

Anchored in ethics



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Omaha, Nebraska

Center for Health Policy & Ethics

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**Creighton**  
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## **Fall 2010**

### ***Director's Report***

#### **Revisiting Core Values**

***by Amy Haddad, PhD***

### ***Also in This Issue***

#### **M.S. in Health Care Ethics Program Celebrates First Year**

***by Chris Jorgensen, MSLIS***

#### **The Meaning of the Nursing Practice of Spiritual Care**

***by Susan Tinley, PhD, RN***

***Nancy Shirley, PhD, RN, CNE***

***Maribeth Hercinger, PhD, RN, BC***

#### **CHPE's Roundtable Forum Flourishing after 10 years**

***by Helen B. Shew***

#### **CHPE Faculty Publications 2009-2010**

#### **The 8th International Congress on Dental Law and Ethics**

***by Jos VM Welie, PhD***

#### **Personnel Happenings**

***by Marybeth E. Goddard, MOL***

#### **Praise for Dr. Helen Chapple's Book**

#### **Psychiatric Advance Directives-Then and Now**

***by Christy Rentmeester, PhD***

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## *Revisiting Core Values*

*by Amy Haddad, PhD*

Anchored in the Catholic and Jesuit educational traditions, CHPE faculty and staff are devoted to excellence in teaching and scholarship, service to others and promotion of justice with a focus on socially marginalized members of society. The same could be said of numerous academic departments at Creighton. What makes CHPE different? At a time when many universities, Creighton included, are critically reflecting on what each unit contributes to the good of the whole, it is important to reflect on the breadth and scope of CHPE's impact at Creighton and beyond.

Although CHPE fulfills the same academic core functions as other academic departments, that is, teaching, scholarship and service, CHPE is unique at Creighton due to its purposeful interdisciplinary composition and focus on the wider world of health policy and ethics. CHPE was specifically established to provide a truly interdisciplinary environment where scholars have a space in which to collaborate and inform each others' work. CHPE strives to be a literal and figurative space for convening a variety of perspectives in a respectful, safe atmosphere both within the academic community and without to the broader society.



***Amy M. Haddad, PhD,  
Director of the Center for  
Health Policy & Ethics***

Over the past 26 years, CHPE has become a nationally recognized leader, partnering with many Creighton colleagues as well as national and international groups, to understand and influence the ethics of health care and policies. New technologies, treatments and innovative research promise opportunities to help shape high quality health care. At the same time rising costs, epidemics, and unjust allocation of resources threaten our ability to provide equitable care to all. Confronting these challenges with insight and influence summarizes our mission. Faculty and staff in collaboration with community colleagues work to foster an awareness of and thoughtful responses to ethical dilemmas encountered in health care locally, across the country and the world.

The majority of the Center's focus on teaching has been in the area of graduate education since the inauguration of the Master of Science in Health Care Ethics degree in August 2009. In addition to serving the needs of our own degree seeking students in the MSHCE program, CHPE has responded to requests for students from other online and on-the-ground graduate programs at Creighton to take MSCHE courses. Furthermore, CHPE faculty co-direct and teach in required on-the-ground ethics and online courses in all of the health science programs at Creighton. The Jesuit approach to education integrates intellectual excellence and personal formation with concern for our students' character as well as their sensitivity to social justice and service with and for others. The focus on the marginalized and vulnerable informs all of the work of CHPE whether in teaching or scholarship. All of the ethics courses in the health sciences were either developed by CHPE faculty or involved CHPE faculty in collaboration with faculty colleagues in the health science schools. Our "students" also include health professionals who attend seminars and conferences where CHPE faculty take a leadership role in continuing professional education offerings such as the Distinguished Lecture series in the School of Medicine, School of Nursing Alumni continuing education, the Clinical Ethics Series, and the Roundtables at the Center.

