In This Issue

Feature Articles

PAGE 2
Narrative and Ethics Consultation
Lynn Maitland, Ph.D.

PAGE 6
Raising Our Voice for Health Reform: A National Priority and Moral Imperative
Jeff Tieman and Ron Hamel, Ph.D.

From the Field

PAGE 9
Aging and Long-Term Care: Some Ethical Challenges
Msgr. Charles J. Fabey

PAGE 13
Tools for Discernment on Health Care Reform

Ethical Currents

PAGE 15
Emergency Contraception Revisited

PAGE 16
When Has Death Occurred and When May Organs Be Procured?: The Next Major Bioethics Controversy

Of Note

PAGE 18

Resources

PAGE 24
Health Care Reform
Narrative Ethics
Donation after Cardiac Death and the Dead Donor Rule

PAGE 27
Book Review
For more than twenty years, there have been many within the bioethics world who were unconvinced that the principles approach to case consultation offered the objective and universal guidance that had been envisioned.1

Physician and philosopher Howard Brody has written extensively about how principles have turned out to be less transparent and universally helpful than hoped. In fact, the process of applying principles to real cases in bioethics has proven to be challenging because most often there is so much information lacking about the situation and the individuals involved. As Brody puts it, “Principles tell us … to respect patients’ autonomy; but what might it mean to respect the autonomy of Mr. Smith in Room 1303? Principles cannot instruct us how to act unless we first add quite a long list of facts and assumptions about Mr. Smith, his mental capacity, how he relates to various people around him, his medical condition and so forth.”2

Others offer similar criticism. Margaret Urban Walker points out that a diverse group of moral philosophers and bioethicists has challenged theories based on a system of principles built on impersonal, action-guided formulas, such as utilitarianism or Kantian deontology that are deductive processes that render moral judgments through a top-down application of codelike theories.3 Walker suggests that these criticisms generally fall under three common themes. First, principles lack appreciation for the social situation of morality. Second, principles miss the importance of viewing morality in the context of particular situations. And third, principle-based theories lack the recognition that moral deliberation and decisions often change communities, relationships and sometimes moral ideas themselves.4

What most critics argue for is the appreciation that narrative understanding of moral problems and narrative as a means of moral deliberation better capture the particulars of the situation and enrich the case with context and details often cut off when a case is framed by principles. Walker believes that moral understanding and resolution require an understanding of the person’s history of trust, expectation and responsibility. There must be consideration of the stories of relationship, identity and beliefs to see how decisions will affect the patient as well as those who are close to the patient. She argues that when health care providers or ethics consultants talk in terms of informed consent or confidentiality, they may be speaking a different language than patients and families who are concerned about filial obligations, gratitude, trust and self respect.5

In the introduction to Stories Matter, physician Rita Charon traces the recognition of narratives’ centrality to looking at cases. She states: “[N]arrative approaches to ethics recognize that the singular case emerges only in the act of narrating it and that duties are incurred in the act of hearing it.”6 In her essay “Narrative Contributions to Medical Ethics,” Charon offers a rather loose framework for using narrative knowledge in the practice of ethics consultation. Charon argues that narrative helps to contextualize and particularize the conflicts in which medical ethics consultants find themselves. Using a narrative approach in ethics deliberation allows the ethicist to look for some narrative coherence in the patient’s life. This coherence often is the clue needed to help family and caregivers make decisions for the patient who cannot speak for herself. The ethics consultant often must wade through multiple tellings of the patient’s story, as well as the different interpretations of that story. There may be contradictions in the various tellings and the ethicist must try to sort out truth from fiction. But if the ethicist or ethics consultant develops the skills to do this, her effectiveness and accuracy in ethical deliberations will increase.7 The following case illustrates the importance of hearing the patient’s narrative from various viewpoints.

Mrs. Smith is ready for discharge and her physician believes she should go to an extended care facility for rehab. Mrs. Smith’s daughter, Ann, agrees with the doctor that her mother would benefit from rehab. However, Mrs. Smith is adamant about going straight home. Her husband has
Parkinson’s and she has been his caregiver for over five years. Ann thinks her mother is just being stubborn, as she often is. In fact, her mother is the reason that Mr. and Mrs. Smith haven’t moved to assisted living as Ann has suggested. The doctor thinks Mrs. Smith is unrealistic about her ability to go home and care for John and that it will be unsafe for both Mrs. Smith and her husband. Mrs. Smith stands her ground and refuses to consider an extended care facility, even for a short time.

One could argue that the patient’s autonomy should trump and it is Mrs. Smith’s decision to make, but much would be missed if the stories of both the patient and the family aren’t filled out. For example, is Ann’s anger at her mother long standing and does that make it difficult for her to be sympathetic to her mother’s concerns? Does the doctor just want to discharge the patient and not worry about the “whys”? Has anyone offered Mrs. Smith other options or asked why she is so steadfast in making what appears to be an unsafe decision? An ethicist skilled in eliciting the patient’s story and assessing the narrative for authenticity and trustworthiness would want this information before making a recommendation. Although filling out the narrative takes time up front, it may actually facilitate a timely and appropriate resolution of the impasse.

Howard Brody believes that narrative ethics has a democratizing influence on the process of resolving challenging ethics cases. He claims that narratives of the kind told by people are inherently democratic, a point that Brody makes about the moral choice imbedded in honoring a patient’s story. Brody says that ordinary people strive for clarity when they tell their story or the story of a loved one. The democratic underpinning is that everyone has a story and that each of us is in the best position to tell it. However, Brody also cautions that in some sense every narration is also an exercise in political power. Communities are generally organized in a way that not just anyone can tell a story and be sure of an audience’s attention or acceptance of the story. Brody claims that some stories and storytellers are marginalized even before the telling begins. Others are privileged by power and authority and gain ready assent of the audience, even when the story appears to fly in the face of known facts. Obviously, in the health care setting it has been the physician’s telling of the story that has always had more influence, more “truth”, and is more worth listening to. Although the doctor’s version invariably carries more weight than the nurse’s or the social worker’s, the patient’s version frequently carries the least weight of all. So Brody cautions that without serious consideration of all versions of the narrative, using narrative in ethics consultation risks being as elitist as he believes the principlist process to be. For all of us involved in ethics consultation, Brody’s words ring with some truth. When a consultation request is made, we read through the chart and speak with the physician before we attempt to see the patient or family members. How often are we unwittingly prejudiced in some way by what we have heard or read before we have even spoken with the patient whose story we are to consider? Brody suggests that without serious consideration of all versions of the narrative, the narrative process will be driven by those with power to determine whose version of the story gets told and accepted.

In spite of Brody’s concerns, he and others believe that using narrative as the basis for moral deliberation is not only respectful, but is more reflective of how we come to know about one another and understand our similarities and differences, as well as how we look at moral problems. From the time we were children, when we went to our parents or teachers with a problem, the first question we were asked is, “Tell me what happened?” In our everyday interactions we are often asking for the story or narrative in order to have greater understanding of a problem, a hurtful event, or an ethical dilemma.

Walker claims that story is the basic form of how we represent moral problems. She argues that it is important to know who is involved, how they understand themselves and each other, what in the relationship brought them to a situation that is morally problematic, and what social or institutional boundaries shape their options. She also suggests that narrative is better at capturing the process of moral resolution in a way that is mindful that moral problems are snapshots in the ongoing histories of the people involved.

This recognition of the importance of narrative in uncovering moral problems should resonate with those of us doing ethics consultation within a Catholic hospital or system. Our faith tradition, so deeply committed to human dignity and the importance of community, inevitably leads to the appreciation that narrative is the most respectful
means we have of discovering who a patient is and how his story should impact ethical decision-making. Sr. Patricia Talone, CHA vice president, mission services, reminds us that as Christians, we know that Jesus revealed truths through the telling of parables. Jesus’ appreciation of the power of story should guide us in our efforts to reveal the truths present in every consultation.\textsuperscript{11}

It’s important to keep in mind that none of these writers totally rejects a role for principles. In fact, Rita Charon believes that principles are and should be the underpinning of any resolution of an ethical dilemma. She claims that narrative’s role is to particularize the decisions and increase involvement of patients and providers.\textsuperscript{12} Brody doesn’t take a strong stand on this. He believes that regardless of whether one uses a process grounded in principles and gives narrative a more peripheral role, or one that rejects the use of principles as an essential to ethical decision-making, ethical discernment that employs narrative in some way is always superior to doing ethical analysis without narrative at all.\textsuperscript{13}

Of the three, Walker takes the strongest stand that narrative should ground the ethics consultation process, but she does not dismiss the role of principles either. She claims that their role should be to mark broad areas of value or to define generic priorities.\textsuperscript{14} Her argument is that only the content of individual and family histories can define what in this situation is owed to whom and why and what different moral resolutions of particular cases will mean to those individuals involved. For example, sending one’s mother to an extended care facility may be clinically the best choice, but to do so may cause a breach of trust between a mother and her adult child who has promised that he will never do that. The stress on that relationship might last much longer than the actual stay in a facility and such an effect needs to be considered.

