

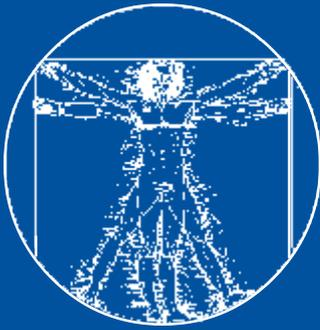
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2005*

Mid-Atlantic Ethics Committee
Newsletter, Fall 2005-Winter 2006

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
Published by the Law & Health Care Program, University of Maryland School of Law
and the Maryland Health Care Ethics Committee Network

Fall 2005-Winter 2006

CULTURAL COMPETENCE, ANYONE?

Help someone complete an advance directive. That was the assignment my colleague, a faculty member at Hunter College in New York, gave to students in her undergraduate nursing ethics course. They could pick someone inside or outside of their family for the assignment. Most students chose a family member. Students were also asked to write about the experience. Their responses illuminated an ever-growing reality in U.S. health care: the basic values and assumptions underlying many U.S. health care practices (such as completing an advance directive) are not always shared by those from 'non-mainstream' cultures. Students from different cultural backgrounds described less-than-ideal responses from family members they approached. A Vietnamese student wrote, "My grandmother was angry and hurt that I was putting her in her grave." A Mexican-American student worked with her grandmother, who agreed to become an organ donor, only to have her mother object to the idea, believing it was wrong to "deface the body" after death. A Haitian student wrote of how her father refused to complete the form for fear of not getting adequate health care were he to need hospital attention. A Korean student described her grandparents' response—they reprimanded her, explaining that filling out a form to make life and death decisions demonstrates a lack of faith in God's will and could engender 'bad karma' or the wrath of ancestors.

The Mid-Atlantic Ethics Committee Newsletter is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland School of Law's Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities in Maryland, D.C., and Virginia. Each issue includes a feature article, "Network News," a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing and related disciplines.

Diane E. Hoffmann, JD, MS
Editor

These value conflicts are inevitable in health care encounters involving patients, families, and health care providers (HCPs) from different cultures. And based on the shifting demographics in the U.S., such scenarios may well be the norm rather than the exception in a growing number of cities. A recent article in *JAMA* highlights the self-reported shortcomings of resident physicians' abilities to provide 'cross-cultural' care.¹ Efforts to remedy such deficits have emerged in the past ten years, with various organizations developing standards and models for 'cultural competence.'² But just what is

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NETWORK NEWS

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or opinion and should not be acted
upon without consulting an attorney.

MARYLAND HEALTH CARE ETHICS COMMITTEE NETWORK (MHECN)

MHECN sponsored a conference
on the Patient's Plan of Care
(PPOC) Form on November 29
at Broadmead in Cockeysville, MD. The
program was jointly sponsored by
Broadmead, the Beacon Institute, and
Lifespan, a senior care provider
association serving Maryland and DC.
The goal of the conference was to help
attendees implement the PPOC legislation,
which went into effect on October 1, 2005.
The PPOC form serves to document the
patient's or proxy's current preferences
regarding life-sustaining treatment, to
inform medical orders in the health care
facility where the PPOC form is filled out
or filed, and to communicate information
about treatment preferences when a
patient is transferred to a different facility.
MHECN is considering ideas for a
research project to evaluate outcomes of
the PPOC form. Contact us if you would
like to be involved. More information on
the PPOC is available at [http://
www.oag.state.md.us/Healthpol/
PPOC.htm](http://www.oag.state.md.us/Healthpol/PPOC.htm).

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THE METROPOLITAN WASHINGTON BIOETHICS NETWORK (MWBN)

MWBN invites members to attend
workshops sponsored by the
Inova Health System Center for
Ethics & Inova Learning Network this
spring, as well as the April 5 Leikin lecture
at the Children's National Medical Center.
See the CALENDAR for more information

about these events. MWBN will hold
another guardian training session this
spring with the D.C. Superior Court
Probate Division (Judge Jose Lopez).
Training materials for the course will
include the ABA Commission on Law &
Aging's handbook, "Assessment of
Older Adults with Diminished Capacity."
ABA's Charlie Sabatino, one of the
authors of the handbook, will be the
featured speaker. The date is to-be-
announced.

Contact: Joan Lewis, Executive
Director, 202-895-9408, jlewis@iona.org.

RICHMOND BIOETHICS CONSORTIUM (RBC)

RBC members are invited to attend a
three-day educational program for
those who are new to the work of
ethics committees. The workshop,
"Orientation to Clinical Ethics: Three
Days of Education for Those Who are
New to Ethics Committees," is being
hosted by the Hunter Holmes McGuire
Veterans Affairs Medical Center.
Workshop dates are March 15, 24, and 29.
(The days are spaced to allow participants
time to complete reading assignments and
to process the information.) Speakers are
drawn from the RBC community and come
with a rich knowledge of clinical ethics.
The text for the course is *Introduction to
Clinical Ethics*, 3rd edition, by John
Fletcher. Questions about the program
should be directed to Marian Baxter, RN,
MS, MA, at marian.baxter@med.va.gov.

For more information about RBC,
contact: Gloria Taylor, RN, MA, CPTC,
RBC President, at taylorgj@unos.org.

Cultural Competence, Anyone?

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cultural competence? Can it really be achieved? If so, how?

