

Fall 2011

Director's Report

Advancing an Ethic of Service, Justice and Compassion for Others

by Amy Haddad, PhD

Also in This Issue

Medical errors and the role of hospital ethics committees

by Linda Scheirton, PhD & Jos Welie, PhD, JD

Quest for Excellence in Research Conference Co-sponsored by CHPE

by Amy Haddad, PhD, and Helen Shew, MBA, MS

International Conference on Palliative Sedation

by Jos Welie, PhD

Book Review - *Natural Law: A Lutheran Reappraisal*

by H. Ashley Hall

Salvation without Transformation?

by Helen Chapple, PhD

21st Women and Health Lecture Features Author Rebecca Skloot

by Marybeth E. Goddard, MOL, BSBA

Dr. Gail Jensen Delivers the American Physical Therapy Association's 42nd McMillan Lecture

by Teresa M. Cochran, DPT

Maya Languages, Health, and Ethics: Issues in a Health Needs Assessment Study in Omaha

by Luis Marcos, M. Renzo Rosales, Alexander Rödlach, and John R. Stone

Honorary Fellowship in the American College of Dentists awarded to Dr. Jos Welie

Alumni News

Editor: Amy Haddad, PhD; Associate Editor: Jos Welie, PhD; Design & Layout: Kate Tworek, BA

© 2003-2011 Center for Health Policy & Ethics - Creighton University - 2500 California Plaza - Omaha, NE 68178

Director's Report - Advancing an Ethic of Service, Justice and Compassion for Others
by Amy Haddad, PhD



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

In addition to teaching and scholarship activities integral to the responsibilities of faculty members at Creighton University, service to the university community and beyond is of particular importance. Why? Ignatian pedagogy relies on professors to serve as model “women and men with and for others” both in and out of the classroom. Tangible evidence of the ways the Center faculty members model this particular Jesuit charism is in the variety and scope of service and leadership activities they contribute to the community. Service isn’t always highlighted as are special events like lectures or accomplishments like funded grants or the publication of a new book or peer-reviewed paper. Perhaps service activities are a bit taken for granted as they are ongoing, not discrete, isolated events. However, service does consume a great deal of energy and time and reflects the commitment of Center faculty members to broader political, policy, professional and social issues. So it seems appropriate to highlight in this issue of Focus some examples of faculty service outside the confines of Creighton on local, state, national and international levels.

Helen Chapple, Ph.D. is currently the Chair of the Credentialing Council for the Association for Death Education and Counseling (ADEC). The Council oversees ADEC’s certification efforts, including applications, testing, and recertification. The Council also works toward matching ADEC’s credentialing efforts with national standards set by the Institute of Credentialing Excellence. The position of Council Chair involves liaison responsibilities with the ADEC Board. She has served on various task forces during her membership since 1989. She was ADEC’s president (2007-08) and has been an ADEC Board member.

Dr. Beth Furlong has been appointed to a three-month Ad Hoc Task Force by the Douglas County Board of Commissioners to evaluate the following Douglas County services—Long Term Care, Assisted Living, the Community Mental Health Center, the Health Center, and General Assistance program because of a projected 2012 12 million dollar County budget deficit. She also serves as Chair of the Quality Improvement Committee of the Visiting Nurse Association in Omaha and on the Board of Directors of the Interfaith Health Services, Families in Action.

Dr. Christy Rentmeester was initially appointed in 2007 to the State of Nebraska Board of Psychology on which she serves as a Public Member of the Board. She was re-appointed in 2010. Dr. Rentmeester has also been a member of the American Society for Bioethics and Humanities since 1997. Additionally, she serves in a leadership role in ASBH as Director of the Mental Health Ethics and Policy Affinity Group, a role she has held since 2007.

Dr. John Stone has been involved with the Omaha Maya Guatemalan community organization, Comunidad Maya Pixan Ixim (CMPI) in the following areas: 1) Four years of teaching in English-as-a-Second Language (ESL), level one, for individuals with limited English language proficiency. This is a collaborative program with Creighton’s Center for Service and Justice (CCSJ). CCSJ recruits and supervises Creighton undergraduates who assist with child care and ESL teaching. 2) Mentoring of the CMPI Health Team in medical terminology and disease concepts to help with their work as health interpreters. Dr. Stone has worked on both of these efforts with his wife, Janet Stone.

Dr. Jos Welie is serving as a Board Member on the newly established international organization “Bioethics Beyond Borders” (BBB). This organization brings together bioethicists, academics, health professionals and policymakers to volunteer worldwide in promoting the application of a human rights based approach to bioethics around the world. In doing so, BBB seeks to build bioethics capacity around the world for universal application of bioethical principles. The Board is chaired by Dr. Henk ten Have, former Senior Visiting Fellow at CHPE and currently the Director of the Center for Healthcare Ethics at Duquesne University. CHPE

Related websites:

Association for Death Education and Counseling
www.adec.org

Visiting Nurse Association
www.thevnacares.org

Interfaith Health Services, Families in Action
www.interfaithhealth.org

American Society for Bioethics and Humanities
www.asbh.org

Mental Health Ethics and Policy Affinity Group
www.emhr.net

Comunidad Maya Pixan Ixim
www.pixanixim.org/partner.html

Creighton’s Center for Service and Justice
www.creighton.edu/ccsj/

Bioethics Beyond Borders
<http://www.duq.edu/healthcare-ethics/bioethics-beyond-borders.cfm>

faculty member Dr. Rentmeester and faculty associate Dr. Linda Scheirton are also involved, serving as Resource Experts on behalf of BBB.

