

## DIRECTOR'S REPORT

The Center for Health Policy and Ethics' mission as an academic center of excellence in the tradition of Catholic and Jesuit education manifests itself in our commitment to scholarship, service and teaching activities.

One expression of our commitment to the mission is the preparation of publications to foster discussion of pressing ethical issues, contribute to discernment and promote strategies for purposive action. Jack Glaser, STD, highlights three "realms" in which such ethical issues arise — individual, institutional and societal.\* In recent months CHPE members have had books accepted for publication or experienced the joy of having a book released. Their topics address health-related ethical issues in all three spheres.

*When the Bough Breaks: Parental Perceptions of Ethical Decision-Making in NICU* by Winifred Ellenchild Pinch (University Press of America, 2002) takes a hard look at ethical issues at the interface of health care institutions and individuals (parents). She chronicles how this beginning often leads to a lifelong interaction among them, pitched against a backdrop of inadequate societal support. Pinch presents "the unvarnished reality of parental experiences," providing a focus heretofore not found in the bioethics, health policy or clinical

literature on intensive care. Page three features her description of this signal contribution.

*Ethical Foundations for Palliative Care Approaches In Alzheimer's Disease: An International Dialogue* (accepted for publication, Johns Hopkins Press) is co-edited by Ruth Purtilo and Henk ten Have. This book continues the Center members' exploration of ethical foundations needed for the toll Alzheimer's disease takes on individuals, families, health care institutions and the larger society as the global population ages. The 22 contributors (a multidisciplinary, international group of scholars whose work was supported by the Greenwall Foundation, New York) describe demographic, economic and clinical challenges, critique the role of "palliative" measures, and, at the heart of the book, examine ethical challenges in the treatment of Alzheimer's disease from family, health care institutional and societal justice perspectives.

*Health Professional and Patient Interaction 6<sup>th</sup> edition* by Ruth Purtilo and Amy Haddad (W. B. Saunders Company, 2002) beams attention on ethical challenges at Glaser's realm of the patient and health professional. Designed for beginning health professions students, it examines their opportunities for promoting respect within the professional encounter, taking into account the powerful

influence of institutional and societal policies. In addition to the bioethical themes often covered, it addresses respect in everyday communication in the health professions context, rethinks what "professional boundaries" entail and emphasizes the professional's self respect as an essential ingredient in the respectful relationship.

*Dutch Designs of Death and Dying: Euthanasia and Physician Assisted Suicide in the Netherlands* (accepted for publication, Indiana University Press), co-authored by Henk ten Have and Jos Welie, discusses and critiques developments on these issues from historical, medical, cultural, political and ethical perspectives. Dutch experiments with euthanasia are presented as an invitation to other countries to explore alternative modes to compassionate, effective end-of-life care.

This list illustrates the breadth and depth of inquiry by CHPE members that bring us into constant discourse with students, other professionals and the larger community. Living out our mission sometimes keeps us at the computer but the content of and inspiration for our writing are found in these engagements.

Ruth Purtilo, PhD

\*John W. Glaser, 1994. *Three Realms of Ethics*. Kansas City, Kansas: Sheed and Ward.

# The Challenges of “Navigating Life” with Alzheimer’s Disease: The 2002 Women and Health Lecture

**A**s part of the continuing focus of the Center’s work in the area of palliative care and Alzheimer’s disease, the 2002 Women and Health Lecture’s featured speaker was Steven Sabat, PhD, professor of psychology at Georgetown University. This year’s lecture was collaboratively sponsored by Creighton University’s Center for Health Policy and Ethics, the Alzheimer’s Association — Omaha and Eastern Nebraska Chapter and the Creighton University Medical Center for Aging, Alzheimer’s Disease and Neurological Disorders. During the spring semester, several members of the Center faculty and associates read and discussed Dr. Sabat’s book, *The Experience of Alzheimer’s Disease: Life Through a Tangled Veil* (Blackwell, 2001). Those who participated in the reading group were so impressed by the book’s insights that we extended an invitation to Dr. Sabat to visit Omaha to present the annual lecture.

Dr. Sabat specializes in neuropsychology. The main emphasis of his research has been the intact cognitive and social abilities (including aspects of selfhood) of people with Alzheimer’s disease. He deals especially with those in the moderate to severe stages of the disease, with the person’s experience, from her or his own point of view, of having the disease and the ways in which communication between these people and their caregivers may be enhanced.

Dr. Sabat spoke to a large audience composed of interested members of the faculty, students and the general public — many of whom care on a daily basis for a patient or loved one suffering from Alzheimer’s disease. He stressed that a person with



**Dr. Steven Sabat**

Alzheimer’s disease is a person. Although many believe that these patients are unaware of the way others treat them, he maintains that they are aware of their difficulties and aware that others often deal with them as “different.” Dr. Sabat noted that family members and professional caregivers frequently act in ways that highlight, rather than alleviate, the patients’ deficits. In this way, normal responses to everyday irritations get labeled as manifestations of the disease. In addition to presenting a lively presentation, Dr. Sabat played segments of audio-taped interviews of persons with whom he has worked so that the audience could hear their voices. The fundamental message of the lecture was that “someone in there is home” and that persons with Alzheimer’s disease should be treated as if what they have to say or express truly matters. It was evident from Dr. Sabat’s remarks and from the extensive question and answer session, that he is committed to helping families and other caregivers nurture the relationships they have with their loved ones and patients over the months and years of the disease’s progression.