Hunt³ believes recent approaches to teaching “cultural competence” in health care settings (e.g., presenting a list of beliefs and practices of various cultures) may paradoxically lead to stereotyping instead of better understanding of and respect for cultural differences.

In my opinion, “cultural competence” grows out of cultural self-awareness, and the latter is partly developed by providing examples of how culture influences one’s own and others’ values, beliefs, and practices. The examples should be viewed with the understanding that cultural generalizations *alone* have limited applicability to the HCP-patient/family encounter.

I recall a few years ago hearing of a nursing student who was taken to the psychiatric ward after suffering a “psychotic break,” triggered apparently by having failed an exam. I asked if she was one of the international students, and indeed, she was from Nigeria. I knew that in some African (as well as other) cultures, education is highly regarded—particularly the opportunity to study in the U.S. Failing a test or a course could bring tremendous shame not only on the individual but on his or her family. I also knew that in certain parts of Nigeria, responding to shock and loss with loud wailing and prostration is common. In the U.S., we might (and did) interpret that as psychosis.

My generalizations about Nigeria (which is itself a highly diverse country) did not alone explain the student’s behavior. Had I judged her based *merely* on knowing she was Nigerian, that would have constituted stereotyping. However, seeing behavior that might fit within the norms of a particular culture led me to question whether culture might be involved. The result was my heightened sensitivity to what the student might be experiencing and how she might best be helped, as well as my own enhanced awareness of the cultural norm in which I was raised. That norm included not displaying strong emotions openly. In addition, I became acutely aware of Western medicine’s labeling of persons who do display such emotions as “psychotic” and in need of psychiatric intervention.

This process of learning about other cultures leading to greater self-awareness is in line with what Hunt³ refers to as “cultural humility.” HCPs displaying cultural humility may use patient-focused interviews to explore differences and similarities between their own and their patient’s values, beliefs, and preferences. Hunt states, “[I]n this model, the most serious barrier to culturally appropriate care is not a lack of knowledge of the details of any given cultural orientation, but the providers’ failure to develop self-awareness and a respectful attitude toward diverse points of view.” Similarly, Campinha-Bacote⁴ defines cultural competence as “a continuous process of effectively developing the ability to work within the cultural context of a community, a family, and individuals from a diverse cultural and ethnic background.” (See the box on p. 4 for examples of cultural assessments that can help accomplish these goals in clinical encounters.)

Less attention has been paid to cultural competence in ethics consultation. Carter and Klugman⁵ provide a model that ethicists can use to address culture. Rather than focus on achieving cultural competence in a particular culture different from one’s own, or on seeking a compromise between two or more presumably incompatible cultural perspectives, these authors promote cultural understanding as a goal of ethics consultation. They call this process “cultural engagement,” which is based on three assumptions: (1) that all persons involved are seen as morally equal; (2) that certain elements of the illness experience (e.g., fearing pain, loss, or death, feeling dependent on others, needing comfort and protection) are universal across cultures, creating vulnerabilities that HCPs are obligated to respect; and (3) that trust is the groundwork of the patient-provider relationship. The ethics consultant should explore and respect how culture informs the patient’s personal beliefs, values, and decisions.

In the Cultural Engagement (CE) model of ethics consultation, the consultant or team separately asks the HCP and the patient (or family member) how each interprets what the health care problem is, what caused it, and the preferred course of treatment. Verbatim answers (through

an interpreter with non-English-speaking patients/family members) are recorded in a table, with the HCP’s and patient’s responses side-by-side. Carter and Klugman assert that by comparing and contrasting the responses, the consultant facilitates cultural understanding by making differences in values, beliefs, and illness constructs of both patients *and* HCPs more apparent (p. 25).

The authors describe how they applied the model to a case involving a Mexican woman with end-stage renal disease, her son, and an internal medicine resident from the Ivory Coast, who all came together to make decisions about the patient’s plan of care. They demonstrate how the CE model helped achieve a positive outcome for the patient and her family. However, in the process, they mention leaving the patient’s son with advance directive information (written in Spanish) and encouraging the family “to begin a frank discussion of the kinds of end-of-life decisions they might be required to face in the near future.” They state, “respecting their reluctance to talk about death, we simply left the document with [the son] and did not push the matter at this point. We made ourselves available to answer his questions at a later time.” Is this the most culturally sensitive approach?

Based on my colleagues’ international/first generation students’ experiences discussing advance directives with their family members, it seems that a more culturally-congruent approach to end-of-life planning might be more appropriate. This might involve focusing more on appointing a health care agent rather than filling out a written directive. Cultural differences and the realities of Western “hi-tech” medicine could be addressed more openly, along with an explanation of how making one’s wishes known can help families and HCPs make difficult decisions in the future. To do this, one could use the same kind of CE dialogue that Carter and Klugman promote. These authors state that, while the patient from Mexico never completed the advance directive, they felt confident that “some degree of trust was created between the patient,

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Cultural Competence, Anyone?

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family, physician, and health care team” (p. 29).

Accomplishing the increasingly complex task of communicating across cultures, generations, politics, and socioeconomic status within the constraints of current health care delivery settings is indeed a challenge. Perhaps establishing trust is an appropriate main focus. To achieve that goal with patients and families from different cultures, we need some specialized knowledge and skills, but most importantly, we need an attitude of questioning, open-mindedness, and a commitment to life-long learning—which includes accepting that we will make mistakes. If we can learn from our mistakes, which requires thoughtfully evaluating patient-family-HCP encounters, we are certainly on the road to becoming culturally competent, which may be more of a journey than a destination.