Finally, I am serving my second term as a member of the Women's Fund of Greater Omaha Board of Directors which oversees a permanent fund exclusively devoted to improving the lives of local women and girls. The Women's Fund supports grants and projects that focus on the most pressing needs of women and girls in the community. Additionally, I was elected in 2010 to serve on the Board of Directors of the American Society of Bioethics and Humanities, a national, educational organization whose purpose is to promote the exchange of ideas and foster multi-disciplinary, inter-disciplinary, and inter-professional scholarship, research, teaching, policy and professional development, and collegiality among people engaged in all of the endeavors related to bioethics and the health-related humanities.

Women's Fund of Greater Omaha
www.omahawomensfund.org

Medical errors and the role of hospital ethics committees

by Linda S. Scheirton

*Associate Professor, Department of Occupational Therapy
and Faculty Associate, Center for Health Policy and Ethics*

& Jos V. M. Welie

Professor, Center for Health Policy and Ethics

It is estimated that nearly 100,000 people in the US die in hospitals each year as a result of errors by health care providers (Institute of Medicine, 1999). Another 7,000 deaths occur from medication errors. In addition, some 1,000,000 injuries are the result of errors each year, of which 28% are considered preventable. These statistics underscore that iatrogenic errors are a major health concern. The economic costs are considerable as well. The US costs are estimated to be at least \$19.5 billion in total costs (Society of Actuaries, 2008). But maybe most important is the damage that can be done as a result of such errors to the confidence that patients and the public at large have in health care providers as well as the erosion of the morale of those providers.

In the past decade we have studied and learned much about medical errors. Errors have been studied extensively in medicine, nursing, pharmacy and more recently in occupational therapy, physical therapy, and dentistry. A major conclusion of these studies is that to err is human, as the first major report on errors by the Institute of Medicine was appropriately entitled. While error prevention strategies can reduce the number of errors, even the best health care practitioners make mistakes; it is the inevitable accompaniment of the human condition. Additionally, most errors result from inherent flaws in the system and not just from individual error.

If errors are going to happen, and if they are going to happen with quite regular frequency in our hospitals and health care facilities, we need to develop appropriate strategies for responding to such errors. Such an error management strategy will have to pay close attention to the many moral issues raised by errors, including the duty to report the incident to appropriate supervisors in the institution, truthfully disclosing the error to the patient, apologizing, making reparation and supporting colleagues who made errors. The question thus arises whether Hospital Ethics Committees (HECs) should play a formal role in an institution's error management strategy. We addressed this question in our presentation at the 7th International Conference on Clinical Ethics and Consultation, entitled "Moving Ethics," which was at the Free University of Amsterdam Medical Center, May 18-21, 2011.

Not much research has been done on this question. Tapper and colleagues (2010), reporting the results of their retrospective review of all 285 ethics consults performed at a large urban teaching hospital, concluded that only 1% of consults concerned error disclosure issues. On the other hand, there is no question that policies and educational interventions on error disclosure related issues surely will benefit from the cooperation between ethicists, patient safety experts, human factors engineers, risk managers, and other parties involved in the health care institution. The VA's effective multi-disciplinary approach is a well-known case in point (see, e.g., Cantor et al, 2008). But that leaves more specific questions regarding the role of HECs, such as "should HEC members play an active role in the error disclosure process?" or even more expansive, "Should HECs add error management to their traditional three tasks of clinical consultation, policy development, and clinical education?"

A variety of reasons can be proffered both favoring and cautioning against such HEC involvement. We pointed out that HECs already get involved occasionally when clinical consultations are requested after an error occurs. One of the justifications for doing so may be related to communicative expertise. Not all clinicians are good communicators, and they may be too distraught and even devastated by their knowledge that they have been part of an incident that ultimately caused harm to a patient. Conversely, the patients themselves or their family members may be too angry at the clinician to engage in a constructive discussion shortly after the error occurred, even if it was a system error and not the individual clinician who caused the harm. Thus it may be important that the disclosure communications are handled by individuals or small teams who are very good at delivering bad news in a caring, compassionate way (Scheirton et al, 2011). Experienced HEC members may have such expertise. But so do many others, including social workers, chaplains, and health professionals.

Furthermore, many HECs, either as an entity or through their members, have amassed considerable knowledge about ethically relevant aspects of the error disclosure process, such as the moral importance of truth telling, the legal impact of openness towards patients, confidentiality and related HIPAA regulations, the patient's right to information and record access, and the healing impact to all involved when a sincere apology is offered. HECs can contribute greatly through educational offerings in transitioning an institution from a culture of "name & blame" to a culture of learning from our mistakes. Moreover, the HEC's collective knowledge should be brought to bear on policy development about error disclosure.

But it is important that error management does not become the prerogative and responsibility of the HEC alone; only an institution-wide effort and commitment will result in an effective error disclosure culture.

Cantor, M.D., Barach, P., Derse, A., Maklan, C.W., Wlody, G.S. & Fox, E. (2005). Disclosing adverse events to patients. *Journal of Quality and Patient Safety*, 31(1), 5-12.

