A message from the Center’s DIRECTOR....

According to PubMed, not a single article was published in 1973 for which the terms “futile treatment,” “non-beneficial treatment,” or “medically inappropriate treatment” served as key words. But since 1993, there have been over 3200 such articles – and there is no evidence suggesting this number won’t continue to grow significantly in the years to come.

With all of this discussion, one might conclude we’ve gained some clarity over the past 20 years concerning just which treatments are futile, non-beneficial, and/or inappropriate. Alas, it isn’t so; there is still much debate and disagreement about these terms.

Consider “futility.” In everyday, ordinary parlance, an action is said to be “futile” if engaging in it will not, or cannot, lead to the results for which that action is meant. For instance, given my age, height, and (limited) athletic abilities, it is futile for me to attempt to dunk a basketball. Whether I get a running start from the foul line, mid-court, the entire court, or otherwise, I simply am incapable of jumping high enough. Unless I jump on a trampoline strategically placed under the basket. Or the basket is lowered to 6 feet. In these cases, it might not be futile for me to attempt to dunk a basketball.

The point is that determining whether or not it is futile for me to attempt to dunk a basketball depends on other factors which, if not clearly articulated, make it very difficult to determine the futility of my efforts. The same holds when determining whether or not medical intervention is futile. Not only will a patient’s condition play a role, but it also depends on the goals of the specific treatment under consideration.

For instance, if the goal of intubating a patient with end-stage COPD is to keep him or her alive for as long as possible (despite failing lungs), then intubation is not a futile treatment. Conversely, if the goal is to restore lung function to a status that will allow the patient subsequently to engage in high aerobic exercise, then intubation is a futile treatment. Determining whether or not a treatment is futile thus depends on knowing the goal of the treatment; in this sense, “futility” is an operational term (its meaning is dependent on various kinds of pre-established additional meanings).

There are similar complexities associated with the terms “non-beneficial” and “inappropriate;” both rely on pre-established understandings of values, goals, directives, standards, etc.

In short, these terms – “futile,” “non-beneficial,” “inappropriate” – do not have stand-alone, independent, substantive meaning. Accordingly, when engaging in those difficult and challenging conversations with patients and families about the limits of what medicine can offer, it is best not to use such terms unless one is also prepared, able, and willing also to provide the fuller account of the contextual elements which give these terms their particular meaning in the specific circumstance.

The writer Barry Lopez has written, “Sometimes a person needs a story more than food to stay alive.” (Crow and Weasel, North Point Press, 1990, p. 48) My friend and mentor, Dick Zaner, reads Lopez’s quote this way: stories take care of people because they are gifts we give as a way to form connections and share burdens (especially for those facing challenges); and they are gifts we receive, for in the telling and the listening, we gain the potential for deeper understanding.
At twenty-two years old, Paulo was a young man with an unyielding positive outlook despite a haunting diagnosis of acute myeloid leukemia. He had been treated with multiple cycles of chemotherapy, radiation, and finally an allogeneic bone marrow transplant— which, unfortunately, his body rejected. After weeks of countless antibiotics, endless diarrhea, nausea, and vomiting—and multiple trips to the ICU for respiratory distress and failing kidneys, Paulo’s oncologist informed him he had stage IV-grade IV graft-versus-host disease. He had a 5% chance of survival and a prognosis of days to weeks to live.

During shift-change one morning, as both the night- and day-shift nurses greeted Paulo together, he stopped them and said, “It’s not looking good guys. The doctor says I only have two weeks at the most but there are some other treatments I can still try. I don’t want to do it anymore though. My parents are pressuring me to do everything I can but I’ve really tried my best and it’s not looking good. You guys have been so great but I just want to go home to be with my family.”

Paulo’s family was his priority and a source of utmost joy. It was at home, surrounded by their love that Paulo wanted to die, comfortably and peacefully. Taking in the reality of his prognosis and the unbelievable courage he possessed to accept this reality at such a young age, Paulo and his nurses held one another and wept.

