

DIRECTOR'S REPORT

Realizing Our Mission Through International Dialogue

Readers may recall that following CHPE's conference on Alzheimer's Disease (AD) a year ago, CHPE members wanted a way to participate further in the thoughtful shaping of ethical health care practices and policies related to AD. Towards that end we planned a dialogue between United States and European scholars on the ethical challenges of AD, particularly in the area of palliative care interventions for this condition. Compelling reasons were the following:

- Clinicians, policy makers and ethicists on both sides of the Atlantic gradually are beginning to address challenges imposed on individuals, family members and society by the presence of AD;
- Philosophers, theologians and others gradually are rethinking such basic notions as dignity, personal identity and autonomy, in face of the symptoms of AD;
- Policymakers are finding themselves pressed to accommodate financial and other social burdens of the condition;
- Many are beginning to voice the need for a better understanding of how "palliative care" can be harnessed to address effectively the troubling non-curative aspects of AD; and
- Finally, some large areas of overlap in the literature exist between European and US scholars while

striking differences could hinder effective and necessary dialogue in the future. An analysis of their usefulness across national boundaries remains largely unexamined.

To provide leadership in this emerging area, we contacted scholars whom we believed qualified to contribute expertise to a *joint US-European exploration of the ethical foundations for palliative care in Alzheimer's Disease*. Each prepared a draft manuscript in one of several areas:

- (1) ethical challenges related to the diagnosis and prognosis of AD;
- (2) challenges arising from major operative definitions of palliative care (including euthanasia as palliation);
- (3) key philosophical and theological concepts central to the understanding of AD, including their implications for end-of-life decision-making;
- (4) serious issues of distributive justice occasioned by present social and policy trends with respect to AD; and
- (5) clinical and neuropathologic aspects as well as cutting-edge research on AD.

Greenwall Foundation Support

A great boost to the project came from a Greenwall Foundation, New York grant. It created the time and

space so often lacking for sustained, intense exploration and dialogue on issues of great social significance. In late October, twenty-two scholars (half from the US, half from eight Western European and Central European countries) convened for a three and a half day face-to-face exchange in Bergen Dal, The Netherlands, to

- synthesize relevant current US and European scholarship;
- uncover differences in US and European models/approaches;
- critically appraise basic philosophical/theological concepts that undergird present initiatives; and
- propose ethical foundations that can be adopted in both US and European contexts.

Details of planning and some highlights of that conference are conveyed throughout this issue in pictures and additional articles.

Since from its inception we planned that our exploration would yield information to benefit others, the group is working on an edited book, publication of a list of Ethical Principles for Palliative Care in AD and a teaching module on the topic. Until publication of each we have embargoed the actual articles and documents but in future issues of FOCUS we will inform interested parties about how to obtain these resources.

Ruth B. Purtilo, PhD

The Berg en Dal Conference

In the Fall of 2001, some twenty-two scholars from eight different countries convened in the Dutch village of Berg en Dal. This “working conference” was part of an international research project on the ethical aspects of providing comfort care to persons with Alzheimer’s disease (see the Director’s Report, page 1). All of the Center’s faculty members and two faculty associates participated, as well as our Programming and Community Relations Coordinator.

Why did we go?

In an era in which ever more knowledge is generated in laboratories and microchips, other methods of knowledge production are suspect. They aren’t “hard” science – if “science” at all. Today, the word “science” is reserved for disciplines employing empirical and quantitative methods. By focusing on these methods, options for acquiring new knowledge are limited unnecessarily. Complementary methods, such as discourse, tend to be overlooked. Scientific publications and other formal communications among scientists serve largely to transfer existing knowledge, not to generate the new. The rapid succession of ten-minute presentations characterizing contemporary scientific conferences effectively squelches the creative power of discourse. Yet discourse can be very generative if allowed to occur.

As is true of baking bread, one cannot simply blend a variety of ingredients and hope the mixture will begin to rise. One needs a recipe, the right ingredients in the right amounts, the proper manner of blending, an oven at the correct temperature and time for the dough to rise and bake. Likewise, chatter among scholars is not the same as scholarly discourse. But new knowledge does come about if one brings together a select group of



Left to right: Bert Gordijn (The Netherlands), Franz Josef Illhardt (Germany), Henk ten Have (The Netherlands), Pierre Boitte (France), Givi Javashvili (Republic of Georgia), Rien Janssens (The Netherlands), Wim Dekkers (The Netherlands), Jos Welie (US), David Bennahum (US), Judith Lee Kissell (US), Roger Brumback (US), Richard O’Brien (US), Ruth Purtilo (US), Eugenijus Gefenas (Lithuania), Gunilla Nordenram (Sweden), Linda Scheirton (US), Beth Furlong (US), Winifred Ellenchild Pinch (US), Amy Haddad (US). Not Pictured: Søren Holm (Norway & England), Patricio Reyes (US), Marcel Olde Rikkert (The Netherlands).

scholars with complementary disciplinary backgrounds, different nationalities and varying experiences, to engage in three and a half days of constructive analysis of draft papers, sustained dialogue about contentious issues and unstructured conversation about emerging ideas.

How did we get there?

Just as baking bread is not easy, even with the right ingredients, organizing a successful working conference poses significant organizational challenges. In preparing for the conference we relied heavily on electronic media. We developed a website to allow participants to become better acquainted with one another. The site grew as abstracts and draft papers were added. The website also facilitated distribution of practical information about travel and meeting facilities. As the conference drew closer, the frequency of emails between CHPE and our Dutch hosts about logistics increased to a record of eighteen daily exchanges.