Given CHPE's teaching, service on college and school as well as university-wide committees and task forces, scholarly pursuits, conferences, lectures, community forums and other events, it is not an overstatement to claim that we interact with every academic program on campus at one time or another. CHPE makes a concerted effort to engage the humanities, liberal arts and sciences as well as collaborate with colleagues in law and business. CHPE has offered sponsorship to a variety of activities over the years including endowed lectures, artistic exhibitions and performances, community presentations, and film premieres. CHPE seeks out every opportunity to widen the audience for our numerous offerings and to hold events at times and places that encourage broad attendance. The continuing challenge is to grow in new directions, specifically the MSHCE program, and maintain excellence in successful endeavors that link directly to the mission of the Center and Creighton.

Please visit <http://www.creighton-online.com/programs/online-masters-degree-in-healthcare-ethics.asp> for more information about the content of the M.S. in Health Care Ethics program.

***M.S. in Health Care Ethics Program Celebrates First Year***  
***by Chris Jorgensen, MSLIS***

On August 30, 2010, the Center for Health Policy & Ethics celebrated the Master of Science in Health Care Ethics (MSHCE) program's first birthday.

We have had four cohorts begin the program thus far, starting in August 2009, January 2010, May 2010, and August 2010 respectively. Currently, we have forty-eight students enrolled in the MSHCE program. Forty-five of these students are degree-seeking. We are on track to have an inaugural class of 10 students graduate in spring 2011 as well.

Our students range in age from 23 to 62. Reflecting the interdisciplinary nature of the bioethics field, our students represent a wide variety of professions. Our online courses provide a venue for nurses, physicians, research workers, chaplains, medical technicians, dental professionals and a variety of others to study, reflect upon, and discuss the ethical dilemmas inherent in health care and health policy. The online nature of the program enables us to serve students from all over the United States, and we have one student living overseas.

Our students report a high level of appreciation for the online nature of the program. In our most recent student course evaluations, almost 90% of respondents cited convenience as a personal advantage for taking a course online versus on campus. Nearly 80% cited flexibility as another key advantage.

To encourage interdisciplinary interaction, we have developed an arrangement with the School of Nursing so that their Doctor of Nursing Practice (DNP) and Master of Nursing Science (MSN) students can take our Practical Ethics in Health Care Setting (MHE 607) course to fulfill their ethics requirement. In summer 2010, 27 nursing students took MHE 607, and 32 more are enrolled in fall 2010. We also have established a dual MD/MS in Health Care Ethics degree for Creighton medical school students. Even though the application deadline for first-year medical students is April 20, 2011, we already have accepted two students as MD/MSHCE dual degree students. They will take their first MSHCE course in the summer of 2011, and after their M2 year, the students will dedicate a whole year (2012-13) to their MSHCE coursework.

We have also just completed and distributed the MSHCE Practicum Manual to help our first cohort of students start preparing for their Practicum (MHE 608) course which begins in January 2011. We look forward to our students having the opportunity to learn from their practicum site sponsors and, in particular, from the vulnerable populations the sites serve, while at the same time offering their knowledge and skills to the site to address an ethical issue of concern.

Please visit <http://www.creighton-online.com/programs/online-masters-degree-in-healthcare-ethics.asp> for more information about the M.S. in Health Care Ethics program.

And for more information about the MD/MSHCE Dual Degree, go to: <http://www.creighton-online.com/programs/online-medical-doctor-and-masters-in-healthcare-ethics.asp>



***Chris Jorgensen, MSLIS, Assistant Director of the Graduate Program***

## *The Meaning of the Nursing Practice of Spiritual Care*

*by Susan Tinley, PhD, RN*

*Nancy Shirley, PhD, RN, CNE*

*Maribeth Hercinger, PhD, RN, BC*

Traditionally, spiritual care has been identified as an essential element of the role of nurses. However, the majority of nurses do not feel adequately prepared to provide spiritual care due to a lack of education and the multiplicity of spiritual perspectives in our diverse society. The experiences of nurses who do provide this type of care can help to identify the meaning of spiritual care as well as educate other nurses in this important aspect of care.

We conducted a pilot study to explicate the meaning of spiritual care among nurses who provide such care and to demonstrate the feasibility of collecting stories from nurses in a variety of clinical settings and from varied spiritual perspectives with the intent to publish the stories on a website devoted to the education and support of spiritual care by nurses. Because of the diverse and personal meaning of spirituality, this study was designed utilizing a qualitative method, specifically phenomenology. Participants were interviewed by one of the investigators. The interviews were recorded and transcribed, and each transcript was analyzed and coded individually by the team members and then by the group as a whole for consensus.