The challenge for the ethicist of shifting to a model of consultation based on narrative is that it is not as clear a framework as the principle-based model. However, regardless of how the ethicist employs narrative, it is essential to its successful use to hear as many versions of “the story” as possible and then try to sort out the different perspectives in a way that facilitates reasonable and respectful ethical discernment. This ensures that there is active participation by patient and family, along with other caregivers involved in the case.

A few months ago, I received a request from a physician to meet with a family in order to facilitate decision-making for an incapacitated patient. The physician warned me that the family was struggling and would require a great deal of time. The decision-makers were two children of the patient, both of whom were in their early twenties. The patient had been divorced from their mother for many years. The 61-year-old patient had suffered a massive stroke and was unresponsive and on a ventilator. The physician was ready to try weaning the patient, but wanted to know what she should do if the patient failed the trial. She had talked to the patient’s children, but felt they weren’t really able to make this decision.

I scheduled a meeting with the children and asked if anyone else should come. They wanted their aunt and uncle, the patient’s sister and brother-in-law to attend. From the brief conversation with the daughter, it was clear that they were completely overwhelmed by the gravity of the decision they were being asked to make. When I met with them and the other family members, I asked the son and daughter to explain to me what they understood about their father’s condition. It was apparent that they had a good appreciation of his condition and his prognosis. I then asked them, as well as the patient’s sister and brother-in-law, to tell me about the patient. What was he like, what was important to him, what his goals were, and so on? For over an hour they talked about the man they knew, describing him as adventurous, very active and physical, that he was an avid hunter and was consumed by major renovations to his home that he was doing himself. He had been a loving and engaged father and that he loved his dog. At the end of the conversation, I asked the children if he were able to tell them what he would want, what would he say. Almost without hesitation they agreed he would not want aggressive measures if he were not able to return to an active life. Their aunt and uncle agreed. They decided that if he failed the vent weaning that he should be allowed to go peacefully, and either way he should be a DNR.

This is a case in which the family was able to make decisions for the patient after talking about who he was. There was no discussion of principles, but just recognition of the patient’s narrative as they had experienced it. This was likely the final chapter of that narrative and the children and other family members were able to allow it to unfold as they believed he would want.
There are many ways narrative can be an essential part of ethics consultation. It can be a very formal process or a more informal conversation as the one I’ve described. The challenge of narrative is to make sure that the patient’s story is heard in as many forms as may be necessary, so that decisions made reflect and honor who the patient is. As Margaret Urban Walker suggests, using narrative encourages the recognition of each other as moral agents, capable of making reasoned and responsible choices that have been made in consideration of responsibilities and values, and that allows individuals to be responsible to self and to others “… for the moral sense and impact of what they do.”

NOTES
4. Ibid.
5. Ibid., p. 36.
7. Ibid., 260-61.
9. Ibid., 35
15. Ibid., p. 37.

(Editor’s Note: Please see the Resource section for a select listing of theological sources on narrative ethics).
A National Priority

Many primers and essays on health care reform begin with this statistic: 47 million people in the United States are uninsured. Disturbing as it is for so many people to lack insurance coverage, it really only skims the surface of what plagues our health care “system.”

In the wealthiest nation on earth, we indeed spend the most money per person on health care – approximately $6,000, or more than twice what other industrialized nations spend. And, in many measurable and important ways, those nations provide better health care than we do.

According to the Commonwealth Fund, a foundation that conducts research to promote a high-performing health system, the U.S. ranks last among Australia, Canada, Germany, New Zealand and the United Kingdom when it comes to our system’s efficiency, equity and ability to promote long, healthy and productive lives.

This is not to say that those countries do things perfectly, or that we should mimic their systems. It does, however, give us evidence that we can do better—and that if our priorities and our planning were reconfigured, we would do better.

For too many people, the stakes are of the greatest possible magnitude. The Institute of Medicine has concluded that more than 18,000 men, women and children in the U.S. die each year because they lacked health insurance, not because their conditions were untreatable or their disease stages too advanced for intervention. Instead these people died because the lack of coverage prevented them from receiving life-saving treatment before it was too late.

So we spend more and get less for our money. Meanwhile, millions can’t access the system at all, except perhaps when they show up in the emergency department to receive care for anything from the common flu to a serious condition that should have been addressed much earlier by a primary care physician.

The ED, we know, is the most expensive and least effective place to be treated for anything other than a true emergency or trauma. When we treat people in the ED because they have no other option, we pay more for those encounters than we would have by ensuring access to proper preventive and primary care.

Add to this the health care industry’s poor record on implementing life- and cost-saving information technology. A car owner can get an oil change at Grease Monkey in Dayton, Ohio, then drive to a Grease Monkey in Los Angeles and find that the record reflects everything done to the car in Ohio. That car, in other words, has a mobile record reflecting its “medical” history. The same is not nearly as true in health care, where a patient could visit two hospitals in the same city and neither would have any record of his or her treatment history.

Information technology can expedite bulky and expensive administrative procedures but, even more important, can prevent nurses from administering the wrong dose of a medication or a surgeon from performing an operation on the wrong body part. If we can do it for cars, we can do it for people.

The list of other problems in our health care system is too long to examine here but it includes a host of critical issues we need to confront: health disparities that result in (sometimes vastly) different treatments and outcomes for minorities; a growing shortage of nurses and rural health care professionals; and misaligned incentives that do not reward quality.
From an economic standpoint, the status of our health system is both irrational and unsustainable. In 2005, the United States spent 16 percent of its GDP on health care, while the median for other developed countries was 8.5 percent. In 1960 we spent only 5.2 percent of our GDP on health care. Today we spend more on health care than we do on food.

This puts us at a competitive disadvantage globally. A study by the New America Foundation found that U.S. firms spent twice as much on health care in 2005 than their foreign competitors. For every American worker earning $18 per hour, U.S. companies spent $2.38 per hour on health insurance. In contrast, firms in Canada, Japan, Germany, the United Kingdom and France paid an average of $20 per hour and spent $0.96 per hour on health insurance.

Meanwhile, the cost of health insurance hugely outpaces the growth in wages – between 2000 and 2007, the net cost of private family health insurance premiums increased 91 percent. Workers’ earnings in that 7-year period grew only 24 percent.

What all these facts and figures add up to is a system that simply cannot sustain itself over the long haul without intervention and change. Some argue that we do not have a health care “system” at all—that it lacks any kind of strategic and integrated coordination. Health care involves so many players and parts that it can easily defy this kind of coordination. Still, reform efforts can and should recognize the need for better planning among all the stakeholders—patients, providers, insurers, employers, government and charity organizations.

With the recent and growing downturn in our economy, many people will argue that health care reform has to wait, that we simply don’t have the money to make real changes. Given the scenario described here, the opposite is actually true: we cannot afford NOT to reform the system.

It is no longer an option to make this a back-burner issue. The economy and health care are too closely correlated to treat them as separate and isolated issues. Fixing health care can and must be part of revitalizing the economy, and a growing number of policy and economic experts are coming around to this viewpoint.

If we do not opt to repair the health care system for economic reasons, we should do it for moral and ethical reasons. Unless and until we act, millions of men, women and children will suffer needlessly and the economic cost will grow.

A Moral Imperative
In a talk on “The Right to Healthcare” delivered in 1993 to the National Conference of Catholic Bishops, Joseph Cardinal Bernardin observed that “the current health care system is so inequitable, the disparity—between rich and poor, between the sick and the well, and between those with access and those without—is so great, that it is clearly unjust.” That was 15 years ago when there were approximately 37 million people in this country uninsured. The situation has only worsened. What led Bernardin to make this claim is the belief, deeply rooted in the Catholic tradition, especially in Catholic social teaching, that health care is not a mere commodity, but “an essential safeguard of human life and dignity.”

Health care is a fundamental human good. It is one of those necessary conditions for protecting, promoting and enhancing the inherent dignity of all and of furthering human flourishing. It is part of the pro-life commitment of the Catholic community. Here Bernardin is simply echoing the words of John XXIII in his encyclical, *Pacem in Terris*, when he affirms that all have a “right … to the means necessary and suitable to the proper development of life,” which includes medical care. The American bishops, on several occasions, have affirmed this notion that health care is a fundamental human good.

Drawing again on the Catholic social justice tradition, Bernardin also believed that the health care system is unjust because it is a violation of the common good and of distributive justice. The common good speaks to a society’s providing those conditions that are necessary for each person to have the opportunity for full human development. One of our major social institutions—health care—which ought to provide a fundamental human good fails to deliver for a large portion of American society. Furthermore, distributive justice requires that the goods of society be distributed in an equitable manner to all members of society. That is not the case with health care.
For these and other reasons, the situation of health care in our country is both a moral failure and a moral challenge. It is a moral failure because our nation has lacked the will to pursue reform of the system so that all our people are accorded this fundamental good. It is a moral challenge because every citizen and every lawmaker can no longer rest content with this “clearly unjust” situation. What will likely be required is a brutally honest examination of our hearts and minds to identify those values, beliefs, assumptions and motivations that perpetuate the current situation and that undermine efforts at reform. A fundamental requirement of health care reform is a transformation of hearts and minds — of individuals, communities and society. Short of this, it seems doubtful that we will make any progress, and 15 years from now Cardinal Bernardin’s words will sadly be as applicable as the day he spoke them.

