



Spring 2011

Director's Report

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**Celebrating a Milestone in CHPE History –
Inaugural MSHCE Program Graduates Receive
Degrees by Amy Haddad, PhD**

*Bit by bit, putting it together
Piece by piece, only way to make a work of art
Every moment makes a contribution
Every little detail plays a part
Having just a vision's no solution
Everything depends on execution
Putting it together, that's what counts!*

- Stephen Sondheim "Putting it Together" from *Sunday in the Park with George*

Although Sondheim's lyrics from *Sunday in the Park with George* refer to the creation of a work of art, they apply equally well to curriculum development. More than three years ago, the faculty at CHPE began the process of putting together the curriculum for the MSHCE program. The simplest view of a curriculum, such as that offered by Beauchamp (1962), is a plan depicting the scope and arrangement of a projected educational program. At the outset of the development of the MSHCE Program more than three years ago, the faculty and staff discussed the vision for the program and how it would fit with the overall vision and mission of the Center, the Health Sciences, and the University as a whole. The following is part of the MSHCE program vision:

The MSHCE degree program is designed for students seeking a deeper understanding of the impact of relevant historical, cultural, philosophical, political, economic and legal issues in health care practices and policies, especially regarding their impact on vulnerable populations. Pursuant to promoting the Jesuit value of concern for the poor and marginalized, students will be encouraged to critically reflect on their own attitudes, actions, and personal development during the program. Faculty will draw strongly upon a variety of disciplines to form and educate agents of change through intellectual and humanistic engagement with the enterprises of health care.

As the Sondheim lyrics emphasize, "having just a vision's no solution, everything depends on execution," the faculty set to work to develop a statement of specific program aims and overall objectives as well as the selection and organization of content that reflect the broader vision of the program. The thread that runs through all of the content, that of particular attention to the poor and marginalized and the formation of women and men with and for others, served as constant reminders of the prominence of core Ignatian values in the program. Additionally, certain methods were agreed upon to reach these objectives such as the importance of structured discussions, faculty-student interaction in the learning process, and the opportunity for writing and feedback that are evident in each course. So bit by bit the program was developed, always with a sense that every component, given the intensive nature of the eight week course structure, had to play a significant part in the learning process.

The program was launched in August 2009 and the execution part of the program began. Although the faculty had confidence in the design of the program and specific courses, using it to teach real students is a different matter. Students know whether or not the design of a course helped them understand regardless of their inexperience with the content (Wiggins and McTighe, 1998, p. 192). So, we have sought formative and summative feedback throughout the program of study so that the program design becomes better with each offering of a course. Such student feedback adds to the testing and adjustment of the program design which is actually an iterative process. In a sense, the curriculum is never



Graduate Hooding Ceremony Attendees

Left to Right: Coco Peterson, Dawn Ann Farnin, Cristina Noriega, Chris Jorgensen (Assistant Program Director), Leigh Thagard-Yeamman, Amy Haddad (Program Director)



Graduates at Commencement

Left to Right Front Row: Laura Stanosheck, Cristina Noriega, Coco Peterson, Leigh Thagard-Yeamman, Kathryn Baxter, Left to Right Back Row: Kenelm McCormick, Lindsey Major, Robert Baker

finished but a “work” in progress. For the first time this spring, we will implement program assessment and evaluation to actively seek input from our first graduates which leads to the most important part of this description of our curriculum development journey.

CHPE is celebrating a landmark event in the history of the Center, that is, the graduation of the May 2011 and August 2011 students in the MSHCE program. Even as we celebrate the first graduates and their accomplishments, we welcomed a new group of students who started the program on May 2, 2011. With three admission entry points a year, we will continue to monitor how well students meet the objectives of the program and how the program supports student learning and meets their expectations. In addition to teaching, the faculty will continue to determine the essential health care ethics content in the program and refine the sequence of courses. We will award degrees and welcome new students almost simultaneously all the while paying attention to the details and how it all comes together to form a constantly developing program that prepares students to be agents of change in a complex world.

References:

Beauchamp, G.A. (1968). *Curriculum Theory* (2nd ed). Wilmette, UL: The Kagg Press.

Wiggins, G. & McTighe, J. (1998). *Understanding by Design*. Columbus, OH: Merrill Prentice Hall.

May 2011 MSHCE Graduates

Robert C. Baker

"Following graduation, I will continue serving as a member of the Life Committee of The Lutheran Church—Missouri Synod. This summer, I will attend the Medical Ethics in the 21st Century Seminar, sponsored by the Witherspoon Institute and held on the campus of Princeton University. Additionally, I hope to pursue additional graduate work concentrating on the nexus between bioethics and Orthodox Lutheranism."



Kathryn R. Baxter

"My current plan is to attend law school, starting this fall. After careful consideration I have decided that a career in law is the appropriate next step to apply everything I have learned as part of this master's program. I hope to be able to practice law while also working with a hospital ethics committee."



Larry J. Cook

"I have taught ethics and professionalism in dental schools, dental residencies, and at national dental meetings for the last eight years. Finishing this program will allow me to provide bioethical articles in my professional literature (something I have never done), expand my horizons of participation in the lecture programs I am involved with, and allow me credibility with the audience in front of me due to my expanded knowledge base."

Jessica M. DeStephen

"After completing my M.S. in Healthcare Ethics, I am better prepared to manage clinical trials and serve as an advocate for the health, safety, rights and privileges of human subjects who participate in research."

Canyon Hardesty

"This program has not given me the answers that I may have been searching for when I started related to the basic question of is healthcare a right or a privilege, but rather it has provided me with the tools to impact my local community by asking how do we make a healthcare access and patient-centered quality ethical care standard throughout our systems."

Kenelm F. McCormick

"I will be working in my small hospital to develop an ethics committee that works, a committee that cares about the quality of its work and has mechanisms to ensure the quality of its work in the future. In addition, I have volunteered for the board of the Bioethics Network of Ohio and have offered to do some writing for its newsletter. I am planning to put my Creighton education to work."



Lindsey J. Major

"After completing the program, I realize how broad the field of bioethics is. I hope to make a career change from RN to something more focused on ethics within the field of healthcare, though I am not sure which direction that will be. My first step is to become more involved with a hospital ethics committee to gain some practical experience. Otherwise, I plan to keep my eyes open for new opportunities in health care ethics."



Andrew P. Schumacher

"My immediate plans are to apply my newly learned knowledge to my current position in clinical research. In the future I plan on pursuing a PhD in health policy in which my background in bioethics will play a critical role when developing or evaluating policies."

Randale C. Sechrest

"My experience in the program has opened my eyes to a whole new world to explore and gave me the foundation to understand and join the evolving conversations in all aspects of bioethics. Whether I ever practice bioethics as part of my professional job title, the insights that I have obtained during the program will forever change my approach to direct patient care. My understanding of the relationships between health care institutions, practitioners, and patients has been enriched."

Christine N. Sutherland

"Now that I have attained my M.S. in Health Care Ethics, I am planning on co-teaching a "Disaster Management and Emergency Preparedness Course" and continuing to serve on my hospital's ethics committee. I also plan on pursuing a stronger educational alliance with two of the local colleges to teach bioethics and nursing."

Customary Law as a Social Determinant of Health for the Northeast Indian Tribal Communities by Melvil Pereira, SJ

The social determinants of health are the quantity and quality of the variety of resources that a society makes available to its members, and they are also the economic and social conditions that shape the health and happiness of individuals and communities (Raphael 2008: 2). They determine to what extent an individual possesses the physical, social, and personal resources to discover his or her potentialities, identify aspirations, and face life's challenges.

In this article I argue that for the tribal communities in Northeast India, customary law is one of their most important social resources. This law is in everyone's minds and hearts and functions as a community exercise, and so its easy accessibility and use can enhance the general health and well-being of the members of tribal communities.

