



## ETHICS AT THE CENTER



University of Colorado at Denver & Health Sciences Center

### CENTER CORE MISSIONS

#### **1. Be an educator:**

To educate health profession students & health care practitioners to address ethical issues, to adopt high professional standards, and to exhibit a proper balance between the humanities and the sciences.

#### **2. Be a convener :**

To create a space & forum of conventional broad sections of professionals, administrators, trustees, academicians, government, & community representatives for honest credible problem solving of moral issues in healthcare.

#### **3. Be a source of knowledge**

To create, advance and disseminate knowledge in bioethics & humanities.

#### **4. Be a resource to others:**

To share our expertise in bioethics and humanities with health care institutions, health care professionals, ethics committees, IRB's, administrators, trustees, policy makers, scientists, organizations & individuals.

Center for Bioethics  
& Humanities  
University of Colorado at  
Denver & Health Sciences  
4200 East Ninth Avenue  
Box B137  
Denver CO 80262  
303-315-5096

### THE CENTER FOR BIOETHICS & HUMANITIES CORE PURPOSE:

**TO PROMOTE ETHICAL, JUST & HUMANE HEALTH CARE**

FROM THE DIRECTOR: MARK YARBOROUGH, PhD  
**THE ROLE OF RESEARCH IN BIOETHICS**

If you were a parent whose children were at risk for inheriting a gene that might cause a life-threatening genetic disease later in life and if there was a genetic test that would determine whether or not your child inherited that gene, would you want to test your children for the gene? Many parents would. If you yourself were at increased risk for acquiring a life-limiting illness such as cancer and there was a genetic test that would inform you whether or not your chances of getting cancer were greater than the average risk, would you want to be tested? Many adults choose not to be tested under these circumstances, and therein lies one of the great paradoxes for testing children for genetic diseases that will not be manifest, if ever, until well into their adult years. If you know in advance that many adults would prefer not to know their own risk for genetic disease, how do you grant parents the ability to learn important health information about their children without depriving children of their "right not to know?" Many of them would likely choose, if only given the chance, not to know just as their adult counterparts choose not to know.

There are many variables to consider while trying to resolve this paradox, most notably whether or not there is anything to be done to prevent a child from acquiring the disease later in life if the gene is identified during childhood. In order to better understand how to help parents and their children make these complicated choices, bioethics is developing a robust research agenda in this and other areas of medical genetics. The Center for Bioethics and Humanities is contributing to this growing field of research. In the fall, Dr. Coors will initiate a study, in collaboration with other researchers at the University of Florida and the Medical University of South Carolina, whose results can assist future parents as they decide whether to test their children for a type of inherited adult emphysema.

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**WHO'S WHO ON  
THE CENTER FOR BIOETHICS & HUMANITIES  
ADVISORY BOARD**

**G**erry Lewis-Jenkins has been a member of the COPIC Companies organization since 1991. She has held various positions including Senior Vice President of Business Development and Communications and Executive Vice President and COO of Gadrian Corporation (a national credentials verification organization). In her current role as Executive Vice President, she oversees all aspects of Sales, Corporate Marketing & Communications and Information Technology for COPIC Companies, and COPIC's wholly-owned subsidiary COPIC Financial Services Group. Gerry also oversees COPIC's book of business in Nebraska, new products and expansion or acquisitions that COPIC may consider, and patient safety initiatives.



*Gerry Lewis-Jenkins*

Prior to joining COPIC Companies, Gerry was Executive Director of Humana Health Plans of Colorado. She is a registered nurse with more than 20 years' experience in clinical and hospital management. She holds a degree in Health Care Administration and a MBA from Regis University.

Gerry serves on the Board of the Physician Insurers Association of America's Marketing Section. She participates on the Susan G. Komen Alumni Committee and the Advisory Board of the Regis University Health Services Administration Graduate Program. Gerry is currently chair of the Education Committee of the Advisory Board of the Center for Bioethics and Humanities.