Institute of Medicine (1999). *To Err is Human. Building A Safer Health System*. Washington DC: Institute of Medicine
Available on-line at: <http://www.iom.edu/Reports/1999/To-Err-is-Human-Building-A-Safer-Health-System.aspx>

Tapper EB, Vercler CJ, Cruze D, Sexson W. Ethics consultation at a large urban public teaching hospital. *Mayo Clin Proc*. 2010 May;85(5):433-8.

Scheirton L.S., Mu, K., & Mahern, C. (2011). What to Do When Things Go Wrong. In: Galt KA & Paschal KA (eds): *Foundations in Patient Safety for Health Professionals*. Jones & Sudbury MA: Barlett Publishers.

Society of Actuaries (2008). *The Economic Measurement of Medical Errors*. Schaumburg, IL: Society of Actuaries. On-line at <http://www.soa.org/research/research-projects/health/research-econ-measurement.aspx>

Quest for Excellence in Research Conference Co-sponsored by CHPE

by Amy Haddad, PhD, and Helen Shew, MBA, MS

The presumed right of basic science and clinical researchers and institutions to use human tissue in the development of health advances has benefitted countless individuals. The demand for human tissue has sharply increased and will continue. Yet for all the collective good that has and will come from the vast collection of human tissue that is already available through various storage systems, there continue to be conflicts with other equally important moral goods such as respect for persons, disclosure, privacy, and protection of the interests of vulnerable populations. The Center for Health Policy and Ethics (CHPE) was awarded one of four national “Quest for Excellence in Research” conference grants to explore the aforementioned ethical concerns.



Dr. Stone and Dr. Hardy

The U.S. Department of Health and Human Services (HHS) Office of Research Integrity (ORI), Region VII of the Public Health Service, and the Center for Health Policy and Ethics collaborated on a national conference on Monday, September 19, 2011 at Creighton University in the Ahmanson Ballroom of Creighton’s Harper Center. The conference was free and open to the public. The conference explored the spaces between the science community and the public, particularly vulnerable populations, on the use of human tissue in research and challenges to public trust. It brought together scholars in the basic and social sciences and the humanities as well as members of academic and lay communities to exchange perspectives on the complicated and largely unsettled issues that surround use of human biological samples. The issue of trust and ethics is one that applies to all, but is especially relevant to minority communities who have experienced abuses in the past, and, most sadly, are still at risk of experiencing them in current scientific research.

The one-day academic/community collaborative conference drew 147 local and regional participants including researchers, health science professionals and educators, administrators, consumers, and policy makers. The conference opened with a video interview of Kevin FitzGerald, S.J., Ph.D., who is the David Lauler Chair of Catholic Health Care Ethics in the Center for Clinical Ethics at Georgetown University. The video interview with Dr. Amy Haddad, Director of CHPE, focused on 21st century biobanking and the alignment of research and health care goals. Marshall Kapp, J.D., M.P.H., followed the video with a presentation titled, “A Legal Approach to the Use of Human Biological Materials for Research Purposes.” Professor Kapp is the Director of the Florida State University Center for Innovative Collaboration in Medicine and Law. The implications of emerging knowledge in genetics and involvement of members of the community in research on scientific developments was the topic of Barbara Koenig’s presentation. Dr. Koenig is a nationally recognized expert in medical anthropology and a professor in the Department of Social and Behavioral Sciences in the Institute for Health and Aging at the University of California, San Francisco. Claudia Hardy, M.P.A., Program Director for the Deep South Network for Cancer Control at the University of Alabama at Birmingham and Professor John R. Stone, M.D., Ph.D. gave a joint presentation on trust and trustworthiness.

The plenary presentations were followed by an interactive session on research integrity presented by Dr. John Galland of ORI and actors Art Gruenberger and Matt Tabora-Roberts. The final activity in the afternoon was a panel discussion of the plenary speakers moderated by CHPE faculty member Jos Welie, MMedS, J.D., Ph.D., with the addition of panelists Dr. Edward Cohn of Boys Town National Research Hospital in Omaha and Mr. Steve Jackson, M.P.H., of the Douglas County Health Department. The recurring themes throughout the conference were noted by Dr. Welie in his introduction of the panelists, i.e., that traditional informed consent as a gold standard of protection of human subjects in research is increasingly under fire and that the shift to an implied or presumed consent is fraught with difficulties.

The plenary speakers will prepare manuscripts based on their presentations for future publication in a scholarly, online journal so that the content of the conference can reach a wider audience.



Edward Cohn, MD; Marshall Kapp, JD, MPH; Claudia Hardy, MPA; John Stone, MD, PhD; Barbara Koenig, PhD; Amy Haddad, PhD; Helen Stanton Chapple, PhD

International Conference on Palliative Sedation

by Jos Welie, PhD

Last July, three of CHPE's faculty members participated in the bi-annual expert conference of the International Association of Catholic Bioethicists (IACB) which was held in Philadelphia. Dr. Henk ten Have, former CHPE Senior Visiting Fellow and currently the Director of the Center for Healthcare Ethics at Duquesne University in Pittsburgh, gave a keynote lecture entitled "Palliative Sedation Considered in Relation to Euthanasia." CHPE faculty member Dr. Jos Welie was the respondent to Dr. Ten Have. He focused his comments on the moral nature of unconsciousness. Dr. Linda Scheirton, CHPE Faculty Associate and Associate Professor in Creighton's School of Pharmacy and Health Professions, was the co-facilitator of one of the three discussion tracks that ran longitudinally throughout the conference.