Northeast India refers to the eight states of India located at its easternmost part. It is home to over 420 ethnic groups which are culturally, ethnically, and linguistically distinct from the other states of India. The Siliguri corridor, popularly known as a 'chicken neck', with an average width of 21 to 40 km and a length of about 37 km, connects this region to the rest of the country. The Northeast has a high concentration of tribal population, with five of the eight states having a preponderance of tribal people.

A cursory glance at the literature on the tribal communities of Northeast India by ethnographers, anthropologists, and missionaries reveals that tribal communities in Northeast India have had their own rules and regulations by which they were governed. These are known as customary laws. Their origin lies in habits that grew into customs through imitation and acquiescence to the values the community cherished. A norm becomes a law when the community members respect and adhere to it as integral to their culture and heritage. Such laws maintain social order and are a stabilising factor in that society. Customary Law can thus be defined as a set of rules that attain the force of law because a society observes them continuously for a long time. These customs gradually become part of tribal culture and play a vital role in identity formation (Singh 1993: 17).

The approach to conflict resolution in a customary law system is largely palliative rather than penal; it is restorative rather than adversarial. It aims at restoring a relationship between two parties that has been disturbed due to a dispute. An attempt is made to satisfy both parties to the conflict, paying sufficient attention to the possible criminality of an act. Ideally the resolution to the dispute is arrived at looking not only at the well-being of the individuals who are party to the conflict but also at the well-being of the community. The goal is to restore the equilibrium in society that is disturbed because of the conflict between two persons and not simply to settle a score. Thus, the overall emphasis of customary law is the well-being and happiness of individuals which translates into the well-being of the community.

The British acknowledged the presence of customary laws and the self-governing institutions of tribal communities and did not interfere in their internal affairs. They treated the tribal habitats as 'excluded' and 'partially excluded' from regular administration. After the nation gained independence in 1947, the Government of India largely followed this approach and even went a step further by enacting the Sixth Schedule in the Constitution which provided autonomy to various tribal communities to live a life according to their social customs and practices.

The introduction of external inputs in the form of formal education, liberal democratic institutions, non-tribal religions, and market economy have ushered in changes in tribal communities that threaten the erosion of tribal rights and cultures. For instance, the bachelor dormitories, which were the forums for the dissemination of customary laws and practices, have vanished and no institution has taken their place to continue imparting tribal wisdom and knowledge. This has led to a gradual erosion of customary laws in many tribal communities in Northeast India despite the presence of protective measures in the Constitution of India.



Father Melvil Victor Pereira, SJ, PhD, is the CHPE's current Senior Visiting Fellow. He arrived from India in January and will stay in Omaha until June, 2011. Father Pereira is a Jesuit priest and has a PhD in Political Science from New Delhi's Jawaharlal Nehru University. His doctoral studies focused on the interface of customary laws of the indigenous people in Northeast India with the state laws. Father Pereira is a member of the Kohima Jesuits whose projects in Northeast India are located in the primarily rural, mountainous surroundings in the Himalayan hills and valleys between Bhutan, China, Myanmar, and Bangladesh. The Kohima Jesuits are active in sustainable development, legal advocacy and forest preservation to protect the livelihoods of indigenous people. Father Pereira is associated with The North Eastern Social Research Centre (NESRC) whose task is to provide publications, forums, and programs on critical social issues in the region.

The intrusion of liberal democratic institutions into tribal polity has also adversely affected the tribal self-governing institutions like the council of elders or the village courts. The well-oiled state machinery with its executive, legislative, and judicial branches has made inroads into tribal political institutions, and this has weakened tribal governing structures.

At a time when their culture is in the throes of extensive change, most tribes in Northeast India consider their customary law intrinsic to their identity and part and parcel of their culture and tradition. For tribal communities, customary law is the storehouse of their ideals, values, aspirations, and practices. It is the epitome of what is desirable and aspired to in a tribal community. Recent literature has highlighted the role played by customary laws and legal systems in preserving the culture of various societies (Weyrauch 2001).

Political scientists have argued that it is essential for the well-being of human beings that their community be recognized both politically and socially (Taylor 1992). It is within the horizon of these communities that human beings are able to develop their identity. Taylor argues that individuals are anchored in a particular community and its traditions. It is the community which provides them resources and the capacity to make sense of their lives and to make choices.

According to Taylor, human beings do not develop their identities in a vacuum. They are culturally situated beings and form their identity through relations of recognition with significant others. The recognition and non-recognition of a social group and its culture by a larger society or political system can form or deform an individual or a community. In many ways, identities are shaped by the recognition of one's person, which is deeply anchored in one's culture and meaning system. A lot of the tribal culture and values are deposited in customary laws. The recognition of customary laws and their practice has immense significance for tribal societies.

A tribal community can suffer real damage if the larger society and the political system that governs it fail to recognize its right to a distinct culture and identity. As Taylor puts it, "Non-recognition or misrecognition can inflict harm, can be a form of oppression, imprisoning one in a false, distorted, and reduced mode of being" (Taylor 1992: 25). Thus state policies that recognize tribal ways of life, their distinct life styles, and their unique conflict resolution systems can help in creating meaningful contexts for the exercise of freedom and choice for tribal communities. Conversely, state policies that do not recognize the existence of distinct communities can endanger their culture and heritage. The non-recognition of a community and its practices can impede the freedom and flourishing of its members.

Kymlicka reiterates Taylor's observation that recognition of a community and its culture is vital for the overall growth of its members. To him, culture provides people with a sense of belonging and a context for making meaningful choices (1995: 82-89). Culture is that shared vocabulary of social life which includes language, customs, norms, forms of interaction, legal system, family, school, media, and various forms of socialization. Thus human beings need easy access to their familiar culture in order to exercise freedom and have real choice. The general well-being and happiness of an individual is linked to, and dependent on, culture. An individual cannot make meaningful choices in the absence of a cultural framework.

Since customary laws are a vital aspect of tribal culture, it is of paramount importance that they be recognized and allowed to function according to the terms laid down by the members of tribal communities in Northeast India. Because customary law is integral to their cultures, it has to be recognized by the state, and protective measures spelled out in the Constitution should be practiced in letter and spirit.

It has already been noted that customary law is a vital aspect of culture of tribal communities. As an important part of culture, customary law provides individuals with resources to deal with disputes in a holistic manner laying stress on palliative approach to conflict resolution. Further, an individual's well-being in a tribal community is guaranteed if he or she remains faithful to the tenets of customary law and is allowed to adjust these laws as necessary to deal with new situations. Thus it is evident that customary law is one of the important social determinants of health in tribal societies of Northeast India. Ensuring this context, the recognition and affirmation of people's unique cultural identity, seems a decisive pre-condition for guaranteeing the emotional and physical health and well being of tribal people.

References

Kymlicka, Will. 1995. *Multicultural Citizenship: A Liberal Theory of Minority Rights*. Oxford: Clarendon Press.

Raphael, D. 2008. "Introduction to the social determinants of health," In D. Raphael (ed.), *Social determinants of health: Canadian perspectives*. 2nd ed. Toronto: Canadian Scholars' Press.

Singh, K. S. (ed.), 1993. *Tribal Ethnography, Customary Law, and Change*. New Delhi: Concept Publishing Company.

Taylor, Charles. 1992. "The Politics of Recognition," In Amy Gutmann (ed.), *Multiculturalism and the Politics of Recognition*. Princeton, New Jersey: Princeton University Press.

Weyrauch, Walter. (ed). 2001. *Gypsy Law: Romani Legal Traditions and Culture*. Berkeley: University of California Press.