*12th Annual Genetics & Ethics Conference  
July 20- 21st, 2007*

*"DNA Identification and the Law:  
New Horizons and Outer Limits "*

*The Given Institute of the University of Colorado  
Aspen, Colorado*

*Register online at [www.uchsc.edu/cme](http://www.uchsc.edu/cme)  
\$ 325.00 Student Discount \$ 150.00*

The focus of this year's conference is the ethical impact that current and emerging forensic genetic and DNA database practices are expected to have on the criminal justice system, the individual and society. Law enforcement agencies around the world have been using DNA databases to identify violent criminals for a over a decade. Conference attendees will explore the scientific and ethical concerns of current investigative practices involving use of DNA databases, as well as newer approaches to developing investigative leads such as familial searches or rare allele geography.

Any questions ? Contact Marilyn Coors at [marilyn.coors@uchsc.edu](mailto:marilyn.coors@uchsc.edu)

## FULGINITI PAVILION FUNDRAISING REPORT

By Field Glover  
CU Foundation



Momentum continues to build behind the Center's development effort.

The commencement of summer marks the construction on the exterior of the Fulginiti Pavilion nearing completion. With the advent of warm weather, there has been a palpable increase in fund raising activity led by Dr. and Mrs. Fulginiti. Board members have augmented the Fulginiti's efforts and their work has resulted in outstanding new friends becoming more familiar with the Center for Bioethics and Humanities.

I want to take this opportunity to thank all of the members of the board. The membership works together to create a strong, outstanding organization that has given selflessly of time, contacts, and assets. This project would not be as far along as it currently is without the board's guidance and vision. Ultimately, this project's success is a reflection of each member's commitment to creating a regional force in ethics at the University of Colorado; thank you.

The next few months of donor activity promise to serve as a reliable indicator of the project's final completion date and conclusion of capital fund raising campaign. I look forward to working closely with board members, donors, and faculty to bring this campaign to a successful conclusion.

There remains high-level interest within the University and Foundation in seeing this project completed. If you know of individuals, corporations, or foundations that might be interested in learning more about the Fulginiti Bioethics Pavilion please contact Field L. Glover, CFRE at 303-813-7926 or e-mail me at field.glover@cufund.org.



### 7th Annual Quandaries in Health Care Conference



September 27-29, 2007  
The Given Institute  
of the University of Colorado  
Aspen, Colorado

#### Sponsored by:

- Center for Bioethics and Humanities  
University of Colorado at Denver  
and Health Sciences Center
- Institute for the Medical Humanities  
University of Texas Medical Branch at Galveston
- Center for Biomedical Ethics & Society  
Vanderbilt University Medical Center
- Project Biocultures  
University of Illinois, Chicago

Power and Health Care

### Center for Bioethics & Humanities Advisory Board

*Next Meeting—  
Tuesday, July 17th, 2007  
4:00—6:00 pm*

*Location—  
Skaff Conference Room  
School of Pharmacy  
9th Ave Campus*

*Parking tokens available  
Agenda will be emailed  
prior to meeting.*

## HIGHLIGHT ON CURRENT FACULTY WORK

### Rural Bioethical Issues of the Elderly : How Do They Differ From Urban Ones?

*Jackie Glover, PhD*

*Excerpted from J. Glover “ Rural Bioethical Issues of the Elderly : How Do They Differ From Urban Ones ?” Journal of Rural Health. 2001:17(4)332– 335.*

You have stopped at the local grocery store for a few things on your way home from the clinic. Before you can make it down the first aisle, you are stopped by two patients with various questions about their treatments. All the shoppers greet you with a friendly smile and hello –all are either patients, or family members or friends of patients. Many have questions or comments. You don’t want to be unfriendly but you also have concerns about patient confidentiality. This issue of confidentiality is one of the most challenging ethical issues in your small rural practice.

Yet the sorts of ethical questions raised while shopping in the grocery store are not the usual fare for discussions in health care ethics. The usual questions (Do we withdraw the breathing machine? Who gets the liver transplant? Who speaks for the elderly patient with dementia?) are much more likely to be seen as ethical issues and more likely to be discussed in the literature. But for clinicians, patients, and families in rural settings, these may not be the most pressing ethical issues.