Dr. Welie and Dr. ten Have

The main goal of the IACB is "faith seeking understanding." The association, which is supported by various national associations of the Order of Malta, seeks to advance the thinking of Catholic bioethicists on controversial and emerging questions in health care. The conference in Philadelphia was sponsored by the American, Federal, and Western Associations of the Order of Malta, hosted by the National Catholic Bioethics Center, and held at St. Charles Borromeo Seminary. Approximately 70 scholars from around the world attended as well as a small number of graduate students in bioethics.

The previous conference, held in 2009 in Cologne (Germany), was entitled "Human Life with Cognitive Impairment: Caring and Giving Hope in a World of Change." One of the outcomes of that congress was a consensus statement entitled "Caring for and Giving Hope to Persons with Progressive Cognitive Impairments," to which Drs. Welie and Scheirton contributed (1). The ethical principles contained in that consensus statement were modeled on "The Declaration of Berg en Dal on the Ethical Principles Guiding Palliative Care of Persons with Alzheimer's Disease – A Commentary," which was developed by members of the Center for Health Policy and Ethics with colleagues from Europe (2). A similar consensus statement is currently being developed capturing the outcomes of the 2011 conference on Palliative Sedation.

(1) International Association of Catholic Bioethicists. Caring for and Giving Hope to Persons with Progressive Cognitive Impairments. *The National Catholic Bioethics Quarterly*, 10,3 (2010): 549-567.

(2) Jos V. M. Welie and Bert Gordijn. The Declaration of Berg en Dal on the Ethical Principles Guiding Palliative Care of Persons with Alzheimer's Disease - A Commentary. In: Ruth B. Purtilo and Henk A. M. J. ten Have, eds., *Ethical Foundations of Palliative Care for Alzheimer Disease*. Baltimore and London: Johns Hopkins University Press, 2004; Appendix A, 343–347.

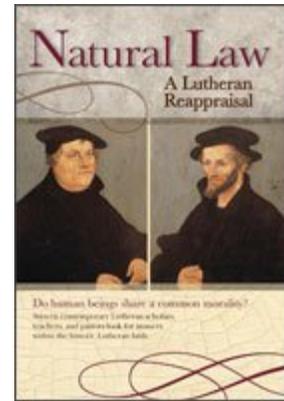


Participants in the 2011 Congress of the International Association of Catholic Bioethicists.

Book Review - Natural Law: A Lutheran Reappraisal

by H. Ashley Hall, Assistant Professor of Reformation and Protestant Theology

Robert C. Baker, an alumnus of CHPH's graduate program in health care ethics, and the other contributors to *Natural Law: A Lutheran Reappraisal* have provided a much needed forum for the role of natural law – typically understood to be the exclusive enclave of Roman Catholic thinkers – within a Protestant context. Further, as the book makes clear, the natural law tradition informed the perspectives of both Roman Catholic and magisterial Protestant traditions up until the Enlightenment. The fifteen articles explore the understanding of natural law within the sixteenth-century context, in which the core of Lutheran theology was formed, as well as articulations of how the natural law tradition can enrich the theological and philosophical contributions to contemporary ethical concerns. The book offers an engaging and thought-provoking presentation of the natural law from a particularly Lutheran perspective. While focused on the Lutheran tradition, the essays contribute to restoring ethical discourse to an arena that is both more ecumenical and enduring by offering a rousing defense of retrieving elements of the “great” or “perennial” tradition.



***Natural Law: A Lutheran Reappraisal*, ed. Robert C. Baker (St. Louis: Concordia Publishing House, 2011), 320 pgs. ISBN: 978-0-7586-2733-9. \$24.99.**

Though the book deals with a relatively abstract theological category, the tone and purpose of the project is to make such discussions accessible and applicable to a general audience. In particular, the editor took care to include an extensive glossary, study questions for each article, and indices, all of which will help facilitate personal study and group discussion within congregations as well as for undergraduates and seminarians.

While most of the contributing authors are academics, some are also pastors. This reality gives the essays both a scholarly tone and an eye to the practical concerns and outcomes of the ideas discussed. While the contributors are primarily from a North American context, the editor has wisely sought to include European and African perspectives. For readers familiar with the state of Lutheranism in North America, they will notice that the bulk of contributors come from the Lutheran Church-Missouri Synod, its German counterpart SELK, the North American Lutheran Church, and the Evangelical Lutheran Synod. Two of the contributors are from the larger Evangelical Lutheran Church in America, one of which is written by an *éminence grise* of Lutheranism in America, Carl E. Braaten; both articles are quite critical of the ELCA for its recent decision to allow for openly gay clergy in committed relationships.

The essays are divided into three sections: (1) Natural Law and Early Lutheran Tradition, (2) Natural Law and Later Lutheran Tradition, and (3) Natural Law and Contemporary Issues.