CHPE Conference Examines the Use of Human Tissue and Public Trust

by Amy Haddad, PhD, and Helen Shew, MBA

The Center for Health Policy and Ethics (CHPE), with funding from the U. S. Department of Health and Human Services, will present a regional conference coordinated through the U.S. Public Health Service Office of Research Integrity. The conference will take place Monday, September 19, 2011, 8:00am to 4:00pm, at Creighton University's Harper Center, Ahmanson Ballroom, 602 N. 20th Street and is entitled, *The Use of Human Tissue and Public Trust: The Chasm between Science and Ethics*. Registration is required in advance; however, there is no charge to attend. Registration will be available on the CHPE website beginning mid May 2011.

- Kevin FitzGerald, S.J., Ph.D., David Lauler Chair for Catholic Health Care Ethics, Center for Clinical Bioethics, Georgetown University;
- Dayle DeLancey, Ph.D., Medical Historian, University of Wisconsin School of Medicine and Public Health;
- Marshall Kapp, J.D., Director, Center for Innovative Collaboration in Medicine and Law, Florida State University;
- Barbara Koenig, Ph.D., Professor of Medicine at the Mayo Clinic College of Medicine and Faculty Associate Center for Bioethics, University of Minnesota;
- John Stone, Ph.D., M.D., Professor, Center for Health Policy and Ethics, Creighton University.

Members of the plenary presenters will be joined by Edward S. Cohn, M.D., Boys Town National Research Hospital and John C. Galland, Ph.D., U.S. Department of Health and Human Services, Office of Research Integrity for a panel discussion at the close of the conference.

While the issue of trust and ethics is central in all human subject research it is especially relevant to minority communities who have experienced abuses in the past and, despite vigilance, still experience them in scientific research. CHPE invites both researchers and members of the public to the conference to gain insight regarding the benefits of research on human tissue while highlighting the connection between trust and research integrity. We are hopeful participants will take away a heightened awareness of potential and perceived harms and competing values and interest to research gains with particular emphasis on these topics: 1) current practices protecting the medical histories and identities of the tissue donors and their surviving families, and 2) responsible authorship regarding protection of donor identity including discussion about whether it is appropriate to name a useful tissue after the donor. The conference will also feature a HHS/Office of Research Integrity Interactive Workshop over a working lunch to explore problems and solutions to research issues raised by the audience.

The conference objectives are identified as follows. At the completion of this conference the participants should be able to:

1. Weigh the social benefits of medical knowledge derived from tissue research against competing moral goods such as the protection of cultural traditions and beliefs as well as protection from exploitation.
2. Examine the concept of trust, particularly from the perspective of marginalized populations and its importance in the research enterprise.
3. Identify gaps in knowledge and values between the science community and the public regarding the use of human tissue.

This conference is the first of two CHPE events this fall that raise awareness around the use of human tissue. On October 6th, Rebecca Skloot, author of "The Immortal Life of Henrietta Lacks," will present CHPE's Women and Health Lecture. <http://chpe.creighton.edu/events/wh/2011-skloot.htm>

Ethics and Community-Based Participatory Research

by John R. Stone, MD, PhD

This paper discusses ethical issues and related factors in community-based participatory research (CBPR), a very promising strategy for improving health and reducing health inequalities. CBPR vitally involves (1) communities and (2) investigators (who also may include community members) and their institutions or organizations in mutually designing research projects, conducting investigations, and disseminating results. The aim in CBPR is horizontal and rich partnering that includes full-blown collaboration. CBPR advances a particular community's health in ways that take account of local priorities and contextual factors.

A major departure from traditional research approaches, CBPR builds on relatively new ethical and practical insights regarding research related to community health. Effective CBPR typically involves significant institutional and community capacity-building, new investigator skills, effective community-investigator partnering, and associated relationship building. These elements all raise important ethical considerations.

CBPR and the Master of Science in Health Care Ethics

CBPR poses new ethical issues that bioethics professionals will need to address. Thus Richard O'Brien, MD, and I made CBPR the topic of the final paper that graduate students must write in the graduate course MHE602 Research Ethics. The course is generally taken early in Creighton University's online Master of Science in Health Care Ethics, offered by Creighton's Center for Health Policy and Ethics. For background, one week in the course focuses on ethical analyses of community-based research and suggested guiding principles. (Baldwin 2009, Israel 1998, Wallwork 2008)

In their paper, students are to explain and justify an ethical framework for a hypothetical CBPR project involving either an African American or a Native American community. The "framework" is to include core ethical principles and practical or operational action-guides. The latter are to guide day-to-day conduction of the research. A crucial background feature is that each community has experienced many injustices that have generated reasonable and significant distrust of investigators and their academic institution. Also, the projects are to envision a robust community-investigator partnership that determines all aspects of the hypothetical project.

In their CBPR papers, students typically address issues related to trust/trustworthiness, cultural differences, power imbalances, socio-economic factors, capacity building, and intersections with ethical principles of respect for persons and justice, among others. These foci speak to several moral issues in CBPR.

Ethical and Empirical Foundations

As our graduate students learn in the first week of the Research Ethics course, in the United States modern research guidelines emerged in light of significant research abuses of vulnerable populations, most prominently the United States Public Health Service observational study of untreated syphilis in African American men in Alabama, often called the "Tuskegee Syphilis Study." (For examples, see Arras 2008 and Jones 2008.) With a particular focus on protection, the "Belmont Report" enunciated the ethical principles of respect for persons, beneficence (including a provision about minimizing harm), and justice. (National Commission 1979) The respect principle particularly flowed into conceptions of informed consent. Justice targeted fair distribution of research benefits and burdens, including a stress on avoiding solicitation of participants from vulnerable and convenient populations. The Belmont Report is a major foundation for US federal research regulations that have a primary focus on individuals as potential and actual research participants. (Regulations and Guidelines 2005) Internationally, the Declaration of Helsinki has probably had the greatest influence. (WMA 2008)

The ethical framework for biomedical research has predominantly employed the individualized approach noted above. A primary focus of Institutional Review Boards (IRBs), evident in the federal regulations, has been to ensure that an ethically satisfactory informed consent is provided for each potential participant. To promote fair opportunity for participation and translatable outcomes to the respective populations, the regulations now specifically require justifications if women or minorities are to be excluded. IRBs also focus on assessing benefit and minimizing harm.

Traditional Approaches in Community-based Health Research: Knowledge and Power

Coupled with the focus on individual participants, the predominant research approach regarding community health issues has more or less assumed that investigators and their institutions or organizations:

- Understand the health needs of different populations or have the knowledge and expertise required for ascertaining those needs,
- Have sufficient skills and experience for designing and conducting the research, and
- Know what research priorities would be best for the community.

In this schema, researchers would often need to work closely with key community leaders and organizations to advance the research aims, build relationships, and develop trust. Such community persons might be collaborators or partners in order to meet research objectives.

This traditional way of conducting research obviously ensures that agendas, knowledge, power, and control remain in the hands of investigators and their institutions that allegedly understand what is best for communities. However, new insights are driving the increased calls for and application of CBPR and other community-based approaches to addressing community health, a major move away from the top-down methods and assumptions described above.

New Insights Driving CBPR

One major new insight is that the US predominant and “downstream” focus on (unequally) promoting opportunities for healthcare services offers no hope of preventing or ameliorating many health problems. Rather, it is now clear that *interactive* “upstream” social factors are largely responsible for people’s health problems. (Geiger 2006) When people arrive at downstream interventional sites like health professionals’ offices, clinics, and hospitals, much of their current but also their future health status is already determined.

Social influences (“determinants”) include intersecting factors like environment, education, income/wealth, and opportunities for jobs and positions. In turn, each of these factors includes many potentially positive or negative influences. For example, in the environmental domain, causal factors for poor health include atmospheric pollution, unsafe neighborhoods that not only include violence but also the stress that the threat causes, recurrent experiences of racial/ethnic discrimination, poor access to healthy foods, inferior schools, poverty, and others. Importantly, such social factors also influence health-affecting behavior.