There are two major differences between urban and rural settings that set the stage for how ethical issues are encountered and resolved. The first is familiarity and multiple relationships among professionals and patients. The second is access to care.

Patients are known to the health care professional outside the health care encounter and vice versa. They may have grown up together and their families know each other from way back. They are neighbors and possibly friends. Their kids and grandkids go to school together. Their patients are likely to be their accountants and lawyers as well. Most important, health care decisions are made in this larger context of a shared future. Health care professionals actually live in community with their patients. Patients and health care professionals will both live with the consequences of decisions.

Also, trust may be an important feature of any patient-health care professional relationship, but there are notable differences for rural practitioners. In the

urban setting, patients must rely on health care professionals who are strangers to them. They trust (or do not) because of expectations of the white coat in general. Trust between strangers is built on what happens in a series of health care encounters. Rural professionals are located within the rural community in a way that doesn’t sharply separate professional and private spheres. Trust is woven from threads of a shared community life, not just health care encounters. Trust in rural professionals is based on what patients know about their behavior as a member of the larger community – how they coach the Little League team and what they say at the PTA meetings. Health care providers who separate themselves and don’t identify with the community may be viewed with suspicion and their judgments challenged.

The multiple relationships that are a necessary part of rural practice also raise serious questions about the ethical obligation to respect confidentiality, an ethical issue described by many rural practitioners as the one that is most prevalent and problematic. Anyone living in a rural setting understands that there are very few or no secrets – everyone seems to know everything. From the recognizability of the trucks outside the clinic to the church routinely announcing the status of hospitalized patients, community members have ready access to much knowledge that is not commonly available in more urban settings. Yet the ethical importance of confidentiality remains the same – to respect the patient’s privacy and to encourage their trust in revealing important information.

The health care professional has the obligation to make sure that the information does not come from him or her. Everyone may know it, but it shouldn’t come from the doctor or nurse or other staff. The other implication is that if there are no secrets, then decision making will be subject to the standards on “Main Street”, so to speak. Health care professionals in rural settings quickly learn to be aware of the unspoken community rules, or else they risk being considered outsiders and untrustworthy.

Rural ethical issues grow out of this context of familiarity. Informed consent and proxy decisions are different in that less weight needs to be placed on a small number of statements made in a pressure-packed situation. There is often background information against which such statements can be checked. Decisions need not be based on a snap-shot of a patient’s life – family, friends and health care professionals have seen the whole album. Because of this familiarity, end-of-life decisions about the use of life-sustaining technology, for example, can be easier or more difficult.

The second major difference between urban and rural settings is the remoteness from higher levels of medical care. Transfer of patients to a distant tertiary care center for treatment is often a major issue. Patients and their families often have difficulty dealing with larger institutions and their bureaucracies, and they are reluctant to go. Perhaps most importantly, transferred patients are at risk of losing their social support system. Often rural patients would prefer to receive service locally, even when it raises concerns about scope of practice for local professionals. Also, survival of rural health care institutions is a continuing concern. Transferring patients may jeopardize the financial well-being of the rural hospital.

**RURAL BIOETHICS ..CONT'D FROM PAGE 4**

The financial viability of the rural hospital or clinic may depend on balancing the provision of care to patients who need it with collection of enough reimbursement to meet expenses. If a rural hospital or clinic closes, then remoteness from medical care becomes even much more of a problem for rural patients.

*For about the past decade, I have been working with rural colleagues from around the country to develop resources in ethics for rural professionals.*

*We are currently developing a "Handbook for Rural Healthcare Ethics" that will be available on the web in the next year or so.*

*We most recently presented at the National Rural Health Association meeting in Anchorage, Alaska.*



**Spotlight on Center Faculty Associates & Current Work  
This Month: Dan Johnson, MD**

**THE LIFE QUALITY INSTITUTE: ADVANCING PALLIATIVE CARE IN COLORADO**

*Palliative care* is a holistic, patient-centered model of care for people with advanced illness. This team-based care addresses a patient's (and their family's) physical, psychological, social, and spiritual needs. Most often, palliative care is delivered concurrently with other curative or restorative therapies. In September, 2006, the American Board of Medical Specialties formally recognized Hospice and Palliative Medicine as a medical subspecialty.