The social worker and oncologist were notified and the palliative care team consulted. Together, they spoke with Paulo and his sister to clarify his wishes about a do-not-attempt-resuscitation order and informed him of what hospice care at home would entail. Paulo then composed an advance directive stating his wishes, designating his sister as his surrogate decision maker. Before signing the advance directive, however, his sister took a long look at him and said, “I’m taking you home. You’re not going to get better. You’re not. You are going to die at home. But all of us are going to be with you.”

All treatments were discontinued except for medications for comfort, and Paulo was discharged two days later. He left the unit, smiling and thanking everyone for their care. Despite their deep sadness, the staff delighted in his joy and rejoiced in the peaceful death he himself anticipated in the comfort of his own home, surrounded by loved ones.

Paulo’s story is one of hope and reassurance. This was a case in which a young patient came to terms with the reality of his own mortality rather quickly, communicated his wishes clearly to the entire healthcare team, appointed a surrogate decision maker who understood his wishes, and ultimately, was discharged home at his own request, to die peacefully with supportive care.

Unfortunately, this case, illustrative of well-communicated discussions of end-of-life wishes between patient and healthcare providers, seems to be the exception rather than the norm due to an array of potential barriers to such discussions. One such barrier is potential ambiguity, if not misunderstanding, of the scope of practice of nurses in the context of end-of-life discussions.

As patient advocates, nurses have a duty to promote early discussions regarding end-of-life care, especially concerning “do-not-attempt-resuscitation” orders, among patients who are terminally ill, their families, and the rest of the healthcare team. Initiating such conversations can prove difficult, however, not just given the inherent challenges of talking about such matters, but also in terms of a lack of clarity regarding nurses’ roles versus that of physicians.

Rather, given the nature of the nurse-patient relationship, nurses are often privy to patients’ beliefs and values in a way that physicians are not, and as such, nurses have an obligation to convey these to other health care providers so as to demonstrate fidelity toward their patients. Especially in the context of end-of-life considerations, nurses and physicians must utilize a team approach to engage in open and shared dialogue in order to affect the best outcomes for patients.
A Glimpse Inside cont’s...

Paulo’s story reflects the positive outcomes achieved when nurses execute their roles as advocates and when they open dialogue with patients regarding end-of-life wishes. The success of his story notwithstanding, challenges in determining patients’ values and goals of care towards the end of life, as well as the fears expressed by nurses in having end-of-life discussions rooted in role confusion, are difficult realities to be overcome. Physicians should be challenged to empower nurses to fulfill their duty as patient advocates, and nurses, in turn, should do their best to promote fruitful communication between patients and the entire healthcare team.

Especially in the context of considerations for end-of-life care, only in an environment which promotes respect for patient and family values, a spirit of teamwork shared among healthcare providers, and the fulfillment of fundamental professional obligations, can the best, value-aligned patient outcomes be maximized.

Kirsten Inducil, R.N.
Staff Nurse
Cedars-Sinai Medical Center
Los Angeles, CA

Fall 2013 Ethics Noon Conference (ENC)

This is a monthly conference, held in Harvey Morse Auditorium, 12-1 pm, and is open to all who work within, are affiliated with, or received care at Cedars-Sinai Medical Center. The primary aim of these sessions is to raise the level of awareness and degree of understanding of emerging issues and concerns in the realm of healthcare ethics.

Cedars-Sinai Medical Center designates this educational activity for a maximum of 1.0 AMA PRA Category 1 Credit

September 18, 2013
“The Least Worst Death: Moral Experience at Life’s Edge”
Margaret P. Battin, Ph.D., is a Distinguished Professor of Philosophy and Adjunct Professor of Internal Medicine at the University of Utah. She has authored, co-authored, edited, or co-edited some twenty books, among them a study of philosophical issues in suicide; a scholarly edition of John Donne's Biathanatos; a collection on age-rationing of medical care; a study of ethical issues in organized religion; and a collection of her own essays on end-of-life care.