But no planning, careful as it may be, can prepare for the kind of unexpected disaster that struck on September 11, 2001. The prospect of

international travel suddenly gave all participants pause. We discussed the possibility of postponing or canceling the conference. Most felt there was no way to determine when a more optimal time would be. In retrospect, The Netherlands was probably an ideal travel destination. All of us felt very safe and welcomed by our English-speaking Dutch hosts.

Except for two people unable to attend due to illness, all arrived safely in Berg en Dal. Now that we could finally meet face-to-face, the focus turned to the tight agenda for three and a half, stimulating days. The work completed in preparation of the conference gave all a vested interest in moving the dialogue forward. And although some of the sessions were laborious, even exhausting, the group successfully managed to critically review all papers, lay the foundations for an educational module and reach agreement on the text of a formal Declaration of Ethical Principles. We ate, laughed and shared a relaxed evening in Nijmegen, hosted by our Dutch colleagues. The Berg en Dal conference was a true example of generative discourse.

Jos V. M. Welie, PhD and Helen Shew

CHPE's International Perspectives

The European-US Dialogue on Alzheimer's Disease and palliative care was a highlight in our continuing effort to reflect international views in matters of health policy and ethics. This conference was one expression of a long-standing relationship and friendship we have had with Professor Henk ten Have, at the Catholic University of Nijmegen. In earlier years, even before he came as a CHPE Senior Visiting Fellow, Dr. ten Have visited the Center, and Ruth Purtilo visited the University of Nijmegen.



The Old Weighing Station, Nijmegen

Our meeting at Berg En Dal was not only an occasion to enjoy and learn more about The Netherlands — its food, its beer, its art, its history and its people, but an opportunity for us to augment our insights into international bioethics matters. On the one hand, we share many viewpoints and issues with bioethicists from Western Europe, while some of these same problems take on a different perspective with colleagues from Georgia and Lithuania. These nations are developing not only new health and social support systems but new legal systems that affect such questions as competence to make decisions about health care. On the other hand, despite the many traditions that we share with Western Europeans, the strong social concern reflected in health policy in these countries

contrasts strongly with the crisis-ridden healthcare system in the United States, casting long term care and caretaker issues in a very different light. While European nations give strong social support to these problems, those afflicted with diseases such as Alzheimer's and their caregivers struggle mightily with the financial burden of care.

Readers are aware from earlier FOCUS that the Albert Schweitzer Institute and George Soros Open Society Foundation has tapped members of the Center to assist them in providing professional

ethics education in post-Soviet nations. This affiliation came about partially through the initiative of Dr. Bela Blasszauer, from Pecs, Hungary, who was a CHPE Senior Visiting Fellow in 1999.

Other efforts at continuing our looking at international ethics questions include membership by two of our faculty in the European Society for the Philosophy of Medicine and Healthcare (ESPMH). They have maintained for us over the last six years an ongoing dialogue through the annual ESPMH conference that is held in different eastern and western European cities.

Other faculty have participated for several years in the International Bioethics Retreat sponsored by Loyola University, Chicago; and last year two faculty attended the International

Bioethics Association meeting in London. Jos Welie also is a founding member and secretariat of the International Dental Ethics and Law Society; established to foster an international dialogue guiding the multidisciplinary practice of oral health. This organization addresses the relationship between oral care, ethics, law and related disciplines such as philosophy, the humanities and the social sciences.

Our experience at Berg en Dal has been an encouragement to all of us and a testimony that this kind of discussion can unite us more closely around these important clinical ethics and health policy issues.

Judith Lee Kissell, PhD

In memoriam: We at the Center mourn *Charles Monasee* who died following complications of a hip replacement. We remember him as a prime mover in the Health Future Foundation and as a vocal and highly effective advocate of CHPE. We recall with gratitude that he presided as the honorary chairman of our Anniversary Conference in 1997. For him the idea of serving in this role was to spend many many hours behind the scenes, making things happen. But he wanted no part of public accolades. Still, when it was a great success he smiled like a proud father.

Charles Monasee remains with us today — we may not see him but we feel him. He is with us in what he gave us, what he taught us, how he affected our lives and the lives of many who never knew his name, his face or his person. Those of us who know him and love him will have him always, this happy man, this bright spirit, who brought and continues to bring happiness and joy wherever he was, to whomever he touched.

Calendar of Events

Clinical Ethics Session

Drug Recalls: Whose Duty is it to Warn?

Moderator: Amy Haddad, PhD

Presenter: Alan H. Heaton, Pharm D
Prime Therapeutics, Inc.

Co-sponsored with Creighton University Department of Medicine and Creighton University School of Pharmacy and Allied Health Professions

Wednesday, March 27, 2002

12:00 – 1:00 pm

Morrison Seminar Room,
Saint Joseph Hospital

Roundtables

Genetic Engineering and the Ethics of Posthumanism: Beyond Health, Enhancement, and Humanity

Presenter: Jerold J. Abrams, PhD

Department of Philosophy
Wednesday, March 27, 2002

3:30 – 4:30 pm

CHPE, Conference Room

Ethics after Freud

Presenter: Thomas Svolos, MD

Department of Psychiatry
Wednesday, April 24, 2002

3:30 – 4:30 pm

CHPE, Conference Room

13th Annual Women and Health Lecture

Speaker: Steven R. Sabat, PhD
Department of Psychology,
Georgetown University

Topic: *In Praise of Enduring Relationships with People with Alzheimer's Disease*

Wednesday, September 4, 2002

7:00 – 9:00 pm

Reception 6:30 – 7:00 pm

Creighton University

Skutt Student Center Ballroom

All above events: Free and open to the public

VISIT US ONLINE @:
<http://chpe.creighton.edu>

5th International Congress on Dental Law and Ethics

July 31 – August 3, 2003

Creighton University

Co-sponsored by the International Dental Ethics and Law Society (IDEALS), CHPE and CU School of Dentistry

FOCUS

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