An implication of these upstream influences is that efforts to advance health must function at community levels. Furthermore, it is clear that the standard healthcare approaches to promoting healthy lifestyles of individuals cannot succeed without improving the relevant social determinants at community levels.

Investigators have also increasingly realized that they may be unaware of adverse health influences that community members understand. It follows that to advance community health it is crucial to create a respectful and collaborative atmosphere that facilitates sharing of local knowledge.

The second major insight is ethical. Building on the above and other empirical factors, a cluster of moral considerations explains why CBPR is a crucial move for improving population health, particularly of groups who experience worse health on average. Two key factors are respect for persons and justice, newly interpreted.

Maintaining control and expertise in investigators and their institutions sustains inferior power and ignorance in targeted communities. This failure to empower the latter is a violation of respect. Genuine respect involves supporting and building communities’ capabilities to ensure that their interests and priorities are pursued, including in health. In a similar vein, justice is only really advanced if communities are empowered and thereby enabled to prevent their exploitation. Furthermore, if communities are well represented in planning and implementing biomedical research, then their priorities and interests are more likely to be maintained, which in turn fosters fairness. These are other factors that motivate the robust partnering and collaborative tenets of CBPR. Honoring respect and justice in these ways are moves away from historical oppression and discrimination.

A third ethical justification for CBPR flows from the Belmont research ethics principle of beneficence and its harm minimization feature. I noted earlier that investigators may be ignorant of important health-influencing elements that community members perceive. Thus, how best to help a community can be very dependent on local knowledge and priorities. Moreover, non-community researchers can fail to understand how research may injure communities. This happened, for example, when investigators conducted genetics research that posed significant hazards for a tribe of Native Americans. (Mello 2010) Another example would be investigations regarding interventions to promote healthy exercise without understanding that safe environments are a prerequisite.

Trustworthiness and Culture

As mentioned earlier, a long history of exploitation and abuse has instilled in minority communities a reasonable distrust of investigators and their institutions. Respect and justice call for researchers to be thoroughly trustworthy in serving the community interests that they ostensibly espouse and in avoiding exploitation. (For a detailed discussion of trustworthiness and trust, see the 2008 analysis I wrote with Annette Dula; regarding trust specifically related to community-based research, see Baldwin 2009 and Israel 1998) Such trust can only be earned if researchers adopt a robust attitude of humility. Indeed, such humility takes various shapes.

Epistemological humility. How to show trustworthiness and thus build trust is complex because historical reasons for distrust, current racial/ethnic tensions, and cultural differences may be relevant. Without significant input and guidance from community members, researchers may well repeat disrespectful treatment of community members and unconsciously exert “power over” them. Asserting expertise is one way to do the latter. Thus, investigators should be guided by what we might call “*epistemological humility*” that both motivates and informs CBPR. It motivates CBPR because investigators appreciate that successful research leading to positive interventions depends on building and showing trustworthiness. Such humility about knowledge also fosters openness to the ideas and perspectives of community members, further enhancing the probability of success.

Conflict humility. Epistemological humility is an ethical research principle that rests on the empirical foundation of researchers’ ignorance about community issues and the potential to promote unintentional disrespect, injustice, and material harm as a result of poorly conceived research. This epistemological humility must be complemented with “*conflict humility*”: researchers should appreciate that their career goals, funding priorities, and institutional/organizational priorities may generate conflicts of interest that oppose trustworthiness in faithfully serving community interests and priorities. Conflict humility is another reason that investigators should promote vigorous partnering and collaboration in CBPR to provide a strong check and balance against such biasing factors.

Cultural humility. Yet another source of ignorance is cultural, which in turn is the basis for another important ethical principle: “cultural humility.” It builds on a related concept of the same name that Melanie Tervalon and Jann Murray-Garcia suggested for healthcare. (Tervalon and Murray-Garcia 1998) Biomedical or public health professionals and their institutions or organizations are often very culturally different from and insufficiently sensitive to the diverse communities they hope to benefit. Furthermore, researchers frequently have unconscious biases and stereotypes that infect their relationships with people culturally different. These divides are often related to racial/ethnic designations and related experiences as well as socioeconomic class. Finally, by virtue of their education and organizational experience, investigators have significant professional socialization that promotes a certain biomedical or public health perspective. All of these factors can endanger the development of trustworthiness and require therefore an attitude of cultural humility on the part of the researchers.

A consequence of these divisions is that cultural differences between investigators and communities are typically multiple, including in relation to race/ethnicity, professional training, and socio-economic circumstances, not to mention national origin or ancestry, sexual orientation, gender, and so forth. In its implementation, cultural humility also involves openness to diverse views, beliefs, and behaviors. And it is a very small step to appreciate that being trustworthy and showing it will require significant engagement, education, and transformation that require “thick” partnering and collaboration with communities.

Implications for CBPR

These insights about upstream causal influences on health, the ethics-supported importance of community knowledge and priorities, issues of respect and justice, and factors in trustworthiness and cultural difference, comprise very strong reasons to employ CBPR to promote community health and eliminate health inequalities.

In referring to health inequalities, note that the usual reference is to “health disparities.” However, a colleague emphasizes that the “disparities” term once again labels something as being an adverse aspect of an already-abused population such as African Americans.^[1] Thus this paper employs health “inequalities” rather than “disparities.”

Ethical Guidance for CBPR

I suggested that the ethical principles of epistemological, conflict, and cultural humility are important ethical principles for CBPR. However, in analyzing what should guide CBPR, the Belmont Report is the obvious starting place. As noted, its principles of respect for persons, beneficence, and justice have been widely discussed and understood to be the general ethical benchmarks for current research regulations in the US. Thus the natural approach would be to assess whether these principles are sufficient for CBPR, need modification, and/or require additions.

In assessing whether and how to supplement or modify the Belmont Report, bidirectional considerations emerge. There are two directions because the principles sit between practical applications on the one hand and ethical theory on the other.

The most obvious concerns relate to factors already mentioned: collaboration, partnering, trust, trustworthiness, culture, and racial/ethnic and socio-economic factors. Although the Belmont Report focused on communities regarding justice and fair sharing on benefits and burdens, a major stress was on individual informed consent. But full-blown community partnering and collaborative design and investigation means that the community must agree before a research project can proceed. Thus one concern has been that communities can preempt individual consent. That is, individuals would never have the option to participate if the community vetoed the project. Or individuals might be subject to negative community views if they do not agree to participate in a community-approved research project.

Principlism and Casuistry

A core consideration in the other direction is whether moral theory would be helpful in analyzing what should guide CBPR. However, as Albert Jonsen and Stephen Toulmin wrote, reflecting on their experiences with the National Commission that developed the Belmont Report, “we were independently struck by aspects of its methods and results that were hard to account for in terms of current ethical theory.” (Jonsen 1988, p. viii.) Their remarks highlight two prominent approaches that the National Commission effort motivated in modern bioethics and that do not rely on moral theory.

Most well-known is the “principlism” approach that the Belmont Report illustrates. However most prominent is the principlism promulgated and defended by Tom Beauchamp and James Childress primarily in their multiple editions of the *Principles of Bioethics*. (Beauchamp 2009) They argue that four well-known principles are part of the “common morality” and do not attempt to provide a moral theoretic justification. The other has been Albert Jonsen and Stephen Toulmin’s mutual effort to revitalize casuistry in their *The Abuse of Casuistry: A History of Moral Reasoning* and later publications. (Jonsen 1988) Casuistry primarily involves not core ethical principles but a methodology that reasons from so-called paradigm cases and principles that seem very clear in those cases. Casuists emphasize that the method is very focused on the concrete and the particular.^[ii]

In light of the Belmont Report and the expanded principlism and revived casuistry that it spawned, a reasonable assumption would be that moral theory has nothing to offer in developing ethical guidance for CBPR. However, I suspect that this view is incorrect. Among others, I want to suggest that a recent theory of social justice for public health, work in ethics of care, and post-colonialism analyses may all have something to offer. In what follows I will develop a bare sketch of what these theories may provide. I will then turn to more specific issues in ethical guidance for CBPR.