Practicing nurses in a university medical center and members of a state professional nursing organization were recruited to relate their stories about spiritual care. Interviews were completed with 14 participants. Twelve were females. Ages ranged from 31 to 57 with a mean of 50.7. The participants' religious backgrounds included a variety of Christian denominations (n=12), Vedanta (n=1), and agnosticism (n=1). Participants' clinical sites were medical/surgical (n=4), emergency department (n=2), surgery (n=2) and intensive care, obstetrics, mental health, public health, rural clinic and oncology (one each).

Many stories related by the nurses presented a glimpse of their approach to providing spiritual care. One of the nurses related a story about her time with a 14 year old boy who had been in a tractor accident and her subsequent care for his mother. The boy had been pronounced dead, but was still on life support while preparations were made for organ retrieval. The nurse stayed with him prior to his going into surgery. She related that she held his hand and rubbed his arm while she waited with him. Later she wrote a note to the boy's mother to let her know that she had been with him and cared for him as if he was her own son. She told the mother that "... even when he went through those doors there was someone that knew him and knew him by name and held his hand..." She went on in the interview, "I hope that gave her a bit of peace to know because having a child of my own I would want to know that until that last second someone was with them and someone cared about him."

Each nurse's story about providing spiritual care was very personal, but collectively they provided a view of the essence of the nursing practice of spiritual care. The two major shared themes that were identified were the foundational beliefs and values of the nurses that enabled them to provide spiritual care, and the care itself which honored the humanity of the patient. The foundational values and beliefs included the nurses' personal spiritual outlook; their relationship with God; a sense of their call to nursing being spiritually based; and their commitment to spiritual care as integral to the nursing care they provide. The nurses honored the humanity of the patient through their assessment of the patient's personal spiritual perspective and needs; acceptance and respect for all of their patients; collaboration with clergy and hospital chaplains in meeting spiritual needs beyond the nurse's scope; praying with and for the patients; being present by focusing their total attention on the patient; providing comfort whether physical, psychological or spiritual; and advocating for the patient within the healthcare system especially related to having their spiritual needs met.

Participants also provided recommendations for the nursing practice of spiritual care. These included establishing comfort with one's own spirituality; moving from novice to expert; making practice reflective; increasing education about spiritual care; and respecting individual beliefs and values. This study has increased our understanding of the essence of spiritual care, and we are eager to collect additional stories from nurses across the country to provide a diversity of spiritual backgrounds, clinical situations, cultural and religious traditions.

## **CHPE's Roundtable Forum Flourishing after 10 years**

**by Helen B. Shew**

The Center for Health Policy and Ethics (CHPE) Roundtable forum celebrates its tenth anniversary this year. By the start of this fall semester, CHPE had hosted 117 Roundtables featuring 137 colleagues as presenters/discussants, some making more than one presentation. While the first semester of Roundtables showcased nationally recognized experts, it quickly became apparent the format was ideally suited as well for idea generation and exploration of questions and works in progress among colleagues. The official description states:

The purpose of the Center for Health Policy and Ethics Roundtable forum is to foster intellectual exchange in the Omaha and Creighton community, facilitate interdisciplinary communication and collaboration, give participants opportunities to explore new ideas and to learn about the scholarly interests of other participants in a safe and respectful environment.

The interdisciplinary nature of the field of ethics and the receptivity of CHPE and CU faculty facilitate this collaborative approach. This is evidenced, for example, by the diversity among the 137 individuals who have presented at our Roundtables. Fifty-nine of our presenters have come from the ranks of Creighton University Health Sciences faculty and students. Thirty have been non-Health Sciences faculty and administrators at Creighton. Colleagues from the Omaha community account for 27 presenters while 21 are national and international scholars. The Roundtable forum has been a particularly effective means of crossing disciplinary and institutional boundaries in the interest of greater understanding while fostering the growth of both presenter and audience.