The first thing the reader will notice is that the authors have difficulty articulating just what the natural law tradition is, reflecting the diversity of thought both in the late medieval and early modern traditions. All agreed that the natural law was essential, but just how best to articulate that was a matter of dispute. Indeed, the appeal to the natural law was a double-edged sword. The editor notes that his own curiosity in the topic was stoked when he discovered that Philip Melancthon's argument against clerical celibacy was based on the natural law of humanity to seek companionship – a law no ecclesiastical authority had to violate by demanding celibacy from those who were not so gifted. The first two sections do an admirable job of documenting the many references to the natural law in the works of the Reformers, the Lutheran confessional documents, and among subsequent theologians. There is no doubt that the natural law – or a profound appreciation for the “order of creation” – is inexorable from the foundational documents of the Lutheran tradition. Yet, the different understandings are themselves informative.

The natural law tradition was (and is) neither monolithic nor monochromatic. The authors of this collection are uniform in their assessment that reform of some doctrines and practices did not mean that the Reformers abandoned the traditional methods and conclusions of theology and philosophy, especially when concerning moral issues. The introduction makes this point very clearly: “it is accurate to insist that the Reformation controversies with the Catholic Church were foremost theological and not ethical in so far as the reformers assumed the natural law as a moral-theological bedrock in their system and therein maintained continuity with their Catholic counterparts” (xv). This assessment is both accurate and provocative.

And yet, just what the Reformers meant by “natural law” is not immediately apparent and so some patience and reflection are required. Braaten rightly insists that both Martin Luther and John Calvin believed in the natural law (6). And yet, as Thomas Pearson's sterling article shows, just how far Luther can be claimed for the natural law tradition is a matter of debate. Pearson's contribution to the discussion is to help the reader delineate when and how Luther made use of the natural law tradition: “the natural law does scant work throughout Luther's biblical and theological endeavors, but it does substantial, albeit often conflicted, work when his focus is on the domain of civil righteousness . . . Luther did not, in fact,

regard natural law as a single subject with a secure center, but rather as an inchoate set of common prejudices shared by people everywhere” (41-42). In this regard, Luther’s contributions to the discussion of prior theologians, such as Thomas Aquinas and Gabriel Biel, are not “deviant” but instead part of the complex reception of the natural law tradition. The same diversity of thought in post-Reformation theology is expertly chronicled in section two of the book.

The net effect of this complexity – then and now – compels us, the book argues, to consider the tradition that captivated and enlivened so many great thinkers of the past. As Gifford A. Grobrien notes “even if we cannot assume that appeals to the natural law will result in a common body of moral precepts, natural law theology still provides great potential. For one, it provides within the Christian tradition . . . a principle for practical action informed by Scripture [and] it serves in conversation with other traditions on a foundational level” (37).

The book is rewarding not only for its discussion of Lutheran contributions to the complexity of the natural law tradition, it is also to be commended for its attention to the current consequences of reviving the natural law tradition. Two articles in particular stand out. The first is an interview conducted by a missionary with an African practitioner of traditional Konkomba (Ghana) religion. From this interview, he traces out for the reader a profound inter-religious appreciation for the natural law. The second is a discussion of whether or not the natural law theory can be a basis for Christian-Muslim dialogue, in which the author reaches fairly skeptical conclusions. Also included are essays which articulate the standard implications of the natural law theory for family (as the basic unit of society) and abortion.

Finally, the book concludes with a discussion of “the way forward.” This essay helps the reader to see the larger vistas opened up if an appreciation for the natural law is restored to Lutheranism. Despite the grievances aired, the book concludes on a decidedly confident note; confident not in a particular denomination or policy but confident that the natural law tradition lends itself with ease to those with faith seeking understanding. This provocative book is an excellent beginning to an ongoing conversation both within Lutheranism and Christianity as a whole. I hope that others will follow the lead of this book, not only by initiating other conversations about the natural law across the denomination lines but also across the “traditional”/“progressive” divide. That is, traditionalists in other denominations will see their concerns echoed in this volume. However, there are also some theologians and philosophers (I am thinking here especially of the late Herbert McCabe, O.P.) who have influenced a generation of scholars in a different direction, or at least tone. These individuals have a deep and abiding respect for the natural law (especially as articulated by Aristotle and St. Thomas Aquinas) and who then use the natural law to argue for more “progressive” positions on doctrine and ethics. As with the late medieval/early modern tradition, a shared appreciation for the natural law will not likely bring uniformity, but it just might contribute to a shared perception (and appreciation) of God at work in the world.

The natural law tradition has been unduly neglected and the insights of this tradition lend themselves very well to addressing the dual crises of authority and division in post-modern Western Christianity. It is time to read again the tradition that is both ancient and enduring; at once united in method and diverse in application. This book is an excellent partner in that necessary conversation.

Salvation without Transformation?

by Helen Chapple, PhD

I am interested in exploring the obstacles to dying well, however they might present themselves. I have found such barriers to be complex and multilayered. One is the organizing principle of US health care, the mandate to rescue at all costs and to offer supposedly universal access to emergency interventions aimed at death avoidance. In the course of my explorations of this topic I have become intrigued by the role that whole organ transplantation plays as rescue's presumptive poster child. Both rescue and transplantation seem to represent salvation from what the society believes to be the greatest perceived threat: physical death. (We could add the qualifier "premature," but in biomedical parlance, any and all death is considered untimely until proven otherwise.)