In *Social Justice: The Moral Foundations of Public Health and Health Policy*, Madison Powers and Ruth Faden argue that health is one of the “essential dimensions of well-being” and that justice requires providing everyone with a “sufficient” level of health. (Powers 2006) They rightly stress that the multiple social determinants of health dynamically *interact* to influence health. Thus, to fulfill the demands of justice, research must strive to understand how these factors interact in *concrete*, “*non-ideal*,” or *real-world* contexts and develop corresponding interventions.^[iii] This analysis has significant implications for CBPR.

Justice’s requirement for investigation and interventions regarding social determinants’ influence on health has ramifications at several levels. First, funding opportunities should include provisions that proposals investigate and act on such intersections. Second, academic institutions must foster activities that promote inter- and trans-disciplinary work in conjunction with CBPR efforts. “Trans-disciplinary” work includes efforts to find common language, concepts, and methodologies as well as potentially developing new models. Third, CBPR projects should specifically include investigations and interventions regarding intersecting social factors. An instructive source here is Amy Schulz and Leith Mullings’ edited collection, *Gender, Race, Class, & Health: Intersectional Approaches*. (Schulz 2006)

Another moral theoretic contribution to CBPR may flow from a group of theories called both “ethics of care” and “care ethics” that are part of a large, growing, and very important body of work in feminist theory. Some core elements of care ethics include a major focus on work within relational contexts and analyses of what it means to “care for” and to “care about” others.^[iv] (Held 2006, Carse 1996)

In the CBPR context, I suggest that care theories should be investigated regarding potential ethical implications for community-investigator relationships and how they conduct their work. Thoughtful development of care-related principles should provide helpful guidance about how to ensure deeply humane, empathic, and considerate relationships among not only those who design and conduct research, but also how research participants are *particularly* treated, actual and potential.

Also rising from feminist scholarship has been an increased focus on the importance of “recognition.” As Carol Gould writes, “to recognize others as human beings is in the first place to acknowledge their agency (where individual or joint) and, correlatively, to recognize that this capacity remains abstract and empty unless it is exercised in concrete cases....” (Gould 2004, p. 34) The theoretical consideration of recognition then provokes analysis of what it means to support agency and what should be done in CPBR to do so. Considerations of agency seem particularly relevant because CBPR typically targets historically underserved, oppressed, and unjustly treated communities such that their agency has been suppressed and undermined.

Other potential theoretical sources for CBPR guidance are critical race theory and postcolonial theory. Just as feminist scholarship has often correctly argued that existing social structures and practices maintain male dominance and oppression of women, critical race theory supposes a comparable schema regarding race and ethnicity. (For one collection on critical race theory, see Crenshaw 1995) Also, my colleague and philosopher Christy Rentmeester has stressed that postcolonial theory may have significant implications regarding trans-generational issues related to oppression of various populations. Further, Paul Farmer’s discussions of how society’s conduct “structural violence” against the poor constitutes another theory that may flow into how CBPR should be conducted. (Farmer 2003) Such violence may be particularly important because poverty has had less attention in bioethics and research ethics than have many other issues. Also see comments by Israel et al. regarding so-called deconstruction of ways of knowing and relationships among groups such as communities and institutions. (Israel 1998)

CBPR: From Belmont to Action-Guides

In this final section I will summarize some discussion and suggestions regarding what general principles should guide CBPR efforts and recommendations for more concrete or specific action-guides. I have already suggested some principles that should complement what exists.

In our Research Ethics graduate course students read Ernest Wallwork’s “Ethical Analysis of Research: Partnerships with Communities,” the most thorough analysis we found about what should guide CBPR. (Wallwork 2008) Wallwork found three primary ways of thinking about ethical issues in research involving community partners. In his terms they are:

- “Application/specification” of existing and individualistic guidelines like Belmont and the US federal research regulations. This approach is strictly individualistic.
- “Extension” of present guidelines so as to also include “group interests and values” such as through group consent. As Wallwork sees it, the extension model includes a concept of community respect and group harm. Readers may be interested in his comments about justice considerations in the extension model.
- “Novel moral standards,” such as a concept like “harmony” that Native Americans may espouse and elements from “post-colonial, postmodern discourse” that may stress the social construction of knowledge, among other things. Thus we see here the post-colonial and deconstruction threads I already mentioned. Also, related to my earlier comments, Wallwork notes that the postmodern view includes “the value and validity of ‘local knowledge’,” and the background agendas and biases that investigators may bring.

Wallwork also notes that actual practice may include a mixture of these three types of guidelines.

A relatively separate literature has advocated more specific ethical guidelines for CBPR. For example, in a helpful review of community-based research, Barbara Israel and colleagues stress:

- involving researchers and colleagues equitably through a collaborative approach,
- building on local “strengths and resources,”
- promoting mutual benefit, learning, and empowerment, and
- employing an ecological perspective. (Israel 1998)

In justifications for their model of “community-based research,” Israel et al include that it: “creates better informed/more effective practice,” helps reduce “understandable distrust,” works toward reducing community marginalization, and builds knowledge and capacities that further enable communities. These justifications are consonant with the formal ethical bases that were discussed earlier in this paper.

In addition to the helpful review by Israel and colleagues, our graduate students read another important paper that offers more specific guidelines for CBPR: "Building Partnerships Between indigenous Communities and Universities. Lessons Learned in HIV/AIDS and Substance Abuse Prevention Research." (Baldwin 2009) Here Julie Baldwin, Jeannette Johnson, and Christine Bennally review their experience in research with Native communities. As did Israel et al., they stress the importance of a cyclical or iterative process of community-investigator engagement that includes mutual planning, implementation, and dissemination. Based on their experience, Baldwin and colleagues emphasize the importance of appreciating the following "challenges":

- local knowledge in understanding of concrete local issues that (1) strongly influences what should be done and how to do it, and (2) can pose potential harms that academic researchers do not perceive,
- distrust issues,
- tribal innovations to prevent the community from research "abuse,"
- what constitutes community benefit, and
- culture-related differences in conceptual frameworks.

In light of such considerations Baldwin et al. recommend several mechanisms for developing collaborative partnering. To build trust, for example, they write: "a researcher must know and use appropriate channels to enter into a relationship with a Native community" and "recognize the multiple voices and perspectives in the community." Other recommended aspects include close project monitoring by a community advisory board, hiring community members to work on the project, growing local capacities for research and involving community members in the investigational and dissemination processes. All of these features combine to enhance interventional efficacy. The authors elaborate on all of these points.

I submit that these and other practical recommendations are fully consistent with this paper's earlier comments regarding respect, justice, care, and dimensions of humility.

Toward Excellence in CBPR: Creighton's Center for Promoting Health and Health Equality

This discussion noted that achieving CBPR aims generally requires robust partnerships and significant transformations. On the institutional/organization side, investigator capacities need development and mechanisms must be developed to promote inter- and trans-disciplinary collaboration that in turn flows into a sustained and vigorous partnership with communities. As should be clear from remarks here, such partnerships must build trust; mutual knowledge; bridge cultural, racial/ethnic and other divides; manifest several ethical aspects including respect, justice, and care; and promote three kinds of humility: epistemological, conflict, and cultural.