If the existence of profound injustice in our midst is not sufficient reason for us to care about health care reform, then the Gospel should be. Jesus defined his mission in the world as bringing about the Reign of God (Lk 4:18) or, put differently, making God’s way present in the world, making relationships right. And he told his disciples to “Go and do likewise” (Lk 10:37). Working to realize God’s way in the world, to make relationships right, to bring about justice, is not optional for those who claim to be Christian. This is at the heart of what it means to be Christian. For Christians to ignore instances of injustice is to fail at what they should be about.

So why should we care? We cannot not care, because we should be about promoting the Reign of God. And we should be about caring for those on the side of the road. This parable, the Parable of the Good Samaritan (Lk 10:30-37), is often used as a paradigm of Catholic health care. In so many ways, it is. But in at least one way, it falls short. The parable assumes conditions as they are. In fact, what is needed, is to change the road and to alter conditions so as to avoid having people along the side of the road. Working for the Reign of God entails not only caring for the poor and vulnerable, it also entails transforming unjust social structures, those conditions in our communities and in our society that prevent God’s way from being realized.

There is much injustice in American society as recent events in the housing, investment, and stock markets so well illustrate. And there are many fundamental goods essential to human dignity at stake for so many in our society. Health care reform is one among many issues that needs to be addressed. Even though in the weeks and months ahead, other concerns may take priority because of their importance and their immediacy, it would be unwise to lose sight of the need for health care reform. The current economic crisis is likely to leave millions more in this country uninsured. An already unjust situation will be exacerbated precisely because of the structure of our health care system.

Catholic health care can play a vital role in “making relationships right” in the area of health care. It can do this, as it so often does, by advocating in various ways for reform. But it can also participate in the desperately needed work of transforming hearts and minds. It can do this in the local community and, perhaps, above all within our organizations. Engaging staff in a series of reflections on health care reform, whether sponsored by administration, advocacy, mission, or the ethicist or ethics committee, can be a further expression and exploration of Catholic identity.

NOTES

4. For example, in their 1981 Pastoral Letter on Health and Health Care, the bishops write: “… the Church considers health care to be a basic human right which flows from the sanctity of life” (Introduction). There are other references to health care as a basic right throughout the document, such as in Part V on Public Policy. See also, Economic Justice for All (Washington, D.C.: USCCB, 1986), where the bishops include health care in a listing of “fundamental human needs” par. 90.
Aging and Long-Term Care: Some Ethical Challenges

By Msgr. Charles J. Fahey, Diocese of Syracuse, Researcher, Loretto Institute for the Frail Elderly

Msgr. Charles Fahey is a priest of the diocese of Syracuse, N.Y. and the former director of the Third Age Center at Fordham University, Bronx, N.Y. Currently, he is program officer with the Milbank Memorial Fund and researcher for the Loretto Institute for the Frail Elderly in Syracuse.

Editor’s Note: Msgr. Charles Fahey offers the following reflection as “grist for the mill.” Several questions follow his reflection to further the conversation he has begun. We invite readers to share their thoughts with us and with one another. We will publish your responses either in future issues of HCEUSA or on the HCEUSA page on the CHA website.

Introduction

Reflection on ethical issues in long-term care results in large part from the relative newness and size of an extended “third age,” that is, that time in life that is generally characterized neither by reproduction nor production. This third age has become more common only at the end of the twentieth century with so many people living longer as a result of lifestyle changes and medical interventions. Endemic to this part of the life cycle is progressive intermittent frailty (PIF) which, for many, requires long-term care. Hence, the magnitude of long-term care, at least for older persons, corresponds to a reduction in premature mortality.

This reflection will consider underlying causes of the need for long-term care as well as domains where ethically laden issues lurk.

The Third Age and Frailty

The “three ages” and “frailty” framework may require explanation. Understanding the concepts can contribute to developing and evaluating strategies, programs and policies as well as identifying the ethical dilemmas.

The Three Ages

This “three age” phenomenon is found in all living things. It is biologically driven as nature ever renews itself. Historically, there have been high rates of mortality in the first two ages with relatively few survivors into the third age. However for humans, scientific discoveries, their application and availability have reduced premature mortality, extending life into the third age for most people in developed countries.

During the “first age” — the period in the life cycle from conception until physical maturity — frailty is a reality. Nothing is more vulnerable and in need of external assistance than a child at each stage of its development. However, childhood frailty regresses as a child matures physically, emotionally, intellectually and spiritually. The child gradually moves toward relative sufficiency and acquires the ability to interact positively with his or her environment and to fulfill personal and societal roles. Ideally, the growth of the child is supported by parents and various social structures such as schools.

The “second age” is the period of maximum physiological capacity for reproduction and production. Individuals at this stage are at the height of their capacity to assure the continuation of the species. Ideally, these individuals develop and fulfill their personal life plans even as they, both as individuals and as members of society, contribute to the common good. In this period of the life cycle, frailty may occur, but it is the exception rather than the rule. It is generally a time of maximum cellular organization and balance.

The “third age” — the period after parenting — has become normal in developed countries. Life expectancy continues to lengthen. Improvements in public health, better nutrition, education and medical interventions all contribute to this. However, the third age is also marked by random cellular disintegration with cellular repair unable to keep pace. In turn this makes individuals vulnerable to illness (some age associated and some not), trauma (such as falls), organic failures (such as failing eyesight and hearing loss) and chronic
and/or accumulated weaknesses and illnesses. Individually or in tandem, these may make the person ever more dependent on medical interventions, prostheses, pharmacological agents and the need for personal assistance or a more supportive physical environment. Medical interventions can ease frailty in some instances and even preserve life. However, they cannot obviate death entirely nor are they sufficient to assure people’s ability to perform the activities of daily living.

People in the third age are economically dependent on prior earnings, accumulated wealth and participation in risk sharing mechanisms as well as governmental transfer programs. For most persons, it is period of expending wealth rather than accumulating it.

Throughout life, two realities continually interact—the person and the physical, social and economic environment. Personal capacity and external factors contribute to and/or detract from personal homeostasis. Individuals continually attempt to alter both individual capacities and surroundings in order to maintain the balance necessary for a decent life. In the third age, long-term care becomes a necessity when either fails.

Frailty
Frailty has two meanings. The first is a muscular/skeletal syndrome which is marked by diminished capacity such as in walking, lifting and ascending stairs. The second is social frailty, characterized by difficulties in dealing with the demands of everyday living. The frailty that I am referring to involves, but is not limited to, physiological deficits. It also involves other limitations that make life difficult to negotiate.

Frailty consists in the potential or actual disequilibrium between an individual’s internal capacity and external demands coming from the individual’s environment. In the third age, frailty tends to be progressive, albeit intermittent (PIF). Its ultimate expression is death. Regarding frailty, we can say:

- It may be viewed as a state or as a process.
- It may be viewed as actual or potential.
- It may be unnoticed or obvious.
- Its progression may be gradual or dramatic.
- It may be relatively benign and personally manageable or

crippling and requiring substantial external interventions.

- The effects of PIF are idiosyncratic since physiological underpinnings, psychological strength or weakness, as well as the social and physical environments will differ from person to person and from time to time.
- It involves continual adaptations on the part of the person and/or his/her environment.
- These adaptations involve costs—economic, and/or psychological.
- Formal long-term care becomes necessary when the disequilibrium becomes so great that it cannot be bridged by personal and social resources.
- PIF often goes unrecognized until it reaches catastrophic proportions and its costs become evident.

Long-Term Care
Long-term care consists of those supports and environments that assist individuals with advanced PIF to deal with the challenges of everyday life.

The default place of care for the frail is the community; only with intense frailty do long term-care facilities come into play. For some, the “community” is supportive. A degree of dignity can be maintained despite personal losses. For others, frailty is held in check at substantial emotional and economic costs to self and others. Currently, at both the federal and state levels there are efforts to increase “home and community” based services to relieve care-giver burden and to rein in costs associated with nursing homes.

These efforts include:

- Access to appropriate medical and rehabilitative services.
- Encouragement for early decisions about saving and risk sharing to deal with frailty.
- Health promotion and prevention of disease/trauma.
- Management of chronic illness.
- Attention to and modification of physical environment as necessary.
- Assurance of adequate nutritional services.
- Assistance with activities of daily living (ADLS) and instrumental activities of daily living (IADLs).
- Stimulating social, spiritual and intellectual opportunities.
- Care management.
- Better support of informal primary care givers.
- Provision of cash and counseling.
Implementation of these efforts is uneven among the various states.

**Areas of Special Ethical Concern**

People needing help over long periods of time present common ethical challenges. However, just as regressive frailty is endemic to childhood so PIF is normal in the third age. In both instances, the universality of frailty in a definable part of the life cycle creates a predictable ethical agenda for individuals as well as for society. In the first age, this agenda includes evolving and reciprocal parent/child moral claims, while society recognizes the need to help parents and, in some instances, substitute for them through both voluntary and public efforts. The basis of concern and response is primarily the well-being of the children, but also enhancing their potential to become contributing members of society.