In a recent survey of past presenters (from 2006-2010), twenty-nine respondents identified the following outcomes from their roundtable presentation: Broadened perspectives on their own work including interdisciplinary work, fresh approaches to existing situations such as addressing systemic issues via organizational assessment, and improved interdisciplinary collaboration.

### **Roundtable Outcomes**

"The experience enriched my teaching and led me to some important background reading on the nature of historical trauma for African American people. Following the Roundtable presentation and discussion, I incorporated (this) information in a public health nursing class that I teach. I also shared the most relevant literature with community (members).... The opportunity to engage in discussion with interdisciplinary professional people was invaluable to my students who were co-presenters."

"It gave me a different perspective on the topic with professionals having different training. The preparation for this discussion, as well as the questions and discussion that took place, had me approach my work from a different viewpoint than I normally do, and thus enhanced the scope of the work I am doing."

Forty-eight percent of respondents indicated the Roundtable presentation enriched their interdisciplinary work on campus and 30% reported it enhanced their interdisciplinary work beyond campus. The Roundtable forum also influenced outcomes such as publications, conference presentations, and even grant applications. Ten survey respondents indicated the idea presented in the Roundtable led to subsequent publications. Over 96% of survey respondents indicated they presented on the topic in another venue following the Roundtable. The majority of these were on campus, but 33% of respondents made presentations outside of Creighton within the local community to both lay and academic audiences, and 23% presented at national and international conferences.

What is the unique status of CHPE that leads to such engagements? The importance of a setting and approach that encourages interdisciplinary dialogue, feedback, and creative thinking should not be underestimated nor taken for granted. It is not an overstatement to claim that presentations at CHPE's Roundtable forum are highly sought after: CHPE has averaged two per month during the academic year, all well attended. There are few places on campus where representatives from the police department, clinical psychiatrists, academic philosophers, and nursing students gather at the same table to talk about the policy and ethical implications of the frontline treatment of the mentally ill. The metaphor of having a place at the table is taken quite literally at CHPE as we look forward to another year of interdisciplinary discussion at the Roundtable forum.

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*The 8th International Congress on Dental Law and Ethics  
Information Technology in Oral Health Care  
Helsinki, Finland, August 18-20, 2010  
by Jos Welie, PhD*

Compared to the field of medical ethics, dental ethics is a relatively young discipline. The first professional association, the Professional Ethics in Dentistry Network, was founded only in 1987. In 2005, it was renamed the American Society for Dental Ethics, and it is now slated to be merged into the American College of Dentists as a non-geographical section of the College. The first international conference was held in Louvain, organized by Dr. Yvo Vermylen, a Belgium dentist-lawyer. Subsequent international conferences were held in Copenhagen (1995), London (1998), and Amsterdam (2001). In December of 2000, the International Dental Ethics and Law Society (IDEALS) was established, which assumed the task of organizing these international congresses. In 2003, IDEALS, together with Creighton University's School of Dentistry and CHPE, hosted the first North-American congress here in Omaha on the Creighton campus. The congress then moved to Florence (2005), Toronto (2007) and Helsinki (2010).



The Helsinki congress took place on the medical campus of the University of Helsinki from August 18 to 20, and was devoted to the ethical and legal aspects of information and communication technology (ICT) in dentistry. Scholars from countries as diverse as America and Australia, Croatia and Canada, Iran and Italy participated. Two members from CHPE attended the conference: Dr. Jos Welie, Professor of Medical and Dental Ethics at CHPE as well as the Department of Community and Preventive Dentistry, and Dr. Nicholas Levering, Associate Professor in the Department of Pediatrics and a CHPE Faculty Affiliate.