What does the relentless quest for physical salvation mean to the US health care system? Certainly the cost alone of fighting "to the death" for every life could be ruinous. The transplantation project itself suffers by way of rescue's achievements. As potential recipients live longer, the demand for organs grows continuously while supply remains flat (see link below for chart). Furthermore, what does it mean to Americans as a society to hope that altruistic persons will come forward in ever greater numbers, whose "generosity" can be realized only after their tragic deaths, so that more "fortunate" persons may avoid their own? By feeding public delusions that the possibilities for death avoidance expand infinitely like the universe, rescue and transplantation distract us from the work of transcending ourselves. Perhaps the pursuit of salvation through physical rescue actually prevents us from finding the transformations that might truly help us help each other as we struggle with the problem of finitude.

"Generation(s) and Transformation(s)" was the theme for the annual meeting of the American Society of Bioethics and Humanities in October. In my presentation "Transplantation as a Social Goal: Salvation without Transformation?" I tried to shift the current discourse in transplantation away from the fascinating drama of rescuing some individuals through the transfer of cadaveric whole organs in order to examine the impact on the larger society of this romantic crusade.

Related websites

Organ Procurement and Transplant Network data:
<http://optn.transplant.hrsa.gov/latestData/rptData.asp>

American Society for Bioethics and Humanities
Annual Meeting:
<http://www.asbh.org/meetings/annual/index.html>

21st Women and Health Lecture Features Author Rebecca Skloot

by Marybeth E. Goddard, MOL, BSBA

Rebecca Skloot, author of *The Immortal Life of Henrietta Lacks*, was the 21st Women and Health Lecturer. The lecture was held Thursday, October 6, 2011, at Omaha's Orpheum Theater and garnered the greatest amount of Women and Health Lecture attendees ever---- 2200!

The focus of Ms. Skloot's lecture was Henrietta Lacks, a poor Southern tobacco farmer who scientists now simply refer to as HeLa. Ms. Lack's cancer cells, taken without her knowledge in 1951 as she was undergoing treatment for Cervical cancer, became one of the most important tools in biomedical research and launched a multimillion-dollar industry.

During the lecture it was evident that Ms. Skloot's impeccable research, gift for writing, and easy manner all contributed to her being able to bring a very serious and heady subject to individuals from all walks of life. The book became relevant and powerful to an audience made up of students, academics, retired and current medical professionals, senators, advocates, judges, executives, and book club members. All were in awe of Ms. Lack's story and Ms. Skloot's journey in pursuing the truth. The evening was truly inspirational and concluded with the audience giving Ms. Skloot a standing ovation. Surprisingly, her first!

As in recent years, CHPE partnered with a member of the Omaha Arts Community to provide a tangible illustration of the lecture's topic. This year, The Kent Bellows Studio & Center for Visual Arts produced "The Cell Project". Through a lengthy and intricate process, the high school students in association with the Kent Bellows Studio created three types of "cells": HeLa cells, Human Papillomavirus cells, and Red Blood cells. The "cells" were approximately an inch in diameter, white plastic, and each contained a unique design that indicated its cell type. "Cells" were distributed to lecture attendees as a memento of the evening.

Dr. Amy Haddad, Director of the Center for Health Policy and Ethics, was the evening's Mistress of Ceremonies, and Timothy R. Lannon, SJ, President of Creighton University, provided the evening's welcome.

Special thanks to the 21st Women and Health Lecture Co-Sponsors, Patrons, and Friends. Without your support, this caliber of lecture would simply not be possible.

Read more about the art project that was inspired by this book at this web page: <http://chpe.creighton.edu/events/wh/artists.htm>

The next Women and Health Lecturer is already being pursued. Please check the CHPE website <http://chpe.creighton.edu> for updates and look for a SAVE THE DATE card in your mailbox soon!



Rebecca Skloot



Amy Haddad and Rebecca Skloot

Dr. Gail Jensen Delivers the American Physical Therapy Association's 42nd McMillan Lecture

by Teresa M. Cochran, DPT, Associate Professor, School of Pharmacy and Health Professions and Faculty Affiliate, Center for Health Policy and Ethics

Gail M. Jensen, PT, PhD, FAPTA, Dean of the Graduate School, Associate Vice President in Academic Affairs, Professor of Physical Therapy, and Faculty Associate in the Center for Health Policy and Ethics, delivered the 42nd McMillan Lecture at the 2011 Annual Conference of the American Physical Therapy Association (APTA) in National Harbor, MD. The award, representing the highest honor bestowed upon a member of the APTA, allows the recipient to present a "visionary and provocative" message based on sustained and enduring contributions to the profession.



Dr. Gail Jensen delivering the 42nd McMillan Lecture for the American Physical Therapy Association

A good example of Dr. Jensen's contribution to physical therapy education involves her recruitment to a group of national leaders charged to develop the curriculum for the first entry-level Doctor of Physical Therapy (DPT) degree. It has since become the educational standard for the profession. In the classroom, Dr. Jensen's core message emphasizes the contextual and ethical aspects of patient care. She reminds students of their role as members of the greater human community, and the importance of respect, responsibility and moral agency in providing care for people in times of trauma, illness, pain and vulnerability. Her career has largely focused on the development of health professionals with sufficient ethical foundation to deliberately and consistently advocate for and with others.