The physical, emotional and often financial vulnerability of those in the third age entails serious moral issues for the frail individual, those who care for them and for society as a whole. The individual and society must be engaged in confronting the issues particular to this part of the human journey.

There are four foci that individually and interactively pose ethical issues in a special way in the third age:

- The individual.
- Significant others with moral/emotional/legal ties to frail persons.
- Providers — individual and group.
- Public policy.

**The Individual**

An ethical analysis of frailty in the third age begins with the individual. While not endorsing a “blame the victim” approach, it must be noted that individuals can in some instances affect the course of frailty. Exacerbating or ameliorating factors can be traced to the individual’s behaviors in the area of health, interpersonal relationships, finances and spiritual development. Risky health behaviors can intensify frailty. The development and maintenance of close personal relationships can spell the difference between loving care and isolation. Frailty entails costs ranging from medical interventions and prosthetic devices to personal care and support. Some frail persons have never had the capacity or the opportunity to save or participate in risk sharing mechanisms in order to have resources in times of need. Others may be quite imprudent in making life style choices and become dependent on the largesse of others or the government.

Individuals react differently to losses and limitations. A lifetime of spiritual development and character building, or a lack thereof, sets the stage for how persons will deal with these losses, either with or without some equanimity.

No human event is more personal than dying. However, dying is also a social event that involves others, both loved ones and professionals. For the person, loved ones and providers, there are often excruciating decisions to be made about what are appropriate medical interventions. Unfortunately, the understanding of and commitment to palliative care is still in early stages of development.

**Significant Others**

The social nature of PIF, especially in its most debilitating phases, creates demands on individuals and society.

Frailty within the “traditional” family entails demands on spouses and children. Four and five generation families, single parents, grandparents caring for grand children, the divorced and remarried all challenge the ties that bind and make for difficult moral choices involving competing demands. The intra-familial realities spill over into the policy sector as decision makers attempt to sort out what are private/personal responsibilities and public/governmental duties. What are the affective, instrumental and financial responsibilities in such a confusing set of circumstances?

**Providers of Services**

The professionalization and monetization of caring create new moral and legal, i.e. explicit contractual relationships among the parties. These often involve considerable power imbalances. The frail person is vulnerable to the quality and sensitivity of providers, both individuals and agencies. In both instances, respect for the individual, including that person’s wishes, as well the provision of quality services are essential elements in the legal and moral exchange. To the degree that the frail person is infirm and to the degree the provider is charged with the overall care of the individual, as in the instance of an institution, the greater the moral...
bond and the greater the necessity to exercise careful oversight and to respond sensitively.

The institutional provider should empower the person and significant others, especially surrogate decision makers, with information as well as psychological and spiritual support to make difficult decisions and to live with them.

**Public Policy**

Public policy involves politics. However, “the will of the people” is rooted in their values. Ideally, fundamental option for the poor and vulnerable, maintenance of reciprocity and solidarity and promotion of the common good should be part of the calculus. Unfortunately, it is easier to articulate these concepts in theory than it is to translate them into fair and effective policies and programs.

The ethical/policy decisions will become more acute and more contentious in a period of ever greater national debt, an uncertain economy and growth in the numbers of those in the third age.

**Conclusion**

These reflections are designed to be “grist for the mill.” The idiosyncratic and painful nature of PIF demands attentiveness, ethical sensitivity and sound spirituality on the part of all significant actors, as well as a generous and just response of the body politic.

**Questions to further the conversation:**

1. Msgr. Fahey identifies four areas of ethical concern. What specific ethical issue or issues do you see or encounter in one or more of these areas? How are you or your organization addressing it?

2. What is your organization doing to respond to the needs of the frail elderly now and into the future? Are there practices or programs that you would like to share with the ministry?

Please share your thoughts at HCEUSAeditor@chausa.org
In an article in the January-February 2008 issue of Health Progress, Jack Glaser, senior vice president for theology and ethics at St. Joseph Health System, Orange, California, writes:

Ethical wisdom is the gift not of ethical experts, but rather, as I have argued in a previous Health Progress article, the gift of the right community—the “community of concern.” Different ethical issues require different communities of concern, I noted. “Gathering the community of concern requires people who command essential perspectives on the issue at stake and also share an overarching concern for the common good.” (“The Community of Concern,” Health Progress, March-April 2002, pp. 17-20).

However, in generating ethical wisdom, “communities of concern” consistently need further tools. This article suggests some tools for the moral/ethical challenge of health care reform (“Tools for Ethical Discernment,” Health Progress, January-February 2008, p. 51).

Ethics committees, boards, executive teams, departments and staff can all constitute “communities of concern” in addressing the reform of our health care system.

In addition, in a CHA resource, Building Consensus for Change: A Guide to Organizing Roundtable Discussions on Health Reform, Sr. Carol Keehan, D.C., president and CEO of the Catholic Health Association, writes: “[T]he Catholic Health Association is urging individuals and organizations to take a moment to consider the values and priorities that should drive health reform in America—and how we can build and sustain consensus for productive change” (p.2).

We provide here two resources that can be used to foster discussion about health reform in your organization, parish or community. One is a survey tool from Jack Glaser’s Health Progress article which focuses on identifying priorities that should shape a reformed health system on page 14.

The second resource is a study tool to help you assess various reform proposals. It is on the CHA website at www.OurHealthCareValues.Org.

Additional resources for dialogue and discussion about health care reform are listed in the Resources section of this newsletter.
Values for Shaping the U.S. Health Care System: What Priorities Should Shape the Future?

Health care is an important concern for most people and is an important topic in our government at the national, state and local levels. We want to know your opinion of what should shape the future of the U.S. health care system. From the 15 items below, please select the five priorities that you believe should be shaping the future U.S. health care system. **FIRST, PLEASE READ THROUGH ALL 15 OF THE ITEMS. THEN PICK YOUR TOP FIVE PRIORITIES IN ORDER OF IMPORTANCE.**

1. My top priority is:  
2. My next priority is:  
3. My next priority is:  
4. My next priority is:  
5. My next priority is:  

**01 - Advances in research:** The U.S. health care system should spend more money on research to prevent and treat health problems than it does now.

**02 - Universal access:** The U.S. health care system should make needed services available to all regardless of ability to pay.

**03 - Build on the current system:** The U.S. health care system should expand and improve on the current system -- job-based insurance and public programs like Medicare and Medicaid.

**04 - Comprehensive services:** The U.S. health care system should provide access to a broad range of health care -- prevention, emergency services, trauma, and care for on-going illnesses, as well as care for dental, vision and mental health problems, with the care provided and supported at the most appropriate facilities and locations, including the home.

**05 - Consumer good:** The U.S. health care system should treat health care like other goods and services; it should be available to the extent that you have money to buy it.

**06 - Health care as a business:** The U.S. health care system should allow health care businesses -- such as hospitals, insurance, drug and supply companies -- to make as much profit as they can within tax and other relevant regulations.

**07 - Health care as a national concern:** The U.S. health care system, like homeland security and interstate freeways, needs national planning and financing.

**08 - Minimize the role of government:** The U.S. health care system should reduce the role of government in financing health care (e.g., through Medicare, Medicaid and tax benefits) and providing health care (e.g., through public clinics and the Veterans’ Administration).

**09 - Patient choice:** The U.S. health care system should give patients as full a choice of doctors and other providers, settings and treatments as possible.

**10 - Prevention:** The U.S. health care system should give priority to services and programs that promote health and keep people from getting sick, such as smoking prevention and nutrition/diet education, childhood immunizations and cancer screenings.

**11 - Public participation:** The U.S. health care system should have effective ways for the public to help set priorities for health care, influence decisions about important health care issues, and improve the health care system.

**12 - Quality of health care:** The U.S. health care system should have a more effective way of improving the quality of care and reducing medical mistakes.

**13 - Spend health dollars for direct patient care:** The U.S. health care system should spend as much as possible on direct patient care and as little as possible on administrative costs.

**14 - Stable costs:** The U.S. health care system should keep health care costs from rising faster than the costs of other goods and services.

**15 - Uninterrupted care:** The U.S. health care system should reduce to a minimum the need to change doctors, hospitals, insurance companies and levels of coverage.

Sample Questions for Discussion

1. Working individually, consider your reaction to the survey results. Compare your priorities with those of the group. What do you notice? What surprises you?

2. In small group discussions, create a dialogue in which each person shares an idea or two from his or her reflection on the survey results. As you listen to the conversation at your table, what do you notice?

3. To what extent does the current health care system reflect the priorities of the group?

4. What would need to happen for our current health care system to better reflect the priorities of the group?
Emergency Contraception Revisited

In the spring 2008 issue of HCEUSA (see “Ethical Currents,” pp. 12-13), we provided an update on the controversy over emergency contraception. Among other things, we noted an update article by priest, theologian and scientist, Fr. Nicanor Pier Austriaco, on the mechanism of action of levonorgestrel (LNG) or Plan B (National Catholic Bioethics Quarterly 7 (Winter 2007): 703-707). After reviewing the scientific literature, Fr. Austriaco came to the conclusion that the “studies published in the past few months provide mounting evidence that levonorgestrel has little or no effect on post–fertilization events” (p. 707).