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Questions to ask as part of a basic cultural assessment¹

1. Place of birth. If an immigrant, how long in this country?
2. Primary and secondary languages, speaking & reading ability.
3. Ethnic affiliation and strength of ethnic identity.
4. Major support persons and whether patient lives in an ethnic community; involvement of family in decision-making (ask if patient wants to delegate decision-making and if so to whom).
5. Religion – importance in daily life, current religious practices and restrictions (e.g., food, activity, interaction with opposite sex, etc.).
6. Food preferences and prohibitions.
7. Health and illness beliefs and practices, particularly if birth or death is a possibility during hospitalization.
8. Economic situation and whether financial support/counseling is needed.
9. Preferred styles of communication (e.g., nonverbal & indirect).

Brief assessment of patient/family perceptions of health problems²

1. What do you think caused your problem?
2. Why do you think it started when it did?
3. What does your sickness do to you? How does it work?
4. How severe is your sickness? How long do you expect it to last?
5. What problems has your sickness caused you?
6. What do you fear about your sickness?
7. What kind of treatment do you think you should receive?
8. What are the most important results you hope to receive from this treatment?

LEARN Model for Cross-Cultural Healthcare³

- Listen to your patient from his or her cultural perspective
- Explain your reasons for asking for personal information
- Acknowledge your patient's concerns
- Recommend a course of action
- Negotiate a plan that takes into consideration your patient's cultural norms and personal lifestyle.

Sources:

1. Adapted from Boyle, J.S. & Andrews, M.M. (1989). *Transcultural Concepts in Nursing Care*. Glenview, IL, Scott, Foresman/Little, Brown College Division, and from Lipson, J.G., Dibble, S.L., & Minarik, P.A. (1996). *Culture & Nursing Care: A Pocket Guide*. San Francisco: UCSF Nursing Press.
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MORAL RELATIVISM

Universal Moral Norms and the Confusion Between Culture-Specific Moral Norms and Ethical Relativism

It is certainly true that different cultural groups hold different beliefs about what is morally right behavior and what is not. This fact, no doubt coupled with western intellectual traditions of tolerance towards religious and political differences, has led to our present state of conceptual confusion about the distinctions between ethical relativism and culture-specific moral norms. In the minds of some, these two notions—ethical relativism and culture-specific moral norms—are functionally the same. Conflating these two quite separate ideas, however, causes all sorts of conceptual and practical problems. Most notably, it reduces the ability to: 1) differentiate between what are ethically permissible but different approaches to a moral problem, and 2) make a judgment that some actions are ethically unacceptable. In the particular interest areas of this column's readers, i.e., the ethics of clinical and research medicine, confusion about the differences between the two produces unnecessary complexities and moral distress in the care of patients and research subjects. Thus, bringing clarity to this chronic confusion has both intellectual and practical importance.

In the section titled "Relativism in Ethics" in the *Dictionary of the History of Ideas*¹, the authors raise multiple questions in attempting to sort out whether ethics is relative or not. These questions include:

- Are fundamental moral beliefs sometimes different in different cultures, or between different individuals within a culture?
- Would it follow, if they are, that morality is not objective?
- Are moral beliefs arbitrary?

Although the questions are never completely answered, the weight of argumentation (too extensive to review here) is consistent with current thinking

on the topic. This contemporary position is that there are a "set of norms that all morally serious persons share" which composes the common, or universal,

empirically verifiable (at least theoretically) to determine if the vast majority of human societies, and individuals within those societies, accept

That there are, or may be, universal moral norms does not mean, however, that determining precisely what those norms are is easy.

morality; that "the common morality contains moral norms that bind all persons in all places; no norms are more basic in the moral life"; that these moral norms existed "... prior to moral reflections of the sort found in philosophical and theological ethics"; and that, "... they are not grounded in a particular philosophical or theological theory or doctrine."² While sounding like a claim of objectivity, these assertions are grounded in belief rather than data. Nonetheless, one can marshal both thought and evidence convincingly in support of this viewpoint.

That there are, or may be, universal moral norms does not mean, however, that determining precisely what those norms are is easy. Philosophers throughout the ages have attempted to list what such universal moral norms might be with varying degrees of success. Nor does a willingness to accept that there might be universal moral norms invalidate the notion that there are many acceptable and important moral norms that are not universal or generalizable. In short, accepting that there may be a small number of universal moral norms, which in their operationalization can produce differing culture-specific moral norms, recognizes that moral norms come out of both fact and belief; out of both objectivity and subjectivity. None of the above is the same, however, as saying that "anything goes."

Take, as a plausible example of a universal moral norm, that we ought not unnecessarily harm innocent persons. It is

this prohibition. Looking back across recorded history, there is evidence that ethical evolution, consistently moving in the direction of such a prohibition, correlates with increases in the quality of life for those societies adhering to such a norm. Agreeing that innocent persons ought not be unnecessarily harmed does not, though, help much in turning the norm into a practical behavioral guideline. An abstract prohibition does not define the limits of tolerable harm. In medicine, this problem is nowhere more glaring than when thinking about the issue of placebos in human subjects research.