October 16, 2013 - Weinberger-Vermut Lecture in Genetics & Ethics
“Olympian Dreams: Genetic Enhancement and an Ethics of Meaning”
Thomas H. Murray, Ph.D., is a Senior Research Scholar and the President Emeritus of The Hastings Center. He was formerly the Director of the Center for Biomedical Ethics in the School of Medicine at Case Western Reserve University, where he was also the Susan E. Watson Professor of Bioethics. He is a past president of the American Society for Bioethics and Humanities and the author of more than 250 publications.

November 20, 2013
“Nurses and Physicians: Inter-Professional Communication Challenges and Conflicts”
Sarah Shannon, Ph.D., R.N., is an Associate Professor of Biobehavioral Nursing and Health Systems in the School of Nursing and an Adjunct in the Department of Bioethics & Humanities in the School of Medicine at the University of Washington. Her area of scholarship has been focused on improving the healthcare team’s communication with patients and their families, especially around end-of-life care, the disclosure of errors, and entrenched conflict.

December 18, 2013
“Advance Directives, Exerting Control, and Other Myths about Endings”
Virginia L. Bartlett, Ph.D., is the Assistant Director of Cedars-Sinai’s Center for Healthcare Ethics and one of CSMC’s Clinical Ethics Consultants. Her primary interests and responsibilities focus on helping patients, families, and care providers identify and address the complex moral concerns that emerge in healthcare settings. She also integrates questions about moral experience and clinical ethics practices into themes and programs for ethics education.
**Fall 2013: Educational Sessions & Meetings**

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*ENC = Ethics Noon Conference*  
*ICU Ethics = ICU Ethics Roundtable for all Residents/Fellows assigned to an ICU during the given month*  
*SICU Ethics = Surgical ICU Residents/Fellows Ethics Case Conference*

For descriptions of the Ethics Seminar and Ethics Forum, please visit either our Intranet or Internet websites and go to the link “Educational Opportunities.”

For more information about any of the above events, please call the Center at 310-423-9636

**Good Reads...**

- **The Least Worst Death: Essays in Bioethics on the End of Life.** By Margaret P. Battin (Oxford Univ Press, 1994) Engagingly written, this book offers insight into the controversial & often difficult topics of withdrawing and withholding treatment, euthanasia, and suicide by exploring such concerns as whether there is a "duty to die," counseling in rational suicide, risks of abuse with active euthanasia, religious views about suicide, and whether suicide can be understood as a basic human right.

- **A Century of Eugenics in America: From the Indiana Experiment to the Human Genome Era.** Edited by Paul A. Lombardo. (Indiana University Press, 2011) Indiana has the dubious honor of being the first and one of the last states forcibly to sterilize a US citizen in hopes of protecting the fit from the unfit. This collection explores this mostly ignored epoch of American history and the uneasiness engendered in many persons by the neo-eugenic language used by supporters of the Human Genome Project.

- **The Development of Bioethics in the United States.** Edited by Jeremy R. Garrett, Fabrice Jotterand, D. Christopher Ralston (Springer, 2013) Bringing together a collection of original essays by seminal figures in the fields of medical ethics and bioethics, this volume maps the remarkable development of bioethics in American culture, uncovering the important historical factors that brought it into existence, analyzing its cultural, philosophical, and professional dimensions, and surveying its potential future trajectories.

- **Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life.** Edited by Nancy Berlinger, Bruce Jennings, Susan Wolf (Oxford Univ Press, 2013) Written for physicians, nurses, and other health care professionals, this major new work incorporates 25 years of research and innovation in clinical care, law, and policy, and is structured for easy reference in difficult clinical situations and includes extensive practical recommendations.

Books featured in “Good Reads...” are available in the Medical Library. Please call 310-423-3751 for book availability and reserve a copy today!

If you have missed one of our Ethics Noon Conferences (ENC) Series and are interested in viewing them, the Medical Library has copies of the series dating back to November 2007. We invite you to check them out!

**Note from the Center’s Faculty...**

We would like to thank Kirsten Inducil for her insightful contribution to this issue’s “A Glimpse Inside” as well as for her service as a Unit Ethics Champion – and hence as someone who helps raise ethical awareness among CSMC’s staff.

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**C.H.E. Newsletter is a publication of Cedars-Sinai Medical Center.**

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We welcome your feedback.