Palliative care has not been a traditional feature of health care education. Studies show that medical students, residents and other health professionals feel unprepared, often fearful, to care for patients with incurable diseases. In November 2003, The Denver Hospice received a federal grant to establish the Life Quality Institute (LQI), a palliative care educational institute, whose mission is *to support the achievement of best quality-of-life for people with life-limiting illness by educating healthcare professionals, students and communities about palliative care and supporting the growth and development of palliative care services.*

Under the Directorship of Dr. Daniel Johnson, a Faculty Associate with the UCDHSC Center for Bioethics and Humanities, the Institute has developed and implemented extensive palliative and end-of-life care curricula for Colorado's health care professionals. Over the past three years, through collaboration with the University of Colorado and numerous other organizations, the Institute has provided more than 50,000 hours of experiential palliative care education to medical students and residents, nursing students, physician assistants, practicing healthcare professionals and community audiences. Training topics are diverse and include: effective and compassionate communication; pain and symptom management; end-of-life ethics and law; grief and bereavement; advance directives; and spiritual discourse on meaning and hope for persons facing advanced illness.

LQI also supports Colorado communities. Each year the Institute teams with multiple 9Health Fair sites to deliver the "Five Wishes" advanced care planning tool. A new initiative entitled "Share The Care™" provides education that facilitates the development of community-based networks to reduce the often overwhelming caregiver burdens of persons facing chronic and advanced illness. In addition to improving awareness and understanding of palliative care, these community programs promote the development of systems that can better support the needs of our aging population. In addition to the University of Colorado and the Center for Bioethics and Humanities, the Institute works closely with other academic and community organizations including the Colorado Hospice Organization, the Colorado Palliative Care Partnership, Kaiser Permanente, Exempla and HealthONE hospitals, the Alzheimer's Association, multiple faith-based and hospice organizations. Ongoing funding for LQI's professional and community projects includes generous support from the Rose Community Foundation, the Colorado Health Foundation, Caring for Colorado, and the Mordecai Foundation.

## Community Forum -

### Thoughts on End of Life Conversations

By: Dr. Fred Abrams

Separated by a century and a half, two famous poets gave advice about approaching death. When Dylan Thomas died at age 39 from diabetes and pneumonia abetted by chronic and acute alcoholism, he certainly did not “go gentle into that good night,” nor had he reached the personified “old age” that he instructed not to surrender peacefully but rather to “burn and rage at close of day.” And I’ve always wondered about the sanguine William Cullen Bryant who was sixteen when he confidently advised the dying to be :

...sustained and soothed  
by an unfaltering trust, [and therefore to]  
approach thy grave  
Like one who wraps the drapery  
of his couch  
About him and lies down to  
pleasant dreams.

Do you suppose he maintained his teenage equanimity when advancing years made his death a little more real and imminent?

Well, whether we can be certain about these two extraordinary poets and the circumstances of their actual demise, we know from experience that the two poles of approaching death do exist—from those patients and those doctors who employ every technology available to prolong life regardless of its quality to those at the other pole who accept the inevitable and spend their remaining time and efforts to reconcile their conscious being to its dissolution and to accept whatever they believe follows earthly life. When we in healthcare are disappointed by the small number of persons who make advance directives, perhaps it is because only a minority of persons are capable of considering and preparing for their death in a rational way.

Our legislators have made great efforts to promote the American respect for self-determination by fostering various legal instruments to facilitate the individual’s right to approach death in his or her unique way. Because illness has infinite variety, trying to capture each end-of-life scenario in a legal document is impossible, although many proposed directives have had varying degrees of success. Even entrusting an agent with decision-making has been subject to conflict from the members of the patient’s social constellation. Few patients are actually informed enough about options and alternatives that are unique to their situation to determine their preferences in advance.

