the hospital are available for a health care team when a conflict develops between it and a family, or between family members? How could an ethics committee help? How might family support systems be utilized (e.g., clergy)?

Suggested Readings