We can agree that persons with high blood pressure, schizophrenia or cancer are equally innocent and should be protected from risk of harm in the research setting. We can also agree that we can allow research subjects to be exposed to some risk of harm, because if we allow no risk of harm in research we will have no research. So the question for the vast number of persons and societies is not harm versus no harm, but how much harm is it ethically permissible to expose research subjects to, all other ethical requirements being fulfilled? In the case of placebo controlled trials for high blood pressure, the concern about placebo-induced harms is ordinarily inconsequential. Subjects can be closely monitored for serious rises in blood pressure and returned to their prestudy drug regimen safely. In cancer patients, there is a strong moral consensus that

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harm of placebo is too grave, so a placebo-controlled design is ethically impermissible for most cancer trials. But in the case of psychiatric research in subjects with schizophrenia, there is wide disagreement across societies and individuals within societies about just how much risk of harm is too much risk of harm in such trials. When it comes to defining the limits of unnecessary harm to which we would allow research subjects to be exposed, adhering to the moral norm of prohibiting unnecessary harms to innocent persons produces wildly differing approaches.

Does this variability equate to ethical relativism? No, not even close. We just need to continue working out our definition of 'unnecessary harm.' Nobody would suggest that the outer limits could be ethically set to allow for irreversible harm or death.

Clinical examples abound, as well. Given that reducing or avoiding harms to patients is at the intuitive and formalized ethical core of medicine, prohibitions on inflicting unnecessary harms seems like an easy one to apply clinically. But here, too, the abstraction sounds good but the difficulties remain in the details. Consider the patient dying of widely metastatic cancer. The patient has progressed through the majority of standard therapies, has declined a research participation invitation and is now in the Intensive Care Unit (ICU) on a respirator and nonresponsive. The patient had indicated to her physician and other care providers that when her disease was clearly irreversible, she would not want to be sustained with the use of life-extending technologies. She also had indicated that she was eager to have her overseas daughter arrive in time to say good-bye before she died. Consider that her daughter is enroute from East Asia. She has several days of red tape to cut through before she can begin what will surely be more than a two day journey. The patient's son believes that his sister was given sufficient warning and now her protracted arrival should not prolong their mother's intubation. He believes waiting for his

sister to arrive before extubating his mother is inconsistent with his mother's wishes. What is unnecessary harm in this case? If the patient is truly unknowing of her surroundings, is she being unnecessarily harmed by being sustained until the daughter arrives from East Asia? Is the patient, once all are reasonably confident that she is not experiencing any pain or suffering, the only innocent person who needs to be protected from unnecessary harm? These are questions that accept the notion of a universal moral norm and simultaneously acknowledge that there will, factually, be variability across individuals and societies about how such a universal norm should be played out. Is this the same as saying that everything is relative? Certainly not. There would likely be substantial agreement that this patient should not be sustained indefinitely if the daughter in East Asia is dawdling because she is on vacation.

Intuitively, it seems that persons concur that there are limits on how much unnecessary harm we ought to ethically allow others to experience. The recent political upheaval about tolerating torture—or rather the public outrage and abhorrence resulting from the possibility that our government might tolerate torture—may be a good example of evidence that a universal moral norm exists in prohibiting unnecessary harm to others. Where this intuition originates, of course, is yet to be scientifically determined. If it predates philosophical and religious thought, perhaps it is embedded in our genes. This is an interesting thesis that has already been advanced.³ This possibility is supported by the apparent universal taboo on incest. It appears to be an empirically demonstrable fact that among cultures that have flourished throughout recorded time, there has been a taboo on incest. This taboo undoubtedly springs from the need to protect genetic diversity for mental and physical health, but may also have a substantive moral component. Sexual predation of daughters by fathers and brothers produces grave psychological harms.

These examples are offered in illustration of the claim that the existence of culture-specific moral norms neither negates the plausible existence of universal moral norms nor supports an argument for moral relativism. Whether or not they are convincing, they highlight the complexity of moral argumentation. Because there is so much room for disagreement about what actions to take in everyday life, learning to avoid these conceptual confusions is critical to sound thinking and right action. That the task is difficult is not a sufficient reason to fall back on the weak claim that ethics is relative. Rather, the difficulty of the task ought to motivate thinking persons, and in the case of this column's specific readership, medical professionals and ethics committee members, to become increasingly skilled in ethical argumentation and discourse. Only by doing so can one differentiate a well-considered, culture-specific difference in individual moral norms from an argument mired in an ethically relativist inability to evaluate a judgment or approach as ethically unacceptable.

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CASE PRESENTATION

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Readers are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the patient. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to MHECN@law.umaryland.edu, or MHECN, the Law & Health Care Program, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE STUDY FROM A MARYLAND HOSPITAL

Mr. Juarez is a 61 year-old man who lived most of his life in Cuba. One year ago, he achieved his lifelong dream of seeking political asylum in the U.S.

He joined his 23-year-old niece and her husband in their home. He has no other family members in the U.S. Shortly after his arrival, he was diagnosed with advanced sarcoma, for which he has received radiation therapy. At present, he is hospitalized for a large, open, bleeding tumor on his arm, pain, and increasing weakness. Mr. Juarez speaks only Spanish. The oncologist is concerned that, considering the advanced stage of Mr. Juarez' cancer, there are little treatment options left for him, and that it is time to transition to a comfort care approach rather than continue with life-prolonging measures that hold little, if any, hope for prolonging life.

Furthermore, the oncologist is concerned that the benefit of blood transfusions Mr. Juarez has been receiving for low hemoglobin is minimal, at best, and because Mr. Juarez has a unique blood type, that the blood should be reserved for other patients for whom it would more likely be of benefit.