Dr. Welie gave the third plenary presentation on the opening day on the "Ethical aspects of health promotion and advertising via the Internet." Advertising has been a contentious topic in the world of oral health care ever since the first codes of dental ethics were issued. Forces guiding the regulatory developments have included (i) the profession's desire to restrain the rather outlandish marketing practices of quacks; (ii) public health initiatives to increase people's knowledge about and use of oral health care services; (iii) ethical concerns about the spread of misleading information; and (iv) governmental efforts to foster commercial competition among oral health care providers. These diverse interests underscore the power of information. Regulations on advertising have ranged from overly detailed rules on the exact font type and size of a dentist's name on his or her business card, to vague and largely ineffective general guidelines, or even the complete absence of any regulations. The emergence and extremely rapid expansion of the internet have further complicated the regulation of the information stream from dentists to patients. In his presentation, Welie argued that the impact of the internet has primarily been one of scope, not of kind. That is to say, most of the ethical concerns raised by advertising via the internet are similar to those of print media, except at a much expanded scale. There are, however, some concerns that are particularly pertinent to the internet. These are raised by the dual direction of internet communications. Even if the patient may not be aware of this, there is a constant stream of information going back from the patient to the internet provider about the patient's internet searches. This, in turn, allows for targeted, patient-specific advertising, as well as more potentially troublesome data-mining on patients.

Welie also participated as a panel member in a roundtable entitled "Property and Privacy Paradigms of 'Marketable Spit': An Ethical and Legal Counterpart to Blood?" This discussion was chaired by Dr. Anthony Vernillo from New York University College of Dentistry. The panel also included Dr. Sudeshni Naidoo from The University of the Western Cape in South Africa, and Dr. Daniel Malamud, also from NYU College of Dentistry, who participated via Skype.

Blood has long been used for the diagnosis of various conditions and as a source of commercially very profitable cells and organic products. Hence, it is regarded as a form of property with ethical and legal dimensions. Major advances in the testing of saliva now lead to the diagnosis and treatment of previously undiagnosed conditions. If saliva is to fulfill a similar role as blood, it should perhaps be granted those same protections. The emerging potential for the development of marketable products from oral fluids necessitates effective protections of research participants' ethical and legal rights. In particular, violation of privacy and genetic discrimination may arise from the testing of salivary DNA. The four panel members commented on this set of issues, each from their specific disciplinary backgrounds, after which a spirited discussion with the audience ensued.

The second CHPE member to present at the 8th International Congress on Dental Law and Ethics was Dr. Levering, who talked about "The Need for Explicit Informed Consent for N2O Sedation." Informed consent is an integral component of patient autonomy in the decision to administer nitrous oxide in the dental treatment of the pediatric patient. It is a right and responsibility shared by the dental provider and patient as a necessary condition of any dental intervention. Its urgency is

underscored by the elevated status of nitrous oxide as a routine intervention in contemporary American dental practice, which can lead to overconfidence such that the risks of side-effects and other harms are insufficiently acknowledged. In his presentation, Dr. Levering argued that explicit consent for nitrous oxide is necessary and furthermore that such consent should be written.

The 9th International Congress on Dental Law and Ethics is slated to take place in 2012, once again in Louvain, Belgium.

For more information on the International Dental Ethics and Law Society, visit

<http://www.ideals.ac/>

Abstracts and congress presentations from the Helsinki congress can be found at the following website:

<http://www.hammaslaakariliitto.fi/finnish-dental-association/ideals-2010-helsinki/>

## *Personnel Happenings*

*by Marybeth E. Goddard, MOL*

### **Winifred J. Ellenchild Pinch, EdD, RN, FAAN retires from CHPE**

Dr. Winifred J. Ellenchild Pinch retired from the Center for Health Policy and Ethics on May 31, 2010. During her tenure at the Center, Dr. Pinch, a 1989 founding member of the Center, spearheaded several major initiatives that have distinguished her exemplary career.

In 1985, Dr. Pinch came to Creighton from Boston University and recalls, "When I first came to Creighton University, I had a community health nursing practice out of the School of Nursing's Creighton Home Health Care Agency. It was there that I became interested in ethical decision making and high-risk newborns. The stories that families in my case load shared with me did not exactly mesh with the scholarly work I studied as a doctoral student." Based on these observations, Dr. Pinch began a research project investigating the parental perceptions of ethical decision making in the NICU. The 1985 pilot study was the genesis of a full-scale project that continued to the early part of 2001. A number of publications, presentations, and two videos resulted from the project. The video, *I'm Just the Mother*, received a Sigma Theta Tau International media award. A book, *When the Bough Breaks: Parental Perceptions of Ethics Decision-making in the NICU*, was published in the summer of 2002 by the University Press of America.