Dr. Jensen has also forged an international reputation in the areas of qualitative research methods in rehabilitation and exploration of expertise in physical therapy practice. She has delivered over 170 invited presentations, ranging across arthritis management and orthopedics, development of clinical expertise, rural health advocacy, ethical practice analysis, curriculum evaluation, and interprofessional education. She has authored over 60 peer reviewed articles and written several textbooks, with two considered seminal works. *Handbook of Teaching for Physical Therapists* was the first text of its kind and has been widely used in physical therapy education. *Expertise in Physical Therapy Practice* is considered a landmark work in the evolution of the physical therapy profession, providing critical evidence that clinical experts not only possess technical prowess, but also demonstrate reflection and moral deliberation as core intervention skills fundamental to physical therapy practice. Dr. Jensen's scholarly mentorship has also influenced other health-related professions including pharmacy, medicine and occupational therapy.

Dr. Jensen has established a record of influencing the professional formation of strong leaders – women and men who are not only capable, but willing to commit to a moral imperative – to identify and pursue "what ought to be" in making a positive contribution to the profession, their patients and to the world around them. Her lecture, entitled "Learning: What Matters Most", will be published in the November issue of the journal *Physical Therapy*. A brief summary may be viewed at the following link: <http://npta.org/members/upload/789.pdf>

Maya Languages, Health, and Ethics: Issues in a Health Needs Assessment Study in Omaha

by Luis Marcos, M. Renzo Rosales, Alexander Rödlach, and John R. Stone

Background. In 2010 a collaboration between Omaha's Comunidad Maya Pixan Ixim (CMPI) and faculty from Creighton University (CU) and Omaha's College of Saint Mary (CSM) led to a Health Needs Assessment Survey (HNAS) as a first step in addressing health needs of the Omaha Maya community. CMPI is comprised primarily by Mayas who emigrated from Guatemala to the United States in the 1980s. Established in 2007, CMPI has developed many projects for community advancement in mutual cooperation with numerous community organizations and individuals. CMPI has collaborated with CU's Center for Service and Justice (CCSJ) and developed an English-as-a-Second Language (ESL) program that gets assistance from CU students and Omaha-area community volunteers.

We four authors met in conjunction with various CMPI activities and are the leaders for the HNAS. Luis Marcos is a leader of CMPI who focuses on relationships between CMPI and other community or academic organizations such as CCSJ. Luis Marcos is also president of the national organization, Pastoral Maya. Alexander Rödlach is an anthropologist and faculty in CU's Department of Sociology and Anthropology. M. Renzo Rosales is an anthropologist, instructor in Latin American Studies, and Coordinator, Center for Transcultural Learning at the College of Saint Mary. John Stone is faculty at CU's Center for Health Policy and Ethics and Co-Executive Director of CU's Center for Promoting Health and Health Equality.

Health Needs Assessment Survey Development (HNAS).

Discussions led to the decision to conduct a survey that would assess what community members consider their health needs. HNAS is an early step in developing health initiatives for CMPI. The design of HNAS was a collaboration of the authors, which the CMPI leadership informed and approved. HNAS development and conduct has included the following:

- Full partnership with CMPI approval of all aspects.
- Community investigators and interviewers.
- Some 300 families and individuals will be interviewed in three phases (50, 50, and 200). Results from open-ended interviewing in Phase 1 will be used to design interview questions for semi-structured interviewing in Phase 2. Results of the latter will design a survey questionnaire in Phase 3.
- Some 42 family and individual interviews have been completed.

Language Issues. The HNAS had to address issues resulting from the use of different languages used by the Mayas and the university-based researchers as well as varying degrees of language proficiency:

- The Maya language Q'anjob'al is the primary language of most Omaha Mayas. Many but not all speak Spanish with varying fluency. Fewer Mayas speak English and fewer still have full English fluency.
- Community interviewers were guided through successful

Author Contact Information

LM: Imarcos@pastoralmayausa.org

MRR: mrosales@csm.edu

AR: AlexanderRodlach@creighton.edu

JRS: JohnStone@creighton.edu



Maya Community Leaders after CITI Training: Luis (left), Juana (front), Margarita (back), Julia (right)



Maya Women Leaders in CITI Training: Julia, Margarita, and Juana from foreground to back

completion of online requirements for certification as research investigators. *The online tools and exams were almost completely in English.* Several interviewers are fluent in Q'anjob'al and Spanish, but have limited English-speaking capacity. These challenges slowed commencement of HNAS.

- Default conduction of interviews is in Q'anjob'al.
- Recorded interviews in Q'anjob'al are then translated into Spanish and then English—again slowing the process but also triggering valuable discussions on the themes identified during interviews and associated connotations.

Regarding language, the HNAS and development of interpreter services has led to two positive developments for CMPI:

- Omaha Mayas are learning that medical interpretation can be available during their healthcare encounters.
- Mayas in Omaha are taking more pride in their language and have initiated efforts to promote its recognition and preservation.



Maya Leader Oscar and Professor Alex in CITI Training

Ethical and Legal Issues. The Health Needs Assessment Survey is an example of what is called community-based participatory research (CBPR) in public health and biomedical research and participatory action research (PAR) in anthropology. Based in ethical concepts of equal respect and social justice, among others, horizontal collaboration is a key factor that includes (1) equal power and voice of community and academic partners and (2) building community capacity to develop and conduct other programs that would benefit the community. (For elaborations of CBPR issues and principles, see Baldwin *et al.*, 2009; Israel *et al.*, 1998; and Wallwork, 2008.)