His niece insists that the blood transfusions be continued. An interpreter is called in to discuss end-of-life decision-making with Mr. Juarez, including whether a "Do Not Resuscitate" order should be written. Mr. Juarez is weak but fully oriented. Yet, he does not answer the questions about his end-of-life wishes, including whether he would prefer his niece to make health care decisions on his behalf. Instead, he repeats statements such as, "[th]ese are very profound matters," and "[t]hese are questions for God." Subsequent attempts to get Mr. Juarez's input are met with similar results. The ethics committee is consulted to weigh in on the case.

RESPONSE FROM A GRIEF COUNSELOR

Death is a human experience that crosses all racial, religious, and ethnic boundaries. Within our social and cultural parameters lie a wide variety of beliefs and behaviors surrounding death. Different cultures will approach the experience of death in various ways. Culture often shapes choices for life support such as resuscitation and feeding tubes. Culture can also dictate one's desire to be informed of a terminal illness and what quality of life one wants to endure during the last days. Some cultures will accept death as a natural part of the life cycle, as this patient appeared to do. Other cultures may defy death by believing that although the body ceases to exist in the physical form, it moves on to a spiritual realm. Still, other cultures will suggest that death is unnatural. Those who believe the latter will avoid talking about it in hopes that an absence of the conversation will prevent its occurrence. Think of how often we, in the medical profession, refer to the deceased as "expired." Family members will say that their loved one has "passed on." Avoiding the actual word "death" detaches the reality that the loved one no longer exists.

The response that Mr. Juarez gave in reference to his "end of life" decision is similar to a response you would receive from many faithful, practicing Christians facing the same fate. They have a strong

faith that dictates when death occurs it is the will of God. They rejoice and resign themselves to the fact that they will die and live with God. Clinicians need to respect individual cultures and learn how to explain a person's illness and prognosis in a way that allows the person (or designated family member) to make competent decisions concerning his or her health care options.

Fatalism is defined as a belief that events are determined by forces outside of one's control. Mr. Juarez placed his faith in "God's will." Once a believer places his trust in the will of God, there is nothing left to answer. The outcome is already predestined by a higher source. Many terminally ill patients seek spiritual guidance at the end of their lives. They may reflect on the meaning and purpose for their lives and draw comfort in the fact that they have accomplished all they have been placed in the world to do. Others may wish for more time but resign themselves to their pending fate.

A major issue that a patient such as Mr. Juarez must face is the shortcomings of medical personnel. Many of us (i.e., health care professionals) present with our own personal beliefs, whether religious or spiritual, our own values, and the most destructive, our personal opinions as to what should happen to the patient. We often forget how the dying experience affects not only the patient but their family and the caregivers involved. The extent of the family involvement in this case is not clear. Family members often make sacrifices to care for ill family members. They often try to protect the patient and carry out the patient's wishes. In this case, the niece wanted the blood transfusions to continue. The ethics committee could recommend a family conference, which could prove beneficial in order to share the plan of care for the patient with the multidisciplinary team or the family. If the hospital had a palliative care team available, the team could assist with communicating the wishes of the patient and assist the health care providers to understand the patient's concerns and culture. Issues such as the pros and cons of continuing with blood

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CASE PRESENTATION

transfusions could be discussed in this forum. This patient may have expressed to family members what his end of life wishes were. When discussing complex and culturally-sensitive issues like end-of-life preferences in the context of a terminal prognosis, it's best to include a skilled interpreter, even if English-speaking family members are also present. The ultimate decision to discontinue blood transfusions should not run counter to palliative care goals of keeping the patient comfortable.

Rationing of health care resources can cause problems for health care providers if it is not clearly presented to those involved in the care of the patient. Discontinuing blood transfusions that are not benefiting a patient is well within the scope of practice for the oncologist. Mentioning the cost or availability of the blood to the patient or family member is what may cause controversy.

Not having advance directives in place is an all-too-common scenario in many end-of-life cases presented to ethics committees. The emotional drain on the patient and family members could be avoided if we as health care providers did a better job of having the patient complete advance directives well before the need arises. The actual form may need to be made easier for the layperson to understand, or perhaps be adapted to align with individual cultural values and beliefs. Additional research needs to be conducted that will encompass culturally diverse populations, address effective communication to the dying, and address end-of-life treatments that promote quality of life and decrease suffering during the final phase of life.

One cannot be sure that this patient actually understood the magnitude of his illness. He most likely placed his trust in his caregivers. We need to accept the trust given to us by our patients and make their end-of-life experience as painless and autonomous as humanly possible. Exploring and respecting how race, religion, and culture may be

influencing the patient's preferences is likely to help establish such trust.

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RESPONSE FROM A PHYSICIAN & ETHICS COMMITTEE CHAIR

In my experience as a member of an ethics committee serving a 250 bed community hospital in suburban Washington, most consults are the consequence of inadequate communication between health care providers and the patient and his or her family.

I would break this consultation down into several distinct problem areas:

1. Family history, social support resources
2. Cultural base
3. Language issues
4. Who is speaking for the patient?
5. Medical history, prognosis
6. Futile therapy, appropriate use of limited resources
7. End-of-life decision making
8. The role of an ethics consultant

Let's go through these, one at a time.