**Dr. Pinch**

Beginning in 1995, Dr. Pinch assumed the role of director for the Women and Health Lecture. As a result of Dr. Pinch's visionary leadership, this annual lecture has become institutionalized as a part of CHPE's programming and service projects. Last year, the lecture celebrated its 20th anniversary.

Dr. Pinch has been involved in numerous other bioethical research projects including the Center's collaborative project on confidentiality and mothers with HIV/AIDS, the healthy elderly perception of ethical decision making, status of ethics committees in state nursing associations, and implementation of the Patient Self-Determination Act in Nebraska. An international collaborative CHPE project resulted in the book *Ethical Foundations of Palliative Care for Alzheimer Disease*, which includes a chapter by Dr. Pinch entitled "Advance directives and end-of-life decision making in Alzheimer's disease: Practical challenges."

In April 2007, Dr. Pinch served as Project Co-director for a Center sponsored conference of historical significance involving 24 nationally and internationally recognized nurse scholars from across North America. The invited seminar, entitled *Nursing and Health Care Ethics: A Legacy and A Vision*, brought together pioneers and noted scholars in nursing ethics. The scholarly work of these individuals served as the beginning knowledge base of nursing ethics and continues today as the foundation. The seminar sought to document and memorialize the contributions of nurse ethicists to nursing and bioethics and look at the future implications of this body of work in health care ethics for nurses and other health professionals. Subsequent outcomes from the conference included a book with the same title as the Seminar. The book won the Award of Excellence from the Washington, DC chapter of the Society for Technical Communications. The Seminar also resulted in a documentary film entitled, *Ethics in Nursing: The Foundation of the Profession*.

In 2003, Dr. Pinch received one of the highest honors in the nursing profession by being inducted as a Fellow in the American Academy of Nursing. One year later she was promoted at Creighton University to the rank of Professor Emerita of Nursing. Dr. Pinch is also a member Sigma Theta Tau, the Nursing Honor Society.

In addition to an extremely successful professional life, Dr. Pinch established a very successful personal life, as well. Dr. Pinch's marriage to Dr. Lewis Pinch has spanned 50 years, and they are the proud parents of three children and grandparents of four. The Drs. Pinch have traveled extensively around the world and just recently returned from a trip to Iran.

No tribute to Dr. Pinch would be complete, however, without mentioning Dr. Pinch's extraordinary skills as a gardener, cook, and baker. At last count, Dr. Pinch has planted on her property over 20,000 daffodil bulbs. To behold her property in springtime is truly breathtaking. Over the years, Center faculty and staff have been the lucky recipients of Dr. Pinch's delicious culinary creations. She is perhaps best known for her decadent cheesecakes.

Congratulations, Dr. Pinch, on a wonderful career and thank you for the many ways you have contributed to CHPE! All the best!

### **Dr. Elizabeth Furlong joins CHPE**

Beginning July 1, 2011, Elizabeth Furlong, PhD, JD, RN, will become a full time member of the Center for Health Policy & Ethics. In her new role, Dr. Furlong's primary teaching responsibility will be in the Master of Science in Health Care Ethics program in the areas of health policy and health care law.

Dr. Furlong has been a Faculty member of the Creighton University School of Nursing since 1971 and currently holds the rank of Associate Professor. In 1993, Dr. Furlong received her PhD from the University of Nebraska where her field of study included Political Science, Public Administration, Health Policy, and Comparative Government. In 2000, she received her Juris Doctor from the Creighton University School of Law. Since 1996, Dr. Furlong has been an extremely valued Associate Faculty member in the Center for Health Policy and Ethics.



**Dr. Furlong**

Dr. Furlong possesses an innate ability to offer a high level of insight and analysis to important health policy issues of which the effects are felt within and beyond nursing and will be able to communicate to the Master of Science in Health Care Ethics' students how the wellbeing of patients, and, for that matter, professionals, is heavily influenced by the policies and values a community embraces.

Welcome to the Center, Dr. Furlong!