*Amy Haddad, PhD*

## *In Memoriam* David Thomasma (1939-2002)

On April 25, 2002, David Charles Thomasma, PhD, suddenly and unexpectedly passed away. Until his death, Thomasma was the Father Michael I. English Professor of Medical Ethics at our Jesuit sister institution, Loyola University of Chicago Stritch School of Medicine. With over 320 publications, including 24 books, David Thomasma was one of the pioneers and shapers of bioethics. He helped, as a consultant, to establish our Center more than 15 years ago. Each member of the Center for Health Policy and Ethics in some form or another has been impacted by his work.

In addition to his work as an author and co-author, Thomasma served for many years as the editor-in-chief of *Theoretical Medicine and Bioethics*, as the founding editor of *The Cambridge Quarterly of Bioethics* and as editor of the Kluwer book series entitled International Library of Ethics, Law and the New Medicine. Indeed, one of his main interests was to foster an international dialogue on bioethics. Many Center faculty participated in the annual conferences of the International Bioethics Forum that he coordinated. His inspiring enthusiasm for the discipline of bioethics will be missed by all of us.

## **Learn at Lunch: How We Stay On Top**

To insure that CHPE personnel have adequate training in the use of available hardware and software computing resources, the Center provides personalized “in-house” training. Oscar Punla offers *Learn at Lunch* sessions, scheduled over a lunch hour. He adapts these learning opportunities from training sessions he attends on a regular basis. The informal sessions provide an opportunity for “hands on” training with the aim of increasing

*continued on page 4, column 2*

# High Risk Newborns: Sharing the Remarkable Journeys of Their Parents

The Focus editors have asked Winifred J. Ellenchild Pinch to tell us about her book, the effort of many years of careful research, much work and even more caring. Below you will find the story behind this effort. Enjoy.

Everyone loves happy endings. When families reach major milestones in their lives not everyone is so fortunate. Regrettably, for a significant number of families, the birth of a child is not a joyous event but rather one fraught with stress, pain and even life long repercussions especially when an infant requires newborn intensive care. However, many people are reluctant to investigate or inform themselves of these tragic cases. Often such parents are ignored and relatives, as well as friends and neighbors, do not know how to interact with these individuals or support them in their struggle. A critical gap in the literature related to the parents' role in ethical decision-making for these infants also exists. Research studies and narrative accounts of high-risk neonatal decision-making have been published but the parental role in the ethical dimension of care can be absent or minimized. Yet, parents are required to live with the outcomes of these decisions and are responsible for the care of the infants themselves. The lack of transparency in discussions of ethical decision-making inspired me to investigate this area.

In 1985, my community health practice included home visits with families whose infants had been discharged from the neonatal intensive care unit (NICU). As I prepared myself for these visits and responded to the needs of the parents, I was prompted to refresh my basic understanding of the ethical dimension of their circumstances.

During this process, I reached the conclusions noted above—the parental involvement was ignored or it did not match the stories that parents shared with me during these home visits. With little realization at the moment my next decision led to almost two decades of work.

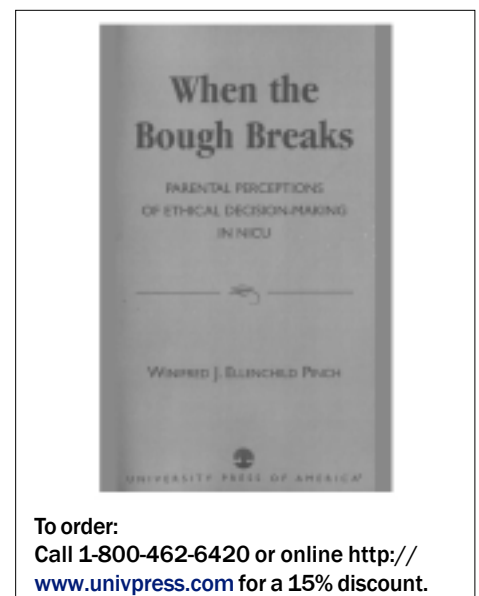
I was determined to interview and report on the parental perception of ethical decision-making in the NICU as systematically and with as much objectivity as possible. To implement such a plan, after discussion with trusted colleagues and informing myself of the possible strategies, I set out to conduct a qualitative study. The study would not be limited to the early discharge phase when parents themselves began to notice the impact of NICU decisions but would begin with interviews prior to discharge of the infant and continue at later intervals. Later interviews occurred at six months and four years post-discharge.