1. If you understand the family, you are usually a long way towards understanding the solution to the problem for which you have been consulted. What are Mr. Juarez's total social resources? Is the 23-year-old

niece truly his only family in the United States? Just how "close" is he to his niece? What part of the family remains in Cuba, and how might they be able to help with this problem? How integrated into American society are his niece and her husband? What community support sources are available to the niece and her husband? What is the religious base for Mr. Juarez? These are all important questions to pursue.

2. Mr. Juarez has immigrated to the United States from a markedly different social, cultural and political environment, and his Cuban heritage may significantly influence the way Mr. Juarez considers end-of-life issues. Whereas Americans tend to view end-of-life decisions through the lens of autonomy and self-determination, Cubans tend to be more attuned to the idea that circumstances are the result of a higher authority or being.¹ This fatalism and acceptance of circumstances is reflected in Mr. Juarez's statements, such as "These are very profound matters," and "These are questions for God." On the other hand, the limited comments by Mr. Juarez may also reflect language and/or interpreter problems.

Cubans are predominately Catholic and many practice *Santeria*, which is a syncretic form of Catholicism where individual Catholic saints actually represent "gods" having influence over certain worldly activities. This polytheism represents vestiges of an African religion that was brought to Cuba by slaves that the Spaniards imported to replace the decimated native population, and *Santeria* persists today within Catholicism in Cuba as well as in other countries, albeit unofficially.

3. There are obvious language issues in this case. The health care team has already made the appropriate decision to use a professional interpreter but the quality of these interpreters can be inconsistent. It would probably be helpful to have another person whom Mr. Juarez trusts implicitly involved in the interview process, just to make him feel

more comfortable. A priest, especially one who serves the Cuban community, might be very helpful. The niece has been serving in this role so far, but she may have her own agenda.

4. It appears that the niece is making medical decisions for her uncle and it is not clear that Mr. Juarez wants her to be his agent. Either the patient speaks for himself or the appropriate surrogate decisionmaker is designated, but no decisions can be made until the decision makers are established. The identification of the decision-maker has so far proved difficult to accomplish but sometimes the entry of a third party, e.g., the ethics consultant, can act as a catalyst to the process.² Again, a Catholic priest may also help to guide the patient and family in assuring them that “God’s children still need to make decisions at the end of life.”

5. In an end-of-life consultation the basis for discussion usually revolves around the patient’s diagnosis and prognosis. This is really the bottom line and it has to be evaluated exhaustively. The emphasis is on thorough discussion and explanation of options and risks of therapy. One has to be absolutely thorough in establishing diagnosis, prognosis, therapeutic options and attendant risks. Without this solid medical base there are no meaningful grounds for discussion of end-of-life care. Bring in additional consultants as necessary, and be sure to identify all the medical and non-medical (including specialty pain management, palliative and comfort care, hospice, etc.) options for the patient.

Even though Mr. Juarez may not be comfortable dealing with all these details, it is the standard of care to explain all reasonable options. If Mr. Juarez wants to appoint someone else (his niece, for instance) to consider all of these choices and to make the final decisions regarding which option to pursue, that is his right.

6. Suggestions of futility are almost always poorly received by family members, especially if there is a lack of trust in the relationship between the family and the health care providers. There is a tendency for families to interpret an assertion of medical futility as a devaluation of the patient’s life, i.e., “this patient’s life is not worth extending.” The fact that the niece “insists that he continue to receive the blood transfusions” means that the subject has already been broached. The actual facts need to be researched thoroughly at this point. Since the initial assumption that the blood was needed by other patients might not actually be correct, the consultant should establish the nature of the antigen problem, the precise requirements for any transfusion, the actual availability and demand for the blood, etc. Then, with this detailed knowledge, and with the full involvement of the attending physician, the consultant will want to discuss again this issue with the patient and niece. Unfortunately, if families believe that they are victims of discrimination, they tend to “stonewall” in such discussions, and the issue may ultimately be non-negotiable, and some other resolution will have to be sought.

7. Once all of the above issues are addressed, the consultant can turn to reaching a decision by the patient and/or his family on how best to proceed. One might anticipate that the only realistic options in this case will be palliative, in that all reasonable therapeutic options, including blood transfusion, have probably been exhausted. The consultation may ultimately be little more than a counseling process where the consultants help the patient and family come to grips with the finality of the situation, and guide them in planning the final days of Mr. Juarez’s life.

8. Consults like this one are interesting in that they raise the question of what the role of an ethics consultant should be. In every case the consultant is an investigator, a facilitator and an educator. In some cases the consultant helps the patient and family identify their own values regarding end-of-life care, and in others the consultant may actually attempt to persuade a patient or family to adopt a particular viewpoint. This idea of “principled mediation”² is an important one but it also reveals that the consultant is not always neutral, and may actually have a role in influencing the patient and her family to subscribe to a particular philosophy or course of action. Does a consultant truly honor patient autonomy in such a situation?

The case of Mr. Juarez, in spite of the complexities that we have discussed, is relatively simple since Mr. Juarez will probably die within a matter of weeks, no matter what is decided. In this case the consultant serves as an educational resource and moral support for the patient and family, and in some cases the consultant can help bring a family together when it is under stress. It is important that the consultant stay connected with the family throughout the crisis, as well as follow-up with specific family members after Mr. Juarez’s demise.