### **Kudos to Dr. Roberta Sonnino**

Congratulations to Roberta Sonnino, MD, on receiving the Association of American Medical Colleges 2010 Women in Medicine Leadership Development Award for an individual! This prestigious award is being given to her in recognition of her commitment to developing women leaders.

Dr. Sonnino is the Associate Dean for Faculty Affairs and Professor of Surgery at University of Minnesota Medical School in Minneapolis, MN. She also holds an appointment at the Center for Health Policy and Ethics at Creighton University as a Contributed-Service faculty member.

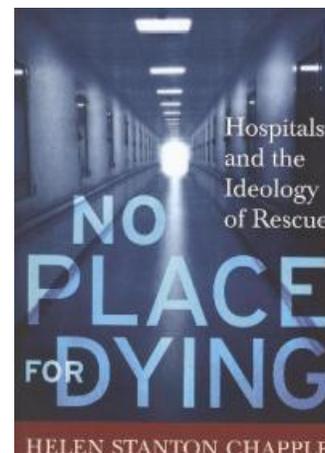


**Dr. Sonnino**

## ***No Place for Dying: Hospitals and the Ideology of Rescue***

***by Helen Stanton Chapple, PhD***

***Assistant Professor, Center for Health Policy and Ethics***



Dr. Chapple's new book was published earlier this year. These are the reviews offered on the website of the publisher, Left Coast Press:

The U.S. hospital embodies society's hope for itself—a technological bastion standing between us and death. What does the gold standard of rescue, as ideology and industry, mean for the dying patient in the hospital and for the status of dying in American culture? This book shows how dying is a management problem for hospitals, occupying space but few billable encounters and of little interest to medical practice or quality control. An anthropologist and bioethicist with two decades of professional nursing experience, Helen Chapple goes beyond current work on hospital care to present fine-grained accounts of the clinicians, patients, and families who navigate this uncharted, untidy, and unpredictable territory between the highly choreographed project of rescue and the clinical culmination of death. This book and its important social and policy implications make key contributions to the social science of medicine, nursing, hospital administration, and health care delivery fields.

### **Praise for the Book:**

"No Place for Dying is candid, realistic, honest (sometimes shocking), and sympathetic in its illustration of how we care for our dying patients. As a critical care nurse, I have experienced the conflicts and issues so masterfully presented by Chapple. The author, who is both an anthropologist and a nurse, truly understands the reality of our systems and provides us with an ethnographic look at how we manage dying patients. I wonder if any other person could so eloquently have framed the issues surrounding the care of the dying. This work is a gift to patients, families, and health care providers, and a must read for all health care professionals."

- Suzanne M Burns, Professor of Nursing and Director of PNSO Research Program, UVA Health System, University of Virginia

"Chapple's focus on the organization rather than the case makes this book stand out. What she does with the institutional conditions of dying is something that only someone who has spent her life at the bedside, the hospice bedside, the ICU bedside, could possibly do. As an anthropologically trained insider, she uncovers the irresistible but invisible forces of ritual, ideology, power, and economics that condition dying in hospitals. Reading this book was a process of increasing understanding, like watching film develop before all cameras went digital. For me as a bioethicist, I actually become less frustrated with the frustrating situations, the deaths that one suffers to watch. It helps to understand why. It helps a lot. This is a rare book."

- Mary Rorty, Center for Biomedical Ethics, Stanford University

"Helen Chapple provides a relentless look at the sequestration of dying in hospitals from ordinary human experiences and from the work that is valued in hospitals. She lets us in on the special language and codes that nurses and physicians use when discussing patients—and also the nuanced expressions that rank a dying patient's position down the ladder of importance at a hospital. Her book gives a whole new meaning to the phrase "Rescue me." It shakes our confidence that hospice and palliative care have changed society's perception of and response to dying markedly. We are let into a world with both explicit and tacit understandings that "more time alive" is all that matters, and into a world where consequences unfold because dying is not a reimbursable code. Thanatologists may conclude that a new Cicely Saunders is needed to face down the hospital culture of avoiding death and of sequestering dying from all else human. From Chapple's book we know, however, that the typical hospital physicians, nurses, administrators, coders, and other staff members argue for the marginalization of dying and of death in order that the hospital may do the work of life prolonging medicine that makes possible more time alive."