That the online research certification training required was not available in Spanish limited and slowed community investigator training and participation. This language certification challenge, at least through the required route for this investigation, perpetuates the relative disadvantage of those not fluent in English—an injustice.

People with Limited English Proficiency (LEP) are legally entitled to have adequate access to and understanding of the services provided by federal funded agencies and institutions (Executive Order 13166). Such legal requirements clearly include healthcare. Whether the legal requirements of Executive Order 13166 encompass research certification options is an issue we have not addressed.

References Cited and of Interest

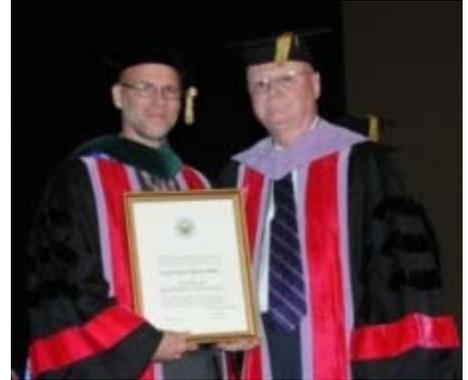
- Baldwin JA, Johnson JL, Benally CC. Building partnerships between indigenous communities and universities: Lessons learned in HIV/AIDS and substance abuse prevention research. *American Journal of Public Health.* 2009; 99(S1): S77-S82.
- Executive Order 13166, Improving Access to Services for Persons with Limited English Proficiency," 65 FR 50121 (August 16, 2000), http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=2000_register&docid=fr16au00-137.pdf (Accessed 30September2011)
- Marcos L, Rosales, MR, Rödlach, A, Stone JR. Comunidad Maya Pixan Ixim and University Researchers: Partnering in Community Health Development. Accepted for publication. *Practicing Anthropology.*
- Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health.* 1998; 19:173-202.
- Stone, JR. Ethics and Community-Based Participatory Research. *FOCUS.* Spring2011. <http://chpe.creighton.edu/publications/focus/spring-2011/spring-2011.htm> (Accessed 23Aug2011).
- Wallwork E. Ethical analysis of research partnerships with communities. *Kennedy Institute of Ethics Journal.* 2008; 18(1):57-85.

Honorary Fellowship in the American College of Dentists awarded to Dr. Jos Welie

On October 11, 2011 during the annual convocation of the American College of Dentists (ACD) in Las Vegas, Dr. Jos Welie from the Center for Health Policy and Ethics was awarded honorary fellowship in the ACD.

The College is the oldest national honorary organization for dentists. In response to serious problems facing the profession, the American College of Dentists was founded in 1920 by the then leaders of dentistry to elevate the standards of the profession. Almost a century later, the mission of the College still is to advance excellence, ethics, professionalism, and leadership in dentistry. The College is currently involved in a wide range of activities, locally and nationally, to accomplish this mission. These efforts include leadership symposia, resource materials for dental schools, a variety of award programs, ethics summits, and online courses in dental ethics. The ACD is currently collaborating with the Center for Health Policy and Ethics to add a graduate elective course on dental ethics to the Center's MS in Health Care Ethics degree program.

In addition to these activities, the ACD awards fellowship status to dentists who have established a record of leadership, excellence, and meritorious achievement in dentistry or public service. The College awards honorary fellowship to individuals who have made similar contributions to the profession but are not dentists and hence not eligible for full fellowship status. Dr. Welie was nominated by four ACD fellows, one of whom was CHPE's former Senior Visiting Fellow, Dr. James Rule. Dr. Welie was cited for his scholarly contributions to the profession of dentistry and his reputation for collaboration and consensus building.



Dr. Jos VM Welie (left) and Dr. Thomas F. Winkler III, President ACD Board of Regents (right)

Alumni News

In May 2011 we celebrated the first graduation in our MSHCE program. Read about our graduates in this article from an earlier issue of *Focus*:

<http://chpe.creighton.edu/publications/focus/spring-2011/graduates.htm>

We have asked our graduates to keep us posted on their new ventures. Here's what we've heard . . .

Natural Law: A Lutheran Reappraisal, ed. **Robert C. Baker** (St. Louis: Concordia Publishing House, 2011), 320 pgs.

Read a review of this book in this issue of *Focus*:

<http://chpe.creighton.edu/publications/focus/fall-2011/review.htm>

Earlier this fall, **Robert Baker** began teaching as an adjunct at Lindenwood University's Belleville, IL campus. He is teaching bioethics and two Intro to Philosophy courses. He reports enjoying this new challenge very much and expects to return in the spring.

Dawn Ann Farnin has been invited to sit in on the Ethics Committee monthly meeting for Hospice of the Valley (HOV) where she has been a home care volunteer for over a year.

Kenelm McCormick made these presentations:

- "Advance Directives: A Party". Summa Wadsworth Rittman Hospital Palliative Care Committee Education Program. Wadsworth, Ohio. July 20, 2011 and August 25, 2011.
- "Ethics Consultation: a True Story". Medina Hospital Grand Rounds. Medina, Ohio. August 17, 2011.
- "Sudden Illness". Medina Hospital Ethics Education Series. Medina, Ohio. September 1, 2011.

Learn more about the MSHCE program at this link:

<http://www.creighton-online.com/programs/online-masters-degree-in-healthcare-ethics.asp>