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NOTES

1. Magaly Queralt, Understanding Cuban Immigrants: A Cultural Perspective, *Social Work*, V.29, pp. 115-121, 1984.
2. Nancy N. Dubler & Carol B. Liebman, Bioethics Mediation: A Guide to Shaping Shared Solutions, United Hospital Fund of New York, 2004.

A GLIMPSE AT THE APOCALYPSE: TWO WEEKS POST-KATRINA

By Brian Childs, PhD

Brian Childs is the Director of Ethics and Spiritual Care at Shore Health System in Easton, Maryland, and a licensed clinical marriage and family therapist. He is also a member of MHECN's Executive Board. In the aftermath of hurricane Katrina, Brian responded to a call for mental health triage in the affected areas. Here is a first-hand account of his experience.

I am a member of the Maryland Department of Health and Mental Hygiene (DHMH) Disaster Mental Health Corps. DHMH was asked by the American Red Cross (ARC) to mobilize volunteer members of the Corps to assist in the recovery and relief effort on the Gulf Coast after Katrina. I volunteered and was sent to Gulfport/Biloxi where I worked for two weeks with those who lived there (or used to live there) and with those who were helping to begin the recovery from the devastation of that storm.

My work focus included the geographical area west of U.S. Rte. 90 from Gulfport to Pass Christian, approximately 10 miles of what, I was told, was once a very beautiful stretch of beach road. What I saw was utter destruction. Where houses and businesses once stood one could see only a concrete slab or the shell of a building. The storm surge (estimated at thirty feet) swept in from the Gulf of Mexico, leaving shipping containers, whole ocean-going barges and livestock strewn from the water's edge to about a third of a mile inland. Trees (including live oaks, some of which were well over 100 years old) had debris on their upper limbs: clothing, plastic sheeting and, in two places, whole automobiles and boats. My job was to drive a pickup truck through the neighborhoods offering cold drinks, sunblock, insect repellent, and military meals ready to eat to rescue workers (who were still finding bodies) and residents who were trying to find something of their lives in the ruins. (I could not help but think of Walker

Percy's prescient novel *Love in the Ruins*.) It was during these stops that I became a listener to stories of survival and hope in the face of despair.

I have to say that the ARC does its job well. In my two weeks there I never met a single professional Red Cross worker. Even the Gulfport Headquarters was run by a volunteer (of course she was also a veteran of five major disasters). Red Cross money does in fact go to those who need it. Of course, we volunteers were fed what the survivors got. . . . I heartily recommend the enchilada MRE (Meals-Ready-to-Eat) . . . and I slept on the ground with National Guard men and women from Michigan and Tennessee. Besides the ARC volunteers, the folks I admired the most were the National Guard men and women, most of them older teenagers who happened to carry weapons. I helped some guards stem a riot from occurring when 4,000 people showed up in the stifling heat to get FEMA money. When the FEMA official realized he was unprepared to process such numbers, he decided to 'disappear,' leaving a platoon of Guard men and women and four ARC volunteers to deal with the crowd, some of whom were elderly and sick and passed out in the heat. The Guard lieutenant arranged for help from the local clergy in the crowd (a brilliant move by this young man) and arranged for folks to be sheltered, watered, fed, and then gave the FEMA official a terse lecture about morality of promises not delivered. (Immanuel Kant was not mentioned, though God was mentioned in several colorful ways.)

Probably the lasting impression I have of my experience is how terribly unprepared we are to face such disasters. We had warning about this one and still the response seemed to be more reactive than proactive. I also was reminded of how weak and inaccessible our health care system is. Some of the folks who received medical treatment from the ARC had more treatment

in those few days than they had had their entire lives. The mortality rate of Katrina will not consist of those who died in the storm itself. The victims of Katrina continue to rise as the poor and the sick suffer more deprivation and inadequate health care. Additionally, after Camille in 1965, the people of Mississippi decided that the Gulf economy was going to be saved by casino gambling. The casinos were swept away and those who depended on them for their meager incomes are now unemployed, unskilled, have no housing, and have grim futures.

I believe that in some small way we ARC volunteers helped in the short run. It is the long run that concerns me. The survival of the area and perhaps even our souls will depend on a change of political and public will, which at this point in time I do not see coming.

Erratum

In the *Personhood* article contained in the Summer 2005 issue (*Philosopher's Corner*, p. 6), the word "perceived" should have preceded "need" in the following sentence: "For example, they oppose abortion, but do not demand social policy reform to eliminate cultural and social influences that perpetuate the need for abortion." Our apologies to co-author Brigit Ciccarello for failing to incorporate this requested edit.

CALENDAR OF EVENTS

FEBRUARY

- 16 **What have we learned from Terri Schiavo? – Medical Perspective.** Michael A. Williams, M.D., Co-chair of the Johns Hopkins Hospital Ethics Service, Associate Professor, Neurology. Johns Hopkins Hospital School of Nursing Alumni Auditorium (525 N. Wolfe Street), 4-5 p.m. with Q & A to follow.
- 23 **Beyond the Schiavo case: Principles and practice of artificial nutrition and hydration.** David Casarett, MD, MA, Center for Health Equity Research and Promotion. Medical Humanities Hour Lecture, University of Maryland Medical Center, Shock Trauma Auditorium, 4-5PM.
- 27 (12:15pm - 1:30pm) **Assent in Research with Children,** Rick Kodish, MD, Professor and Chairman, Department of Bioethics, Cleveland Clinic Foundation, Lerner College of Medicine Johns Hopkins Bloomberg School for Public Health, 615 N. Wolf St., Feinstone Hall.