To achieve such goals we believe that a crucial element is to develop and sustain a major center that equally involves community and the university. Thus we proposed and Creighton University Medical Center provided three-year initial funding for the Center for Promoting Health and Health Equality (CPHHE).^[v] The Center is governed by a board of community members and academic individuals who represent diverse interests, organizations, and disciplines. To ensure that community interests have first priority and to promote an equitable relationship, community members are the majority on the governing board and the chair is always a community member. CPHHE emphases include CBPR and related research, interventions that stress community education, and training and development of related capacities. (Interested readers should see the CPHHE website at <http://www.creighton.edu/health/cphhe/>)

The formation of CPHHE has drawn heavily on what we have learned especially from colleagues at the Minority Health and Health Research Center at the University of Alabama-Birmingham (MHRC), but also from individuals at Morehouse School of Medicine in Atlanta (MSM).^[vi] Also, Dan Blumenthal's paper about the Southwest Atlanta community and MSM collaboration has been very informative. (Blumenthal 2006)

I invite readers to visit the CPHHE website and to contact me regarding this paper or CPHHE issues.

Conclusion

Community-based participatory research (CBPR), also called community-based research, is a very important development in addressed community health and targeting upstream influences. CBPR raises important ethical issues that include considerations in moral theory, ethical principles, and specific action-guides. Historical abuses of communities and related distrust; numerous multicultural and socio-economic factors; research models that relate to ways of understanding and addressing local issues of knowledge, power, and hierarchies; and the intersecting causal influences of social determinants all have ethical relevance in determining how CBPR should be conducted. This essay has pulled together some of these issues in advocating formal ethical principles of

epistemological, conflict, and cultural humility, the latter drawing on suggestions originally targeting healthcare. These principles are important in establishing and showing trustworthiness. I have argued that recent moral theory in social justice and public health can help CBPR. The account explained why and how CBPR is the topic for the final paper in the graduate course on Research Ethics that is part of the Master of Science in Health Care Ethics offered by Creighton's Center for Health Policy and Ethics. In summary, an important way to advance CBPR efforts is to develop centers that involve robust community-academic partnerships like the Center for Promoting Health and Health Equality at Creighton University Medical Center and similar centers elsewhere.

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References

1. Arras, JD The Jewish Chronic Disease Hospital Case. In Ezekiel J. Emanuel, Christine Grady, Robert A. Crouch, Reidar K. Lie, Franklin G. Miller, and David Wendler. (Editors) *The Oxford Textbook of Clinical Research Ethics*. Oxford University Press, 2008, 73-79.
2. 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.
3. Beauchamp TL. Childress JF. *Principles of Bioethics*. Sixth Edition. New York. Oxford Univ Press. 2009.
4. Blumenthal DS. A community coalition board creates a set of values for community-based research. *Prev Chronic Dis*. 2006; 3(1):A16.
5. Carse AL, Nelson HL. Rehabilitating care. *Kennedy Inst Ethics J*. 1996; 6(1):19-35.
6. Farmer P. *Pathologies of Power: Health, Human Rights, and the New War on the Poor : With a New Preface by the Author*. 2005 Berkeley. Univ. of California Press, 2005.
7. Crenshaw K, Gotanda N, Pellar G, Thomas K. (Eds.). *Critical Race Theory: The Key Writings that Formed the Movement*. New York. The New Press, 1995.
8. Geiger HJ. Health Disparities. What do we know? What do we need to know? What should we do? In: Schulz AJ, Mullings L (Editors). *Gender, Race, Class, & Health: Intersectional Approaches*. San Francisco: Jossey-Bass, 2006, 261-288.
9. Gould CC. *Globalizing Democracy and Human Rights*. New York. Cambridge Univ. Press, 2004.
10. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. *Annu Rev Public Health*. 1998; 19:173-202.
11. Held V. *The Ethics of Care: Personal, Political, and Global*. New York. Oxford Univ. Press, 2006.
12. Jones JH. The Tuskegee Syphilis Experiment. In Emanuel et al., 2008, pp. 96.
13. Jonsen AR, Toulmin S. *The Abuse of Casuistry: A History of Moral Reasoning*. Berkeley, Ca. Univ. of California Press, 1988.
14. Mello MM, Wolf LE. The Havasupai Indian Tribe case: Lessons for research involving stored biologic samples. *N Engl J Med*. 2010; 363(3):204-207.
15. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research. April 18, 1979. <http://ohsr.od.nih.gov/guidelines/belmont.html> (Accessed April 24, 2011)

16. Powers M, Faden R. *Social Justice: The Moral Foundations of Public Health and Health Policy*. New York: Oxford Univ. Press, 2006.
17. Regulations and Ethical Guidelines. Office of Human Subjects Research. National Institutes of Health. 2005. <http://ohsr.od.nih.gov/guidelines/45cfr46.html>. (Accessed April 24, 2011)
18. Schulz AJ, Mullings L. (Editors). *Gender, Race, Class, & Health: Intersectional Approaches*. San Francisco: Jossey-Bass, 2006, 261-288.
19. Stone JR, Dula A. Race/Ethnicity, Trust, and Health Disparities: Trustworthiness, Ethics, and Action. In: *Cultural Proficiency in Addressing Health Disparities*. Editors: Kosoko-Lasaki S, Cook CT, O'Brien RL. Sudbury, MA: Jones & Bartlett, 2008, pp. 37-56.
20. Tervalon M, Murray-Garcia J. Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *J of Health Care for the Poor and Underserved*. 1998; 9(2):117-125.
21. MHRC. Minority Health & Health Disparities Research Center. University of Alabama-Birmingham <http://mhrc.dopm.uab.edu/>. (Accessed April 23, 2011)
22. MSM. Morehouse School of Medicine. <http://www.msm.edu/HomePage.aspx> (Accessed April 24, 2011)
23. Wallwork E. Ethical analysis of research partnerships with communities. *Kennedy Institute of Ethics Journal*. 2008; 18(1):57-85.
24. WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects. World Medical Association. 2008. <http://www.wma.net/en/30publications/10policies/b3/>. (Accessed April 24, 2011)

Notes

[i] Frank Peak, PhD, has emphasized this point about the health disparities terminology.

[ii] For an interesting and illuminating set of exchanges about principlism and casuistry, as well as a nice overview, see the special collection in the *Journal of Medicine and Philosophy*, 2000, Vol. 25, No. 3.

[iii] That justice should address these interactions of different social spheres is a departure from some other accounts of justice. Interested readers should review Powers and Faden's discussion.

[iv] Authors have argued that care ethics and care issues are also relevant to distant peoples. For example, see Gould 2004 and Held 2006.

[v] Community and academic members of the CPHHE Governing Board have been crucial in its initial development. The leadership of the CPHHE Governing Board, Mr. Stephen Jackson (chair) and Ms. Freddie Gray (chair-elect) has been essential. Dr. Sade Kosoko-Lasaki and I have closely collaborated in all aspects of proposing CPHHE to Creighton University Medical Center and in functioning as co-executive directors. Dr. Henry Lynch has been vitally important in leading CPHHE's initial cancer focus. Ms. Reba Donahue has provided invaluable assistance in her full-time and multiple roles with CPHHE.

[vi] MHRC. Minority Health & Health Disparities Research Center. <http://mhrc.dopm.uab.edu/>. (We are especially indebted to the director, Dr. Mona Fouad, who has visited Creighton University Medical Center, given wise counsel, and been very receptive to having Creighton faculty and CPPE Board Chair visit Birmingham and learn from many experienced MHRC personnel. Also, Ann Smith, MPH, of MHRC, continues to be very helpful in multiple intersections with the UAB Center). MSM. Morehouse School of Medicine. (We owe significant thanks to Dr. Dan Blumenthal who both came to Creighton and hosted faculty in a visit to the medical school in Atlanta.)