As the decades have passed since the first advance directives were offered, another significant factor has arisen in our country, the culture of a large number of persons that does not put autonomy as their first priority. Some do not permit discussion to prepare the patient for approaching death because it is felt to hasten death. Others do not wish to burden the patient with decisions and want a family member to make all health decisions. Conditions such as persistent vegetative state do not translate into all cultures. Buddhists, for example, would not treat cortex injury different from injury to any other organ system, hence would consider withdrawal of nutrition and hydration a violation of the duty to another human being. Cultural competence takes a while to learn.

So, back to the basics. The only way to find out how best to serve the patient approaching the end of life is to help develop the sensitivity among caregivers to interpret the clues given by patient and family about their wishes, usually from virtually continuous conversation. Uncertainties must be admitted but the more likely prognostic probabilities clarified. In the dynamic and often unpredictable set of circumstances that characterizes serious illness, changes in the patient’s clinical condition and how response to treatment bears upon therapeutic choices and prognosis must be carefully explained. Look for the time when direct questions may be asked of the patient if that is appropriate, or the family if that seems to be where decisions will be made. Options may then be presented so choices may be made. If the patient and her family have been kept aware of changing influential events, then trust will have been established. It’s the rare cases that make headlines.

Using the legal instruments that legislators have provided solves many problems, but it cannot resolve the conflicts of culture and religion or the irrational thoughts and wishes that permeate considerations of the finality of death. The law has become the first rather than last resort because of the serious economic consequences of lawsuits in our society. Far better would be honest explanation and continuous communication with ongoing revisions as needed in the medical care plan so misunderstanding that leads to conflict may be prevented rather than litigated.

**Dr. Fred Abrams is a Denver physician who founded the first center for the study of ethical issues in a community hospital setting in the U.S. He has served on numerous hospital ethics committees and has taught biomedical ethics to various health care practitioners. He is the author of Doctors on The Edge, Will Your Doctor Break The Rules For You? Dr. Abrams currently is a member of the UCHSC Center for Bioethics & Humanities Advisory Board.**

## CLINICAL ETHICS FORUM

### Evidence Based Medicine: Is There Room For Ethics ? By Jean Abbott, MD

One of the most recent additions to medical school and residency curricula is an approach to medical information acquisition called “evidence based medicine.” There is a huge need to figure out how to integrate new scientific information into daily clinical practice. The translation of scientific knowledge into clinical practice is difficult, given the massive amounts of information that accumulate, the difficulties of keeping up with even a relatively specialized body of medical knowledge, and time pressures on practicing physicians. Seminars and think tanks are increasingly focusing on how to bridge the large “knowledge translation gap.”

This week I participated in a workshop designed to teach my faculty colleagues and myself how to teach “EBM” to residents and medical students. In the process, we, as faculty, needed to get more facile at performing computerized searches of appropriate databases, asking clear questions of the literature, and integrating answers obtained by rigorous appraisal of the literature into care of the patient in front of us. Should we use thrombolytics (clot-busters) in this patient presenting 6 hours into a significant stroke? Will this woman with an acute cough illness do better with antibiotics or not? What are the odds that this child with pneumonia will need admission?

I was prepared to be un-impressed. The focus on “scientific knowledge” often appears to squeeze out the particulars and details of the doctor-patient relationship. But EBM leaders are very clear that clinical expertise involves integration of 4 components

- Scientific Evidence
- Patient Values and Preferences
- Clinical Context
- Resource Issues

Thus, the decision to treat sepsis (overwhelming infection) with major invasive monitoring, or even with antibiotics, involves integrating our best understanding of the scientific recommendations, as well as knowing what the patient wants, whether this infection is occurring in the context of terminal underlying disease or an otherwise healthy 48 year old patient, and other factors.