In the most recent issue of the same journal (National Catholic Bioethics Quarterly [Autumn 2008]: 418-425), Fr. Austriaco published another article in which he replies to his critics. Readers of this column are referred to the entire article. Here we report only Fr. Austriaco’s conclusions.

If Plan B is abortifacient, the author observes, it can have this effect in three primary ways. The first is by increasing the rate of ectopic pregnancies. However, he notes that the combined data from five clinical trials with nearly six thousand women showed that the rate of ectopic pregnancies in women who have used Plan B is 1.02 percent as compared to the overall national ectopic pregnancy rate between 1.24 percent and 1.97 percent. In light of this finding, it is unlikely that Plan B increases the ectopic pregnancy rate …” (p. 422).

The second way in which Plan B could be abortifacient is by preventing implantation of an embryo. This can occur by altering the lining of the endometrium, making it inhospitable to implantation. “[M]orphological and biochemical analyses of endometrial biopsies of women who had taken Plan B eight or nine days prior to the biopsy have revealed that the drug does not dramatically alter the structures of this tissue. This suggests that the drug does not compromise endometrial development” (p. 422).

It could also occur by disrupting the function of the corpus luteum which releases hormones that are necessary for the proper development of the endometrium, including making it receptive to an embryo. After reviewing the scientific literature, Fr. Austriaco concludes that “[T]ogether, these data suggest that the risk of a post-fertilization effect from this mode of action for any particular individual woman, if it is real, would be vanishingly small” (p. 423).

Or, it could occur by directly interfering with the implantation process itself. Fr. Austriaco replies: “[O]ne study that directly tested the ability of human embryos to implant on endometrial tissue exposed to LNG—though grossly immoral—does not support this mode of action for Plan B” (p. 423). Two other more recent studies confirm this conclusion.

A third way in which Plan B could be abortifacient is by destroying an already implanted embryo. With regard to this possibility, Fr. Austriaco says: “[A] report from the FDA shows that Plan B does not increase the rate of pregnancy loss or the frequency of fetal abnormalities once a pregnancy has been established” (p. 423).

Fr. Austriaco concludes his article: “[I] stand by my earlier conclusion: In light of the available scientific evidence and given the inherent limitations of the studies, it is unlikely that Plan B is an abortifacient” (p. 424).

—R.H.
When Has Death Occurred and When May Organs Be Procured?: The Next Major Bioethics Controversy

This summer marked the 40th anniversary of the Harvard Medical School’s report that recommended “brain death”—the irreversible cessation of all brain function—as the definition of death. This definition of death and the accompanying criteria have been broadly accepted around the world.

The church itself has accepted the concept of brain death. In an Aug. 29, 2000 address to the 18th International Congress of the Transplantation Society, for example, Pope John Paul II stated that “the criterion adopted in more recent times for ascertaining the fact of death, namely the complete and irreversible cessation of all brain activity, if rigorously applied, does not seem to conflict with the essential elements of a sound anthropology” (par.5). The pope went on to say: “[A] health-worker professionally responsible for ascertaining death can use these criteria in each individual case as the basis for arriving at that degree of assurance in ethical judgment which moral teaching describes as ‘moral certainty.’ This moral certainty is considered the necessary and sufficient basis for an ethically correct course of action. Only where such certainty exists, and where informed consent has already been given by the donor or the donor’s legitimate representatives, is it morally right to initiate the technical procedures required for the removal of organs for transplant” (par.5, see www.vatican.va/holy_father/john_paul_ii/speeches/2000/jul-sep/documents/hf_jp-ii_spe_20000829_transplants_en.html).

The validity and status of brain death criteria, however, are being challenged and it could well be that determining when death has occurred and when organs may be procured will be the next major debate in health care ethics.

In a Sept. 2, 2008 article (“The Signs of Death”) in L’Osservatore Romano, the official Vatican newspaper, Lucetta Scaraffia, a history professor at a Roman university and a member of Italy’s National Bioethics Committee, challenged the concept of brain death. She wrote: “The 40th anniversary of the new definition of brain death seems to be the occasion to reopen the discussion both at the scientific level as well as in the heart of the Catholic Church.”

What has prompted this debate, noted Scaraffia, are a few cases where pregnant women who had been declared brain dead had their vital functions mechanically maintained until their babies could be delivered. It makes no sense, she believes, to call someone dead who can deliver a child—that a living child can be delivered from a cadaver. Furthermore, she argues, “the idea that the human person ceases to exist when the brain no longer functions, while the body, thanks to artificial respiration, is kept alive, implies an identification of the person with brain activity alone. This is in contradiction with the concept of the person according to Catholic doctrine, and therefore, with the directives of the church in the case of patients in a persistent coma.” Scaraffia is also concerned that as the demand for organs increases, doctors are pressured to shift the line that divides life from death, so that they can obtain organs for transplant as soon as possible so that they will be in optimal condition.

Several days later, the director of the Vatican press office issued a statement indicating that there had been no change in church teaching regarding the concept of brain death as a legitimate definition of death. However, it should be remembered that this is not the first time this issue has surfaced at the Vatican. The issue of brain death was taken up in 2005 and 2006 by the Pontifical Academy of Sciences which had twice previously, in 1985 and 1989, affirmed the concept of brain death. Opponents of brain death made their voices heard at the 2005 conference. The academy, however, re-affirmed its position in 2006 in a nine-page statement entitled, “Why the Concept of Brain Death Is Valid As a Definition of Death.” Opponents of the concept published a book shortly after entitled, Finis Vitae—Is Brain Death Still Life? Critics of brain death believe that it
redefines living human beings as dead in order to obtain organs. Consequently, it devalues the lives of the terminally ill, reducing them to little more than sources of tissue and organs.

Meanwhile, in the United States, several articles appeared in the Aug. 14, 2008 issue of the New England Journal of Medicine (vol. 359, no. 7) having to do with organ donation after cardiac death. In one (“Pediatric Heart Transplantation after Declaration of Cardiocirculatory Death,” pp. 709-14), the researchers note that they removed hearts from two infants 75 seconds after the cessation of cardiocirculatory function. The justification given was that no heart is known to have self-started in a child or adult after 60 seconds and time is of the essence in order to ensure that the organs remain in the best possible condition.

In the same issue, two bioethicists, Drs. Robert Truog of Harvard Medical School and Franklin Miller of the National Institutes of Health, call into question the adequacy of the concept of brain death as well as cardiovascular death (followed by the retrieval of organs). Regarding the first, they say: “The uncomfortable conclusion to be drawn from this literature is that although it may be perfectly ethical to remove vital organs for transplantation from patients who satisfy the diagnostic criteria of brain death, the reason it is ethical cannot be that we are convinced that they are really dead” (p. 674).

Regarding donation after cardiac death, the authors write: “Although everyone agrees that many patients could be resuscitated after an interval of two to five minutes, advocates of this approach to donation say that these patients can be regarded as dead because a decision has been made not to attempt resuscitation. … Again, although it may be ethical to remove vital organs from these patients, we believe that the reason it is ethical cannot convincingly be that the donors are dead” (p. 674).

In the estimation of these two authors, the dead donor rule has at best “provided misleading ethical cover that cannot withstand careful scrutiny” and, at worst, “suggests that the medical profession has been gerrymandering the definition of death to carefully conform with conditions that are most favorable for transplantation” (p. 675). Their proposal is that the dead donor rule be abandoned and that organs can be retrieved from patients who have given informed consent in advance and have “devastating, irreversible neurologic injuries that do not meet the technical requirements of brain death” (p. 675). They believe that there is no harm in retrieving organs before death so long as anesthesia is administered.

It seems unlikely that discomfort about current approaches to determining death and the implications of this for organ retrieval will go away. This may well be the next big issue for health care ethics. —R.H.