Initially the publication of a book encompassing the entire project was a nebulous idea. Given the streamlined nature of presentations and journal manuscripts, the idea of a book became compelling as parental stories failed to get the exposure they deserved. Even though regular presentations and publications of the results of the project were completed, these events never led me to conclude that the parents' stories received adequate exposure. Although a more detailed treatment of the three sets of interviews was the major impetus to begin a book, a secondary analysis of the interviews (related to moral orientation) as well as various interpretations of the results (relationship to other theoretical work and some speculation about the future) was also never published.

Only a book could encompass such detail, and work in earnest commenced in 1995. Two costly false starts delayed the process but perseverance finally led to a completed manuscript. *When the Bough Breaks: Parental Perceptions of Ethical Decision-making in NICU* was published by University Press of America in June 2002. Several surprises occurred along the way that led to some reorganization of the book from the original outline. The impact of reproductive therapies on the NICU census was not as evident in 1985 as in the late 1990s.

The interest in parental perspectives past the four years post-discharge point also surfaced. Since at every stage of the project I was asked, "What happens next?" the concluding chapter consists of a description of experiences from parents whose children now range in age between 9 and 18 years of age. Most of all however, parental identification of difficulties and contentment as well as suggestions for change will hopefully make a difference for parents of high-risk infants in the future.

*Winifred J. Ellenchild Pinch, EdD*



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## Calendar of Events

### Roundtables

Held in the CUMC CHPE Conference Room, 2616 Burt Street

#### Information Technology:

##### An Accelerator for Change

Wed., October 23, 3:30-4:30 pm

Speaker: Ravi Nath, PhD, College of Business Administration

##### Universal Healthcare and Catholic School Teaching

Wed., November 20, 3:30-4:30 pm

Speaker: Beth Furlong, RN, PhD, JD, CUMC School of Nursing and Faculty Associate, Center for Health Policy and Ethics

##### Whatever Happened to Managed Care?

Wed., January 15, 3:30-4:30 pm

Speaker: Eugene Rich, MD, Chair, CUMC Department of Medicine and Director of the Center for Practice Improvement and Outcomes Research

##### Why Be Moral? The Development of Moral Self-Identity

Thur., February 20, 3:30-4:30 pm

Speaker: Roger Bergman, Director, Justice and Peace Studies Program

##### Writing About Patients: Ethics and the Author

Wed., March 19, 3:30-4:30 pm

Speaker: Amy Haddad, PhD, CUMC Center for Health Policy and Ethics and School of Pharmacy and Health Professions

##### Subject: Restoring an Inmate's Sanity to Administer Punishment

Wed., April 23, 3:30-4:30 pm

Speakers: Christine Wiseman, JD, Vice President for Academic Affairs and Daniel Wilson, MD, Chair, Department of Psychiatry, School of Medicine

##### Clinical Ethics Series

Title: TBA

Wed., November 13, 12:00-1:00 pm  
CUMC, Morrison Seminar Room  
Co-Sponsored with the Department of Medicine

Speaker: Jos Welie, PhD, CUMC Center for Health Policy and Ethics

#### cont'd—Learn at Lunch

usability of the Center's computing resources. Participants often request topics for each session.

One success of the *Learn at Lunch* sessions is that materials previously available only in print are now produced in *electronic formats*.

These include portable documents (PDF), PowerPoint® presentations, and interactive web-based documents. Because new computing technologies continue to be rapidly introduced, *Learn at Lunch* sessions are likely here to stay.

Oscar R. Punla

## Center News

### Congratulations!

**Amy Haddad, RN, PhD**, Professor in the Center for Health Policy and Ethics and School of Pharmacy and Health Professions, has been named Associate Director of CHPE. Dr. Haddad has been a member of the Center since its inception.

**Richard L. O'Brien, MD**, Professor in the Center for Health Policy and Ethics and Department of Medicine, has been named University Professor. This honor was acknowledged at a university-wide reception in August.

### And Thanks.

We are deeply grateful to **Robert McQuillan, MD**, Chairman, Department of Anesthesiology and to **Frank Dowd, PhD**, Chairman, Department of Pharmacology, for their many contributions to the life and mission of CHPE. Each has found it necessary to discontinue a formal affiliation with CHPE due to other commitments.

### FOCUS

FOCUS is published twice a year in the Spring and Fall by Creighton University Medical Center's Center for Health Policy and Ethics, 2500 California Plaza, Omaha, NE 68178; Telephone (402) 280-2017

Editor ..... Ruth Purtilo, PhD  
Associate Editor ..... Judith Lee Kissell, PhD  
Design & Layout ..... Oscar R. Punla

Center for Health Policy and Ethics  
2500 California Plaza  
Omaha, NE 68178

Address Service Requested

#### Faculty

James Clifton  
Beth Furlong  
Mark Goodman  
Amy M. Haddad  
Gail M. Jensen  
Judith Lee Kissell  
Roderick Nairn  
Richard L. O'Brien  
Ruth B. Purtilo  
Winifred J. Ellenchild Pinch  
Linda S. Scheirton  
Jos V. M. Welie  
Gary Westerman

#### Staff

Marybeth Goddard  
Rita Nutty  
Oscar R. Punla  
Helen Shew  
Jamie R. Waters

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