- David Balk, Brooklyn College, associate editor for Death Studies

"What makes an American hospital No Place for Dying? Helen Chapple offers a complex, multilayered reply that extends well beyond her ethnographic research methods to implicate bioethics, the wider American culture, and health care economics. She explains how rescue becomes a ritual that eventually entraps both patients and staff. The ritual begins by affirming the social value of the patient, but only at the cost of withdrawing recognition and affirmation as soon as the patient is relegated to the category "dying." She offers cogent observations on how the future hospital might continue the work of rescue where appropriate, while still affirming the full dignity and worth of those beyond rescue."

- Howard Brody, MD, PhD, Director, Institute for the Medical Humanities, University of Texas Medical Branch-Galveston; author of *The Healer's Power* and *The Future of Bioethics*

Abstract and comments taken from the book cover, with permission from the publisher.

## Psychiatric Advance Directives-Then and Now

by Christy Rentmeester, PhD

The 1991 Patient Self-Determination Act initiated significant growth in the bioethics literature on advance directives (ADs). Reviews and analyses of practices for formulating and implementing psychiatric advance directives (PADs) are less common and less publicized than those on end-of-life care. One purpose of ADs in the context of end-of-life is to guide decisions that typically occur only once, when a patient nears death. In contrast, PADs typically serve to guide decisions about how to respond to acute exacerbations of mental illness that is chronic and lifelong. PADs can be useful for facilitating long-term treatment planning, promoting processes of informed decision-making by patients and clinicians, and avoiding coerced treatment.

PADs have low completion rates for some of the same reasons that end-of-life ADs do: appointing a proxy can be difficult; making suppositions about possibilities, contingencies, and worse-case scenarios in the future can be unpleasant; and completing the documentation can be time-consuming. Rather than just handing patients informational materials about PADs, formally facilitating PAD sessions is more effective at increasing rates of completion and implementation of PADs (Swanson, Swartz, Elbogen, Van Dorn, Ferron, Wagern, McCauley, and Kim). Peer supporters can be helpful in these processes and, in some places, are assuming important roles as experienced members of the healthcare team caring for patients with mental illnesses. One study even suggests that PADs offer therapeutic value by enhancing decision-making capacity of patients with cognitive disabilities (Elbogen, Swanson, Appelbaum, Swartz, Ferron, Van Dorn, and Wagner). More typically, however, PADs are perceived as useful when they contain specific information about medication preferences, medication refusals, or name specific places where patients hope to be cared for. PADs documenting patients' medication preferences, for example, have been shown to increase adherence to prescriptions (Wilder, Elbogen, Moser, Swanson, and Swartz). Additionally, reasons listed in PADs about patients' refusals of medications influence clinicians' decisions about whether and how to implement the contents of those PADs and how to direct the care of patients in crisis (Wilder, Elbogen, Swartz, Swanson, and Van Dorn). This suggests that specific information about patients' positive and negative past experiences of crisis care management can also be helpful to caregivers.

Barriers to implementing patients' PADs have been shown to be varied. Work environment barriers were identified more than clinical barriers by psychiatrists, psychologists, and social workers, but these professionals' beliefs, attitudes, and sites of employment played significant roles as well (Van Dorn, Swartz, Elbogen, Swanson, Kim, Ferron, McDaniel, and Scheyett). One study also suggests that when professionals are familiar with states' laws regarding PADs, they tend to be more likely to endorse their use with their patients (Elbogen, Swartz, Van Dorn, Swanson, Kim, Scheyett).

In conclusion, PADs provide a possible mechanism for avoiding coercive treatment and empowering patients who foresee crises as inevitable features of their experiences of chronic mental illnesses. Subsequent study of when and how to implement PAD development programs to help professionals, organizations, and communities address patients' vulnerabilities, promote patients' safety, and increase the likelihood of timely and effective mental healthcare patients in crises is needed to implement evidence-based approaches to inpatient and outpatient mental healthcare.

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