(Please see the Resource section for a listing of all the articles in the Aug. 13, 2008 issue of the NEJM on organ donation.)
**Pope Calls for Protecting the Environment**

During his trip to Australia in July 2008, Pope Benedict XVI made several calls to protect the environment. Environmentalism is part of a deeper spiritual shift away from what the pope called the “folly of consumerism” toward a lifestyle rooted in traditional virtues of self-sacrifice and solidarity. Care for the Earth is part of a continuum of moral truths, including defense of human life and dignity. At the Vatican, Benedict authorized installation of more than 1,000 solar panels atop the Paul VI audience hall to provide electrical current, light, heating and cooling. The Vatican also inked an agreement to become the first “carbon-neutral” state in Europe. *(National Catholic Reporter, Aug. 8, 2008)*

**Health ‘Credit Reports’ Help Insurers Assess Risk**

Health and life insurance companies have a powerful new tool for evaluating whether to cover individual consumers: a health “credit report” drawn from databases containing prescription drug records on more than 200 million Americans. Traditionally, insurance companies have judged an applicant’s risk by obtaining records from physicians’ offices. The new electronic tools are fast and cheap with the potential to improve health care and reduce costs. However, privacy and consumer advocates fear the trend is taking place largely outside the scrutiny of federal health regulators and lawmakers. Privacy advocates say the practice illustrates how data gathered for one purpose can be used and marketed for another, often without consumers’ knowledge. *(washingtonpost.com, Aug. 4, 2008)*

**President’s Council Considers Health Reform**

The President’s Council on Bioethics, established by President Bush in 2001, is slated to issue a report after the November election endorsing some form of social obligation for health reform. Current council chairman, Edmund G. Pellegrino, MD, said the goal is not to recommend any political party’s plan but to “lay out in an orderly, systematic and critical way” the ethical implications of various approaches to access to care, medical innovation, and individual freedom and responsibility. Recognized as the father of bioethics, Pellegrino is the founding editor of the *Journal of Medicine and Philosophy*. However, not all members of the conservative-leaning council agree. “Health system reform is ‘a black hole’ – once you get in it, you never get out,” said Gilbert Meilaender, Ph.D., professor of Christian ethics at Valparaiso University in Indiana. “The more we try to fully elaborate all the principles that might be involved in reforming the health care system, the more hopeless and black hole-ish things get.” *(American Medical News, Aug. 4, 2008)*

**More Women Consider Becoming Egg Donors or Surrogates**

In Chicago, there has been a rise in the number of women contacting fertility clinics to inquire about becoming egg donors or surrogates. With compensation for egg donation around $7,000 and surrogates earning up to $30,000, some say that the economic downturn has drawn women to see this as a viable option for financial security. Typically summer is a slow time for donation but the number of calls at Alternative Reproductive Resources has been higher than normal. *(Chicago Sun-Times, Aug. 1, 2008)*

**Consumers Cut Back Health Care Spending**

As the economy tightened, people are cutting back spending on health care. Studies show that even those who have coverage are postponing doctor’s visits, preventive tests, surgeries and prescription refills in order to save money. There is a concern among health policy experts that short-term cutbacks, such as not taking prescription medicines on schedule, could cause more advanced medical problems in the near future which may lead to higher numbers of emergency room visits. As insurance out-of-pocket costs rise and the economy slips, people are reconsidering their need for insurance against their ability to afford high premiums and co-pays. *(The Wall Street Journal, Sept. 22, 2008)*

**Illinois Passes Law Giving Discounts to Uninsured**

A new law concerning discounts to uninsured consumers passed the Illinois House and Senate unanimously following an amendatory veto by Gov. Rod Blagojevich. The bill requires that hospitals give uninsured consumers a discount, making their cost equal to actual cost of care plus a 35 percent markup. This discount will apply to families earning up to 600 percent of the federal poverty level for a family of four in urban areas and families earning up to 300 percent of the federal poverty level for a family of four in rural areas. This would include about 775,000 families in Illinois. The legislation also caps the amount of money an uninsured consumer can spend at a hospital at
Rape Victim Care Can Be Improved

A recent study shows that care for sexual assault and rape victims in hospitals may not be as complete as necessary. The study looked at Illinois emergency rooms and found that only two-thirds offered crisis counseling, 40 percent offered emergency contraception, two-thirds tested and treated sexually transmitted disease and less than one-third provided precautionary HIV treatment. Treatment of physical injuries, possible disease and psychological and legal counseling are crucial. Emergency departments often refer victims to other facilities for the services they do not provide. This referral is not as effective because many women do not have the ability, financially or emotionally, to go to a second facility. (Los Angeles Times, Oct. 6, 2008)

Education Helps Decision Regarding Testing for Breast Cancer Gene in Children

As tests for breast cancer gene mutation reached 100,000 last year, questions arise concerning the gene testing of minors. Medical experts advise against testing before the age of 25. Interviews by the Associated Press show that many people who have the gene, and their children, believe testing minors is the correct course of action. When the faulty gene is present, treatments to combat the increased risk of cancer include administering anti-estrogen drugs or removing the breast and ovaries. These drastic treatments are not advised in young women. Counseling is suggested before making to decision to be tested. (The Associated Press, Sept. 21, 2008)

Report Grades Palliative Care in Each State

A new state-by-state report on the availability and quality of palliative care was recently released. According to R. Sean Morrison, MD, professor of geriatrics and palliative care at Mount Sinai School of Medicine, palliative medicine focuses on improving quality of life for seriously ill patients by addressing pain and the emotional and practical needs of the patient. Vermont, Montana and New Hampshire received an “A” in the ranking while Alabama, Mississippi and Oklahoma received an “F”. Grades were given based on the percentage hospitals with palliative care programs that appropriately met the needs of the seriously ill. About one-half of the nation’s hospitals have palliative care programs. To increase the number of palliative care programs, Morrison advocates lobbying for state funding. (Health Day, Oct. 2, 2008)

Uninsured Spend $30 Billion for Medical Expenses

A study by researchers at George Mason University and the Urban Institute shows that uninsured Americans will spend about $30 billion out-of-pocket for medical expenses. The cost to cover all the uninsured will be $208.6 billion this year. The study also reveals that the government pays about 75 percent of the bill that the uninsured cannot pay. (The Wall Street Journal, Aug. 25, 2008)

The following information was provided by the Center for Health Law Studies at Saint Louis University School of Law. Kelly Dineen, assistant dean for academic affairs and instructor of health law, supervised the contributions of health law student Phillip Terrell (JD/MHA anticipated ’11).

Study Shows Flaws in Merck’s Testing of Vioxx

In a study published in the Aug. 19 Annals of Internal Medicine, researchers concluded that a clinical trial “which tested the drug’s safety in the stomach, was primarily crafted by Merck’s marketing department to get doctors to prescribe Vioxx.” Using about 600 carefully selected family doctors relatively new to clinical research (but who had appreciable influence over other physicians and could boost Vioxx’s general prescription rate), Merck granted each a stipend and fees for recruiting a “handful” of patients. Normally in major clinical trials, only a few academic clinicians are selected, with each gathering hundreds of patients to form a viable sample for making a proper determination as to the drug’s efficacy and safety. Drug companies have long been suspected in this type of activity, but “there has been no ‘smoking gun’ proving as such until now.” (The Wall Street Journal, August 19, 2008)

Reimbursement Rates Fall for Ten Conditions

Beginning Oct. 1, hospitals no longer receive the higher DRG rate of reimbursement for patients with ten specific conditions that develop during their stay in the hospital. These include: Stage III, IV pressure ulcers; fall or trauma resulting in serious injury; vas-
cural catheter-associated infection; catheter-associated urinary tract infection; foreign object retained after surgery; certain surgical site infections; air embolism; blood incompatibility; certain manifestations of poor blood sugar control; certain deep vein thromboses or pulmonary embolisms. Hospitals will still be reimbursed for the patient’s initial diagnosis and associated treatment, but will receive no additional reimbursement if these conditions arise during the patient’s course of treatment. Physician reimbursement will remain unaffected. The Centers for Medicare & Medicaid Services project this rule will save approximately $21 million annually, which some note is but a fraction of actual expenses incurred by patients with such complications. However, CMS Acting Administrator Kerry Weems emphasized that the reforms concern more than just spending reductions: “This is really about making hospitals and the health system just a safer place to be.” (American Medical News, Aug. 25, 2008).

FDA OKs Noninvasive Test for Organ Rejection in Heart Transplant Patients

XDx Inc.’s AlloMap, “a noninvasive test that assists doctors in managing heart-transplant patients post-surgery for potential organ rejection,” has been given marketing clearance by the Food and Drug Administration. Based upon genetic information within a transplant recipient’s white blood cells, the test generates a score measuring whether they are likely to reject a transplanted organ. While the test was legally approved for use in 2005 under other federal laws governing clinical labs, XDx chief medical officer James Yee hopes that the FDA’s clearance will speed its adoption by heart transplant centers on a larger scale. (The Wall Street Journal/Associated Press, Aug. 28, 2008)

Number of Prescriptions Falls for First Time in Ten Years

A tracking firm’s analysis between Jan. and Aug. 2008 revealed a decrease in the number of prescriptions dispensed compared to the same period in 2007. This is the first decline in more than a decade. Faced with tighter budgets, more consumers are cutting the amount of prescription medications they use to trim household expenditures. Some people take less than the recommended dosage to delay refilling the order, or physically split the pills. Others forgo the purchase of medication altogether. The dilemma is especially pronounced for those with compound disorders requiring multiple medications – e.g., diabetes, where insulin cannot be sacrificed, but other medications might be perceived by patients as “less necessary,” such as cholesterol-reducing drugs. Medicare Part D beneficiaries also encounter severe difficulties upon reaching the $2,510 “doughnut hole.” Many Medicare recipients find it all but impossible to meet the next approximately $3,000 in drug costs until coverage resumes without some form of subsidy. The effects of this reduced consumption may be far-reaching according to some public health experts. Those with chronic disorders will experience a worsening of conditions and will require more costly treatment later. However, others note that “over prescription” has always been an issue within American medicine. Despite drug makers’ and doctors’ opinions that medications are one of the most crucial components in overall treatment of illness, patients and their families will continue to act upon their own perception of marginal benefits when times are hard. (New York Times, Oct. 22, 2008)