Fulbright Senior Research Fellow Visits CHPE

by Helen Shew, MBA

Dr. Rajib Dasgupta, Associate Professor at the Center of Social Medicine & Community Health at Jawaharlal Nehru University in New Delhi, India visited the Center for Health Policy and Ethics (CHPE) on February 24th and 25th. Dr. Dasgupta is currently a Fulbright Senior Research Fellow and Visiting Associate Professor at the Johns Hopkins Bloomberg School of Public Health. He visited Creighton as part of the Fulbright Occasional Lecturer Program.

While at Creighton, Dr. Dasgupta presented talks with a global health emphasis tied to his research. On February 24th he presented “Child Health Equity in India: Crying for Attention” as a Community Forum. This topic, the basis for his Fulbright research, examined how the importance of healthy early child development is universally recognized. Yet, its determinants are far too often considered as separate “variables,” particularly in standard frameworks of quantitative analyses. Healthy development is a product of biological factors as well as social and cognitive stimulation. The emergence of life course epidemiology and a social determinants framework have highlighted that parental socio-economic position is a powerful predictor of health in adult life. According to Dasgupta, such analyses pose methodological challenges, requiring data sets that often have repeat measures of exposures and/or outcomes and offer an opportunity to examine and understand dynamic processes and locate sensitive or critical periods in early child development.

Dr. Dasgupta also presented a CHPE Roundtable entitled “Polio Endgame: Focusing on Social Determinants” moderated by CHPE Faculty Affiliate Dr. Archana Chatterjee. Dasgupta shared how a major challenge to the success of the Global Polio Eradication Initiative (GPEI) is the reintroduction of wild poliovirus from the remaining endemic countries (including India) into polio-free countries and countries that are rapidly becoming polio free. He pointed out that social determinants of program implementation have not received the attention that they deserve and may be a ‘game changer’.

Dr. Dasgupta’s visit to CHPE provided networking opportunities around areas of common interest for undergraduate and health sciences students and Creighton faculty alike.



Amy Haddad, Rajib Dasgupta and Archana Chatterjee

Thursday Tea – A Treasured Tradition

by Kate Tworek

For more than a decade, the faculty and staff of the Center for Health Policy & Ethics have been gathering every Thursday at 2:15 for a cup of tea, a cookie, and conversation. We take turns setting the table and making the pot of tea. Sometimes colleagues, family, or friends join us for tea. We also use this opportunity to celebrate birthdays and other milestones. You won’t find cucumber sandwiches or scones at our teas, but you *will* find an assortment of cookies and a fresh pot of tea. And you will always find a warm welcome. The CHPE weekly tea is a treasured tradition. Do join us sometime if you happen to be in town.



***German Scholar Visits CHPE on International Exchange Program
by Helen Shew, MBA***

Lutz Schuetze, a master degree student of nursing science at the Philosophisch-Theologische Hochschule Vallendar in Germany, visited the Center for Health Policy and Ethics (CHPE) the week of March 21st. He was in the US as part of the international exchange program sponsored by his home university. Schuetze's mentor, Professor Dr. Helen Kohlen, visited CHPE under this same program in July of 2005. This exchange program allowed Schuetze a three week stay in the US to further his research, a comparative study on research ethics in the US and Germany. Prior to coming to Creighton, he spent a week each at Boston University and the University of Iowa.

During his stay at CHPE, he presented a roundtable entitled "Nursing Ethics in Germany" moderated by Dr. Susan Tinley, CHPE Faculty Affiliate and Associate Professor, School of Nursing. This roundtable included an overview of the continuing development of the professionalism of nursing in Germany where traditionally nurses have been seen as caregivers only and not as researchers, as evidenced by the fact that in all of Germany there is only one Institutional Review Board (IRB) for nursing research. Schuetze views the incorporation of ethics into the nursing curriculum as a key step in furthering the professionalism of the discipline.



Sue Tinley, Lutz Schuetze, and Amy Haddad

In addition to completing his master studies, Schuetze teaches courses in nursing and is a member of the hospital ethics committee at Klinikum Region Hannover, a medical center in Germany. As in the US, hospital ethics committees (HECs) in Germany focus on ethics consultation, ethical guidelines, education and advanced training, and institutional ethics. At the Hannover hospital, the HEC is a very interdisciplinary team which brings a varied perspective to complex situations. In his role as a member of the HEC, Schuetze is proactive and makes himself regularly available for a cup of coffee and a chat particularly with nurses who may not otherwise feel empowered to bring a potential ethical problem to the attention of the ethics committee. The discussion at the roundtable as well as more informal discussions throughout the week of his stay were very enlightening and engaging for faculty and staff alike.

Medicine? Photography? Why not both?

by Roberta Sonnino, MD

Contributed Service Faculty at Center for Health Policy & Ethics

Medicine is both a science and an art, but few would take this concept so literally as to include the *art of photography* as a legitimate component of a medical career.

For me, the two have always been inextricably linked. As an academic pediatric surgeon, I have always had a camera close by, usually for the purpose of documenting unusual findings for teaching or for scientific publications. Over the years, especially as high quality, tiny pocket-sized digital cameras became available, this evolved into literally having a camera in my pocket at all times... and we know that having a camera available is the first rule of getting good images! So inevitably, the camera, so conveniently at hand, would be called into action ever more often when a patient made a funny face, or just because the babies we cared for were so cute.

At first it was just for fun – after all, “film was cheap”, and digital images even more so. My pictures would be used for teaching and documentation, but it rarely occurred to me to offer them to the patients and their families. A few received a print as a “thank you” when they allowed me to use images of their children for my first photography exhibit “Fragile Beginnings.”

Then came a turning point in my career, both as a physician and a photographer. As my newborn patients thrived and grew older, families would contact me, years after I had treated their child, to see if by chance I had some images of their baby during those difficult days and nights in the neonatal intensive care unit (NICU). The time parents spend with their children in the NICU is difficult and emotional. Most families are intimidated by the highly intense, technical setting, and do not usually feel comfortable taking pictures, even if they do have a camera. Yet months and years later, they think back on how far their child has come, and they often wish they had more documentation of those difficult days, now thankfully a distant memory. Most of the time, I am able to provide a few snapshots - certainly not masterpieces. But I learned something very important in that process. The impact of these pictures on the families, and the children themselves, once they are old enough to appreciate their significance, is extraordinary. They provide healing and closure on a difficult time in the child's life.

A few years ago, I retired from clinical practice, having taken on a full time administrative position in the medical school. But I missed the opportunity to play a role in the lives of these tiny patients. Remembering how much the photos of newborns, especially those requiring prolonged NICU stays, were treasured by the families, I decided to start a project I called “NICU Rounds.”

For a premature baby or a newborn that has undergone major surgery, leaving the NICU to go home is a very special moment and an incredible gift to the parents. It became obvious to me that a photographic journal of their baby's NICU stay would be a treasured gift to these families. So a few years ago, I started making “rounds” in the NICU once a week, photographing every baby in the unit. We obtained written consent to take pictures. Despite my having no doctor-patient relationship with the babies, and therefore not knowing these families, the consent was always signed promptly and gratefully. After discharge, a small album was assembled with a few images from each week the baby was in the hospital, and the album was sent to the family. The response has been uniformly of wonder and gratitude. I continue to be amazed at the deep impact of such a small thing!

The baby pictured in *Sleeping Beauty* was born prematurely, but had grown well during her NICU stay, and had reached her day of discharge. Her mother had been staying with her around the clock to get used to her care, and all had been proceeding well - except for burping. The baby was simply not interested (although she did enjoy all the back patting that went along with the efforts), and by far preferred sleeping to any other post-prandial activity. After a gentle but futile battle of wits with her newborn daughter, the mother finally gave in and allowed the baby to settle down and take a nap in the most accessible and convenient location that presented itself – the palm of mom's hand. I had been taking my weekly pictures of the child, so I happened to be right there and was fortunate to capture this precious moment in her life. This picture, with an accompanying “Artist's Statement,” was recently published on the cover of the main journal for the medical education community, *Academic Medicine*. The cover and article can be found at: <http://journals.lww.com/academicmedicine/toc/2011/01000>



Sleeping Beauty

At some point, I decided that once my medical career was over, I would become a professional photographer, specializing in medical and children's photography. One final experience sealed this plan. A friend heard about an organization called “Now I Lay Me Down To Sleep” (NILMDTS) and encouraged me to find out more about it.