Dr. Edmund Pellegrino, in a JAMA editorial in 2000 (v. 283, 1065-7), emphasizes that a decision about whether to initiate a treatment plan (particularly at the end of life or when questions of futility arise) involves analyzing and balancing treatment *effectiveness, benefit and burden*. He points out that the physician brings to the table his or her understanding of “effectiveness,” or the best scientific evidence. How likely it is that this treatment will alter the “natural history” of a disease? The “benefit”, however, is determined by the patient – how valuable will the result of this treatment to the individual? The “burden” of a treatment needs input from both parties. Medical burdens of, for instance, chemotherapy, should be spelled out by the physician, again using the best available scientific knowledge. But burdens are more global. The patient is the one who knows how the burden of treatment fits into a larger experience of life – does she want to put up with medical burdens to see the birth of a grandchild? Is there nobody at home to take care of the patient, or is the cost too great?

We owe our patients to be aware of and ready to practice the best medicine that science knows. But in both the EBM and Pellegrino models of clinical decision making, scientific evidence is only one component – albeit a very important one. Bioethics consultants frequently sit at a patient care conference to bring the other components of decision-making to the table. Patient values, clinical context, and burdens are often not well heard because the scientific evidence is so privileged. Our job is often to be sure that the “negotiation” involves the patient’s voice, and that clinicians understand that the conversation must not start and stop at “best scientific evidence.” Only then can we deliver the best in patient care.

Thank you to all the contributors for this month’s edition of Ethics At The Center.

We welcome your feedback, comments & future contributions.

Please email: Anne Elgerd

Outreach & Research Director

Anne.Elgerd@uchsc.edu or call 303-315- 0104.

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**MEDICAL HUMANITIES PROGRAM**

The Arts in Medicine curriculum is part of the UCHSC campus– wide Program in Medical Humanities. These new initiatives, under the auspices of the Center for Bioethics & Humanities, bring the liberal arts (broadly interpreted) to the Health Sciences Campus.

Medical Humanities is an interdisciplinary exploration of how the humanities disciplines can engage and illuminate the nature, goals & practice of medicine. The medical humanities include art, history, philosophy, literature and theology as they intersect with the science & art of medicine.

Our goal is to integrate these areas into the experiences of students, faculty and staff, as well as the broader community.

To learn more about the programs, go to [www.uchsc.edu/artsinmedicine/](http://www.uchsc.edu/artsinmedicine/).

**Dr. Henry Claman is the Director of the Program in Medical Humanities.**

***Henry.claman@uchsc.edu***

**STAGE & SCREEN REVIEW**

By Bernard A. Karshmer

**A Diamond in the Rough – A Film and a Character**

Every now and then you see a film that gives you more than you could have, or would have expected. *The Waitress* was just such a film for me. Honestly, I could not have identified Keri Russell from any other Hollywood pretty face before I saw this film. I never saw even a single episode of *Felicity* (there were 84 of them,) and I decided not to reward Tom Cruise by seeing *Mission Impossible III*, and I missed Keri Russell in *Scrubs* – a must for all in the health care field.

Be that as it may, I've made up for my failures by seeing, and thoroughly enjoying, *The Waitress*. Before any male readers sign-off because they think that this movie was just another "Chick Flick," hear me out. While this film did feature the convoluted, and sometimes tortured, lives of three women, it was an uplifting and a very entertaining "Diamond in the Rough."

Jenna (Kerri Russell) is one of those remarkably talented and wonderful people who frequently make bad choices and appear to be burdened with them for good. Jenna, however, an artist of merit (albeit with pies) and a woman of remarkable character has an opportunity to reverse her seemingly impossible plight. Jenna is a true diamond in the rough.

Unfortunately, Jenna's boorish, smothering and psychopathic husband (Earl- Jeremy Sisto) controls her through fear and intimidation – she is a battered woman in every respect. Fortunately, Jenna's remarkable skill and nature are recognized by curmudgeonly Old Joe (Andy Griffith.) I will not ruin your surprise by revealing how this recognition plays out in a bitter/sweet turn of events. See the film for yourself.

For those of us concerned with health care ethics, this film touches on an interesting ethical taboo. While this central theme is frequently humorous (and even touching,) it does cause one to tisk-tisk.

**Dr. Bernard Karshmer is a Professor at the University of Colorado Health Sciences School of Dentistry, a Faculty Associate at the Center for Bioethics & Humanities, and our resident stage & screen critic.**