California Supreme Court Prohibits Discrimination in Treatment of Gay and Lesbian Patients

North Coast Women’s Care Medical Care Group, Inc., et al. v. San Diego County Superior Court, 189 F.3d 959 (Cal. 2008), decided by the California Supreme Court on Aug. 18, 2008, found that doctors with religious objections to gay or lesbian patients must treat them identically to other patients or find another physician who will treat them without objection. The lawsuit was filed by a lesbian couple seeking artificial insemination at a San Diego fertility clinic. “This isn’t just a win for me personally and for other lesbian women,” said plaintiff Guadalupe Benitez. “Anyone could be the next target if doctors are allowed to pick and choose their patients based on religious views about other groups of people.” Citing a 2004 opinion involving Catholic Charities which applied a law requiring company-sponsored health plans to offer contraception for women, the ruling held that doctors may refuse a particular form of treatment to patients in general but may not specifically single out gay or lesbians for refusal. Notably, the doctors could have based their refusal upon a general policy that denies treatment to unmarried couples. The clinic’s legal counsel is consid-
Provena Challenges Claims About Charity Care
Following a state appellate court ruling which could jeopardize Provena Covenant Medical Center’s tax-exempt status based on community benefit-directed care, the hospital’s attorneys announced plans to seek certification and review of the matter before the Illinois Supreme Court. At a time when the charitable practices of not-for-profit tax-exempt health care centers are under scrutiny on a national level, the outcome of this case – if indeed it is accepted by the high court – could set the stage for similar litigation. Provena denies it has administered insufficient care to the poor and uninsured. A Supreme Court decision will frame the methodologies by which not-for-profit centers handle bills of patients who cannot afford to pay for services. (Chicago Tribune, Sept. 10, 2008)

Many Health Care Staff Forgo Flu Shots
Despite recommendations by the Centers for Disease Control that all health care staff receive annual flu vaccine injections, statistics show that 60 percent of health care workers either neglect or refuse to have the shots for fear of contracting the illness through the dormant virus in the vaccine. William Schaffner, president-elect of the National Foundation for Infectious Diseases and chairman of the Department of Preventive Medicine at Vanderbilt University, considers this widespread trend troubling. According to Schaffner, getting a flu shot should be standard procedure for hospital workers, much as washing one’s hands. The injection also helps prevent spread of the disease to patients. CDC recommendations stipulate that all health care facilities offer free flu vaccinations to employees annually. Vaccination patterns and policies at health care centers across the country vary, with some mandating that all employees with direct patient contact get an injection or present a physician exemption (for those with allergic reactions). Other policies are broader, with all personnel including pharmaceutical representatives and volunteers, required to be vaccinated unless they apply for an exception on a religious or medical basis. Joyce Lammert, MD at Seattle’s Virginia Mason Medical Center said her facility lost seven employees when such a policy was enacted four years ago, but “[n]ow, the culture has really changed because of this case – if indeed it is accepted by the high court – could set the stage for similar litigation. Provena denies it has administered insufficient care to the poor and uninsured. A Supreme Court decision will frame the methodologies by which not-for-profit centers handle bills of patients who cannot afford to pay for services. (Chicago Tribune, Sept. 10, 2008)

Medicare Reimbursement Gap May Affect Participation in Cancer Clinical Trials
Older Americans wishing to take part in clinical trials of cancer treatments may be discouraged. Medicare rules prevent Medicare health maintenance organizations from covering the difference between the cost of care and actual Medicare reimbursement when the patient is enrolled in a clinical trial. A report from researchers at the University of Pittsburgh Cancer Center at the meeting of the American Society for Therapeutic Radiology and Oncology illustrated the gap in coverage. Chyongchiou Lin, Ph.D., said, “Medicare HMOs cover the 20 percent difference between Medicare reimbursement and the cost of care,” but, “if patients take part in a so-called ‘qualifying’ clinical trial,” the 20 percent compensation fades away. As a result those enrolled in clinical trials and Medicare HMOs may face as much as a $3,000 increase in out-of-pocket costs. Given the rising number of Medicare HMO participants, this could become a more prevalent problem. Study authors indicated the coverage discrepancy could influence clinical trial results, as samples will be skewed toward those who can afford to participate. (MedPage Today, Sept. 23, 2008)

Government Uncovers Fraudulent Claims by Makers of Medical Supplies and Drugs
After reviewing millions of claims submitted by sellers of wheelchairs, drugs, and other medical supplies, the Senate Permanent Subcommittee on Investigations determined that many were suspect or potentially fraudulent for lack of proper diagnosis codes which could be used to match the claim with a patient’s related medical condition. The subcommittee urged the Centers for Medicare and Medicaid Services to craft better policies that would either reject claims outright if they lack proper diagnosis codes and to cross-reference present codes with patients’ actual diagnoses for viable usage of the goods whose reimbursement is being sought. CMS claims it already has certain safeguards in place, including “red flag warnings” which draw attention to claims for specifically unusual or pricey items. (USA Today/Associated Press, September 24, 2008)
FDA Finds Two Widely Used Treatments Pose Risks to Patients
A number of companies selling a Food and Drug Administration-unapproved eyewash and a papaya-based skin cream have recently come under the agency’s scrutiny. The eyewash (balanced salt solution, used to keep the eyes moist during surgery) is marketed by two companies with FDA approval, while similar offerings from three other firms have no such safety and effectiveness backing by the FDA. Papain, the skin cream used for treating skin ulcers from diabetes and other causes, has no FDA approval for marketing whatsoever; nor have any products containing Papain obtained FDA approval yet. The FDA has received more than 300 reports of serious reactions to the eyewash, and about 40 reports on the papaya creams. Some stated that the ointment offered no marked benefit to patients, and others described having suffered life-threatening allergic reactions. According to the FDA, “Companies must stop making the unapproved drugs . . . by November 24 and stop shipping them by January 21.” (Bloomberg/Associated Press, September 24, 2008)

Blood Thinner Errors In Hospitals Could Lead to JCAHO Accreditation Revocation
The Joint Commission on Accreditation of Healthcare Organizations informed hospitals on September 24 that “strict measures” should be adopted to prevent medical errors in the administration of blood thinners including heparin. Such mistakes have been documented 60,000 times and have caused numerous deaths. Preventive measures could include bar-coding medications, or utilizing computerized drug orders. Moreover, adult-strength heparin should be stored nowhere near units designated for children. Patients on such drugs should be closely monitored. Mark Chassin, Joint Commission President, said that commission investigators would be making unannounced visits to ensure hospitals are adopting tighter measures to stifle blood thinner mistakes. Hospitals, which do not demonstrate preventive measures, could have JCAHO accreditation revoked. (Associated Press, September 24, 2008)

Off-label Use of Medtronic’s Infuse During Surgery Linked to Serious Complications
The Food and Drug Administration issued warnings to surgeons earlier this year concerning risks associated with Medtronic Inc.’s Infuse Bone Graft, a biologically engineered liquid. Life-threatening complications, mainly swelling of the neck and throat tissue leading to compression of the airway and other structures in the neck, have mostly occurred when the liquid was used “off-label” during surgeries on the cervical portion of the spine. The FDA has tracked cases over the past four years, with 38 reports of the above side effects in that period. Positive experiences with such off-label usage of Infuse have been documented in medical journals, websites and at educational meetings by doctors in business relationships with Medtronic. Litigation involving allegations that Medtronic financially induced their products’ use by physicians has already led to multi-million dollar settlements in two cases. A remaining lawsuit claims Medtronic “illegally marketed Infuse for off-label purposes through doctors who were paid inflated consulted fees and bogus royalty payments.” Producers according to FDA regulations may not market drugs’ possible off-label uses. (Wall Street Journal, September 4, 2008)

Stryker Corp. Payouts to Physicians Under DOJ Investigation
$40 million in payments made by Stryker Corp. (the third-largest manufacturer of hip and knee replacement components) to almost 200 doctors during 2007 have caught the attention of the Department of Justice, which is now investigating whether the firm illegally paid surgeons to entice usage of their products. A government lawsuit filed Aug. 26 places at issue the nature of the payments made through “consulting agreements and other financial relationships,” and whether the ant-kickback statute was violated in the process. Under the statute both direct and indirect remuneration in any form to health care providers by suppliers is strictly prohibited. Included among court documents is a note that Stryker is being investigated for violation of the U.S. False Claims Act for possibly fraudulent Medicare and Medicaid reimbursement claims. (Bloomberg, September 4, 2008)

Survey: One-Half of U.S. Doctors Use Drugs for Placebo Effect
Placebos now come in more “flavors” than sugar pills, at least according to a report published by the British Medical Journal, which found through a national survey of United States physicians that 46 to 58 percent admitted using placebos regularly, with only five per-
cent explicitly telling their patients that they were doing so. Usually associated with inert treatments such as sugar or salt pills, or saline injections, the report notes that placebos in reality are any treatment whose physiological efficacy remains unproven. Thus, doctors now admit to using more “active” placebos including vitamins, over-the-counter painkillers, sedatives and antibiotics. The American Medical Association takes a disapproving stance to placebo use without patient knowledge. Other experts and bioethicists find their use improper due to the deceit involved. At the same time, others find such “benevolent deception” acceptable, as there is the off chance the treatment might actually work (scientifically or not). A number of studies have found that patients respond positively to placebos upwards of 30 percent of the time. Two-thirds of doctors report they would inform patients that a treatment being recommended to them is not typically used for their condition. Some physicians stand firmly against giving a patient any medication without informing them of their doubts as to its efficacy; these same physicians have used placebos before, however, in cooperation with patients who firmly believe the treatment will be successful. Garlic, for example, is typically thought to have positive effects against cholesterol. “I don’t believe the garlic will physically help the patient, but it may motivate them to comply with the rest of my recommended regimen, and that’s a good thing,” said Dr. Matthew Johnson of Park Forest. (Chicago Tribune, October 23, 2008)
SELECT BIBLIOGRAPHY (Recent Health Progress Articles)

Health Care Reform


Rodgers, Michael and Jeff Tieman, “Health Reform Overview: Where Are We Headed?,” 88, no. 3 (May-June 2007): 19.