MARCH

- 1-3 **Developing Skills for Hospital Ethics Programs.** Sponsored by the Center for Biomedical Ethics, in cooperation with Continuing Medical Education (UVA). Charlottesville, VA. For more information visit <http://www.healthsystem.virginia.edu/internet/bio-ethics/dshep.cfm>, or contact Carrie Gumm at cg2b@virginia.edu, (434) 924-5695.
- 2 **What have we learned from Terri Schiavo? Legal Perspective.** Margaret R. Garrett, J.D., Senior Counsel, Patient Care, Risk Management and Ethics at The Johns Hopkins Hospital, and Jack Schwartz, Assistant Attorney General for the State of Maryland. See Feb 16 for time & place.
- 8 (12:30-1:30pm) **Interrogation, Behavioral Science and Medical Ethics in the War on Terror.** Jonathan H. Marks, M.A., B.C.L. (Oxon.), Barrister, Matrix Chambers, London. University of Pennsylvania Center for Bioethics (see Feb 4 above).
- 14 **Ethical & Psychosocial Management of the Patient and Family Identified as *Difficult*.** Sponsored by the Inova Health System Center for Ethics & Inova Learning Network. IAMS Conference Center, Inova Health System, 2779 Telestar Ct. (nr. Rte 50 and Gallows Rd), Falls Church, VA. Limited registration. For more information, contact Patti O'Donnell, DSW, Director, Center for Ethics, Inova Health System 703-321-2658 (phone) or patricia.odonnell@inova.com.
- 16-17 **The New Medicine: The Ethics & Policy of Regenerative & Replacement Therapy.** Sponsored by The Program for Ethics in Health Care Systems in the Center for Biomedical Ethics, in collaboration with the Islet Cell Transplant Center, and the Morphogenesis and Regenerative Medicine Institute. Charlottesville, VA. For more information, visit <http://healthsystem.virginia.edu/internet/ethicsandpolicy/stemcellconf.cfm>, or contact Carrie Gumm at cg2b@virginia.edu, (434) 924-5695.
- 22 **Mongrel Nation: Race, Genetics, and the Law.** Paul Lombardo, Ph.D., JD, Director, Program in Law and Medicine, Center for Bioethics, University of Virginia. University of Pennsylvania Center for Bioethics (see Feb 4 above).
- 24 **Global and Ethical Mandates on Reducing Health Care Disparities.** A “mini-conference” focusing on genetic engineering in humans. Joint Symposium with the University of Pennsylvania Center for Bioethics and the School of Nursing, School of Nursing Auditorium, Philadelphia. For more information, visit <http://www.bioethics.upenn.edu/>.
- 27-28 **Islam and Bioethics: Concerns, Challenges and Responses.** Sponsored by the Rock Ethics Institute at the Pennsylvania State University, State College, PA. For more information, visit <http://rockethics.psu.edu/islam%5Fbioethics/>, or contact Kathy Rumbaugh, RockEthics@psu.edu, 814-863-0314.
- 30 **What have we learned from Terri Schiavo? Theological Perspective.** Rabbi Dr. Tsvi Schur, Imam Dr. Yahya N. Hendi, the Reverend Dr. Michael O. Thomas, and Fr. Phil Keane. See Feb 16 for time & place.
- 30 **Therapeutics Misconception in Oncology Clinical Trials.** Henry Gail Henderson, Ph.D., Professor, Department of Social Medicine, University of North Carolina School of Medicine. Medical Humanities Hour Lecture, University of Maryland Medical Center, Shock Trauma Auditorium, 4-5PM.
- 31 **Ethics, Integrity, Leadership and Practice: Meeting the Challenges of Social Work Today, Continuing the Legacy.** The National Association of Social Workers-Maryland Chapter. BWI Marriott, Baltimore, MD. For more information, visit <http://www.nasw-md.org/SWMonth06.htm>.

APRIL

- 5 **Parental Refusal of Treatment.** Lainie Friedman Ross, MD, PhD, Vice Director of the Maclean Center for Clinical Medical Ethics at the University of Chicago. The Children's National Medical Center's Annual Leikin Memorial Lecture, CNMC Auditorium, 111 Michigan Ave., N.W., Washington, D.C.
- 6 **The legacy of Abu Ghraib for military medicine.** Steven Miles, MD, University of Minnesota Center for Bioethics. University of Pennsylvania Center for Bioethics (see Feb 4 above).
- 19 **Current Controversies in Healthcare Ethics.** Sponsored by the Inova Health System Center for Ethics & Inova Learning Network. IAMS Conference Center, Inova Health System, 2779 Telestar Ct. (nr. Rte 50 and Gallows Rd), Falls Church, VA. Limited registration. For more information, contact Patti O'Donnell, DSW, Director, Center for Ethics, Inova Health System 703-321-2658 (phone) or patricia.odonnell@inova.com.
- 27 **What have we learned from Terri Schiavo. Ethical Perspective.** Ronald Cranford, M.D., Professor of Neurology and Medical Ethicist at Hennepin County Medical Center and University of Minnesota Medical School. Discussion to follow led by WYPR's Marc Steiner. See Feb 16 for time & place.
- 30 **Legacy of the Terri Schiavo Case.** Tenth Anniversary Symposium, University of Pennsylvania Center for Bioethics (see Feb 4 above).