NILMDTS is a non-profit organization dedicated to infant bereavement photography. When there is a stillborn baby or a newborn that is not expected to survive and leave the hospital, their members are called to do a professional portrait session with the baby and the family, at no cost. The organization was born out of the chemistry between a mother who lost a baby and the photographer who agreed to go to the hospital to take baby and family portraits for them. I joined the organization in 2006. My work was reviewed and I was formally accepted as a professional photographer. I have since done over 50 sessions. The true impact on the healing of these grieving families has not been studied yet, but anecdotally it is huge. The child they have lost remains forever a part of the family through the photos we provide. As a physician, I am often called to explain, in lay terms, what happened to the child. I find myself helping photographers I have never met cope with the experience of seeing and photographing a dead child, something I have experienced many times, but that is very foreign to them.

As a result of these experiences and the encouragement of some master photographers, I recently took and passed the exam to become a CPP (Certified Professional Photographer), in essence, photography "boards." I still must submit a portfolio of 20 images that fulfill specific criteria before I can add the CPP title after my name. Only about 2500 photographers have completed the certification process – I am halfway there.

So here I am, a medical school administrator, retired pediatric surgeon, and a photographer. Somehow they all seem to fit together. Through my photography I have been able to teach my students the importance of humanism in medicine, I have impacted the patients and their families, and my own practice. Through NILMDTS, I can provide comfort to families that cannot be helped by medicine. To me, the art and science of medicine are intertwined and best illustrated by the images I make.

More on NILMDTS at <http://www.nowilaymedowntosleep.org/>

CHPE Joins Creighton Colleagues at All Things Ignatian Poster Presentation

by Amy Haddad, PhD

In the fall of 2010, Fr. Greg Carlson along with Creighton's Jesuit Community invited individuals across Creighton to create posters representing initiatives that implement the University's Ignatian mission. The All Things Ignatian Committee members Greg Carlson, S.J., Mary Higgins, Rebecca Murray, Susan Naatz, Patty Perry, Tom Purcell, Marcia Shadle-Cusic and Ron Volkmer encouraged Creighton colleagues to look at the work of their departments for examples of innovative projects grounded in and highlighting Ignatian values in action. The committee set out the following objectives:

- stimulating creative thinking about how to be more Ignatian in our activities by observing what we see others doing in theirs;
- celebrating and affirming the breadth and depth of what we already do at Creighton that is authentically Ignatian;
- putting people in touch with those who already have experience with and thought about how to blend Ignatian considerations with academic and other actions; and
- cataloguing existing Ignatian initiatives at a university that is an acknowledged leader in such initiatives.



Fr. Melville, Fr. Carlson, Amy Haddad

To facilitate the process, the committee provided guiding questions, a choice of two templates, and the Jesuit Community covered the cost of printing the poster. Questions a presenter could answer on the poster included: "What do you do? How does it fit Ignatian values? How have you taken the challenge of Creighton's Jesuit mission and put it into action?"

At CHPE, recent events in partnership with various community groups seemed like a perfect fit. CHPE Director, Amy Haddad, and Helen Shew, Programming and Community Outreach Coordinator, worked up the text and photos for a poster entitled, *Connecting Community & Scholarship - Center for Health Policy & Ethics Connects Scholars with Community Members*. The poster detailed how CHPE and community partners from North Omaha met to look for increased opportunities for collaborations and enhanced responsiveness to current ethical issues in health care and policy. This campus/community collaboration hit upon the idea of asking visiting experts to present not only to the Creighton community but to the larger community as well. The intentional and consistent efforts of CHPE and its community partners to bring highly qualified experts in their fields to the community have resulted in a mutuality of benefit and purpose for partners. These initiatives also fully support CHPE's maxim "Anchored in ethics, reflecting Jesuit values" and two of CHPE's Statements of Purpose: Fostering intellectual exchange in solidarity with the human community and advancing an ethic of service, justice, and compassion for others.

The response from the Creighton community to the All Things Ignatian poster session invitation was exceptional. On February 3, 2011 sixty-eight colleagues presented posters describing their initiatives. You can view the posters at <http://www.creighton.edu/allthingsignatian/>. You'll see a number of posters presented by CHPE's Associate and Affiliate faculty. The following clip features Fr. Carlson's perspective on the All Things Ignatian poster presentation and an interview with CHPE faculty member Jos Welie on his poster showcasing the Creighton University Faculty Seminar on Jesuit Higher Education in the 21st Century. <http://www.youtube.com/watch?v=gi1Ah7ihxHc>

***Dr. Richard L. O'Brien Promoted to University Professor Emeritus
by Marybeth Goddard, MOL***

Each year Creighton University commemorates its founding with a series of events during Founders Week, several of which honor students, faculty and administrators who make significant contributions to the University. This year, Father John P. Schlegel conferred upon Dr. Richard (Dick) L. O'Brien, who is a current Center for Health Policy and Ethics faculty member and was integral to the founding of the Center, promotion to University Professor Emeritus.

After graduating from Creighton University Medical School, Dr. O'Brien, his wife Joan, and their four children moved to California where he was a faculty member at the University of Southern California from 1966 to 1982, attaining the rank of professor and, at the time of his leaving, serving as Director of the Kenneth Norris Jr. Cancer Center and Research Hospital. Dr. O'Brien and his family returned to Omaha in 1982 when he was named Creighton University's Dean of the School of Medicine and Professor of Medicine and Microbiology. Dr. O'Brien was promoted to Vice President of Health Sciences in 1984 and served in that capacity until 1999, when he became a professor in the Center for Health Policy and Ethics.



In February 2008, Dr. O'Brien was honored for 25 years of service to Creighton University in his capacity as Dean of the School of Medicine, Vice President of Health Sciences, and University Professor in the Center for Health Policy and Ethics.

Recently, Dr. O'Brien was appointed by Dr. Rowen Zetterman, Dean of the School of Medicine, to oversee the Liaison Committee on Medical Education (LCME) Accreditation process for the School of Medicine.

Dr. O'Brien states, "My career, and my intellectual development, has followed a trajectory of steadily increasing scope, from the deep reductionism of enzyme chemistry and molecular biology to the synthetic examination of human systems and behavior. Though sometimes put in the background by heavy academic administrative and leadership responsibilities, the path has continued unbroken and in the same direction. I am particularly proud of graduate and medical students of mine who are following this same trajectory of growth."

Congratulations, Dr. O'Brien, and thank you for your service and dedication to Creighton University!

***CHPE Faculty Associate Appointed to Inaugural Chair
by Marybeth Goddard, MOL***

Rev. John P. Schlegel, SJ, President of Creighton University recently announced the appointment of Dr. Gary H. Westerman, Professor and Chair of the Department of Community and Preventive Dentistry, as the inaugural chair holder of the Dr. Philip Maschka Chair for Ethics in Dentistry. This appointment is for a three-year term that may be renewed for an additional three years.

Since February 2000, Dr. Westerman has occupied the Dr. Oscar S. Belzer Endowed Chair in Dentistry. In acceptance of the Dr. Philip Maschka Chair for Ethics in Dentistry, Dr. Westerman has resigned from the Belzer Chair. Dr. Westerman has been a Faculty Associate in the Center for Health Policy and Ethics since the fall of 1998.

Congratulations, Dr. Westerman!