**SELECT WEBSITES**

Health Care Reform

The Catholic Health Association  
[www.OurHealthCareValues.org](http://www.OurHealthCareValues.org)  
The Catholic health care ministry has articulated its values and developed principles for health care reform in “Our Vision for U.S. Health Care.” You may visit [www.ourhealthcarevalues.org](http://www.ourhealthcarevalues.org) to learn more. CHA also has a guide for conducting community dialogues. “**Building Consensus for Change: A Guide to Organizing Roundtable Discussions on Health Reform**” (.pdf and also available as an editable Word document). This step-by-step guide provides the tips and templates you need to organize a values-based discussion in your community including a planning timeline, template press advisory, talking points for panelists, and moderator Q & A guide.

Center for Healthcare Reform  
[www.stjhs.org/CFHR/resource](http://www.stjhs.org/CFHR/resource)  
Founded and directed by Jack Glaser of St. Joseph of Orange Health System, the center is focused on conducting community dialogues in order to bring about health care reform. The website has helpful resources and contains an important link to [www.OurHealthCareFuture.org](http://www.OurHealthCareFuture.org) which describes the dialogue process and also provides resources for conducting dialogues.

Kaiser Family Foundation  
[www.kff.org](http://www.kff.org)  
The Henry J. Kaiser Family Foundation is a non-profit, private operating foundation focusing on the major health care issues facing the nation. The foundation is an independent voice and source of facts and analysis for policymakers, the media, the health care community and the general public.

National Coalition on Healthcare  
[www.nchc.org](http://www.nchc.org)  
The National Coalition on Healthcare is the nation’s largest and most broadly representative alliance working to improve America’s health care. Honorary co-chairs are former presidents George Bush, Jimmy Carter and Gerald Ford. Member organizations represent about 150 million health and pension fund interests.

Universal Health Care Action Network (UHCAN)  
[www.uhcan.org](http://www.uhcan.org)  
UHCAN was formed in 1992 to bring together diverse groups and activists working for comprehensive health care for all in state and national campaigns across the country.

CodeBlueNow!  
[www.codebluenow.org](http://www.codebluenow.org)  
The goal of CodeBlueNow! is to change the health care system so it works for the American public with a grass roots, non-partisan approach that focuses first on the outcomes we want from our health care system. Politicians should follow the American people, not special interests.
SELECT BIBLIOGRAPHY

Narrative Ethics

The literature on narrative ethics is vast. The entry on “Narrative Ethics” in the Encyclopedia of Bioethics is helpful, with additional resources in the bibliography. What follows is a select bibliography mostly on theological sources dealing with narrative ethics:


SELECT BIBLIOGRAPHY

Donation after Cardiac Death and the Dead Donor Rule

The following articles are from the New England Journal of Medicine 359, no 7 (August 14, 2008):


Truog, Robert and Franklin Miller, “The Dead Donor Rule and Organ Transplantation,” pp. 674-75.


A Practical Guide to Clinical Ethics Consulting: Expertise, Ethos, and Power


By David Belde, Ph.D.
VP, Mission & Ethics
Bon Secours Richmond Health System

In *A Practical Guide to Clinical Ethics Consulting: Expertise, Ethos, and Power*, Christopher Myers, a professor of philosophy at California State University, Bakersfield and the executive director of the Kegley Institute of Ethics, argues that clinical ethics consultation ought to proceed in a normative fashion. In so doing, he counters what he calls a prevailing “standard approach” to clinical ethics consultation.

The standard approach, the one endorsed in the “Core Competencies for Health Care Ethics Consultation” published by the American Society for Bioethics and Humanities, holds that ethicists should essentially restrict their work in clinical ethics consultation to problem analysis through facilitating agreement, drawing moral boundaries, clarifying values and acquiring consensus among the participants involved in a particular ethics issue. Due to lack of agreement around appropriate moral methods and foundations, the standard approach to clinical ethics consultation in secular bioethics has been one driven by procedural commitments rather than one organized by normative ethical inquiry with a view toward discerning the moral truth in a particular dilemma.

Myers’ assumes the importance of using normative methods in clinical ethics consultation precisely because he argues that its moral ideal is directed toward finding the best possible choice given the situation at hand. For Myers, a normative method in clinical ethics consultation is more likely to arrive at options that best approximate moral truth. Because normative ethics requires specialized knowledge in ethical theory, Myers claims that a philosopher-ethicist can be a moral expert—in the same way a medical specialist is an expert—and therefore the best person to provide clinical ethics consulting within the context of a normative approach.

With intellectual honesty and rigorous research, Myers takes some contrarian views within secular clinical ethics, especially as it relates to the scope and authority of philosophically-trained clinical ethics consultants. He defends the view that ethicists should give prescriptive moral advice in much the same way as other specialty consultants do within clinical medicine. He recommends going beyond a mere consensus driven ethics consultation model and supports a normative model of clinical ethics consultation that is philosophically grounded in Beauchamp and Childress’ principlism. He also challenges clinical ethics consultation to go beyond the clinical reality and consider taking an activist role in changing organizational structures that give rise to ethical dilemmas in the clinical context. Additionally, he urges clinical ethicists to appreciate how the cultural ethos of an organization provides important information for understanding and resolving ethical dilemmas.

I would recommend this book for the experienced clinical ethics consultant who is seeking a deeper understanding of the theoretical grounding and fundamental purpose of clinical ethics consultation. It would be best used in an introductory course in undergraduate or graduate courses or for additional reading for those interested in furthering their knowledge of clinical ethics consultation.

Myers is to be commended for taking views that run contrary to the standard approach. The text does require a more sophisticated understanding of philosophical moral method in order to appreciate the full significance of his argument that philosophically-trained ethicists, given certain caveats and assumptions around adequate training and knowledge set, can be considered moral experts, and clinical ethics consultation should ideally proceed in a way that is grounded normatively in philosophical method.
Health Care Ethics USA

*Health Care Ethics USA* © 2008 is published quarterly by the Catholic Health Association of the United States (CHA) and the Center for Health Care Ethics (CHCE) at Saint Louis University.

Subscriptions to *Health Care Ethics USA* are free to CHA members. There is a nominal subscription fee for non-CHA members. To begin receiving this publication, or to inquire about non-member rates, please contact Ellen Horan at ehoran@chausa.org.

**Executive editor:** Ron Hamel, Ph.D., CHA senior director of ethics  
**Associate editors:** James DuBois, Ph.D., D.Sc., CHCE associate professor, department chair, and center director; and Sr. Patricia Talone, RSM, Ph.D., CHA vice president of mission services  
**Managing editor:** Ellen B. Horan, communications manager

---

**GOT SOMETHING TO SAY?**  
Send all Readers’ Forum comments to HCEUSAeditor@chausa.org.

---

New from CHA!  
**Online Learning Resource for ERDs**

CHA’s new online learning resource provides a convenient, accessible way for CHA members to learn about the ERDs that’s perfect for individual or group learning.

- Interactive module features videos with ministry leaders, case studies, reflection questions and online instruction.  
- Caters to busy schedules — You may participate in one sitting or in stages as time permits.  
- Designed for physicians, nurses, senior executives, mission leaders, ethicists, pastoral care staff, ethics committees — everyone in Catholic health care who needs to understand the Directives and how to apply them.

Visit www.chausa.org/learning. Note: CHA member website access is required.

**Coming November 2008!**

---

**Distance Learning**

**Graduate Certificate Program in Clinical Health Care Ethics**

The Certificate Program fosters clinical ethics skills and knowledge needed by ethics committee members, physicians, nurses, administrators, attorneys, social workers, chaplains and others engaged in health care. It offers a concentration in Catholic health care ethics.

The program consists of eight credit hours that may be completed over a one-year period, and combines distance learning with two on-site seminars lasting two days each.

**Continuing Education Credits** Several associations have approved the Certificate Program for continuing education credits.

**Program Requirements** Applicants must hold a bachelor’s degree.

For more information visit us at http://chce.slu.edu