



Social Inequities Worsened by Stigma: The Experience of Women with Epilepsy in Zambia

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Social scientists have long been interested in stigma and its causes, consequences, and many manifestations. Interest in stigma-related research has expanded substantially in light of the HIV/AIDS epidemic, as care-seeking and risk-taking behaviors related to HIV/AIDS are heavily influenced by the burden of stigma. Stigma accentuates inequities and disparities because it is most aggressively directed at the socially disenfranchised and disempowered. Stigma research has characterized stigma as *enacted* versus *felt*. Enacted stigma is any form of distinction, exclusion, or restriction affecting a person by virtue of some character she/he possesses. In contrast, felt stigma is fear of enacted stigma. One might consider enacted stigma to be a form of discrimination and felt stigma a process of self-imposed limitations related to fear of this discrimination.

Prompted by a 2003 National Institutes of Health Fogarty International Center initiative aimed at encouraging studies of stigma, a collaborative team of researchers from MSU and Zambia acquired funding to study epilepsy-associated stigma in Zambia (EASZ). The EASZ study team conducted both qualitative and quantitative assessments to try to understand as completely as possible the social and economic impact of living with epilepsy in the Zambian environment. Sadly, but not surprisingly, Zambian women were found to bear the greatest burden of disease-related stigma--further confirming that power differentials accentuate the distribution and expression of stigma. Although we anticipated that women with epilepsy (WWE) would be disproportionately burdened, we weren't prepared for the full extent of what it means to be a woman with epilepsy in Zambia. Even those of us who have delivered epilepsy care in Zambia for years were overwhelmed by this reality. For many women with epilepsy, the burden associated with the stigma far outweighs the medical burden of the disease.

Epilepsy is a neurological disorder characterized by sudden recurrent and unprovoked seizures. Seizures can be associated with abrupt loss of consciousness, tongue-biting with oral bleeding, loss of control of the bladder or bowel, and sensory or psychic malfunction. Biblical references to seizures often attribute them to spiritual possession. Similar beliefs still predominate in Zambia where much of the population believes that seizures are due to witchcraft, spiritual possession, or a curse from God. Moreover, contagion beliefs (i.e. the fear that one can "catch" seizures) prevail. Epilepsy is the most common life-threatening neurological disorder among adults in Africa and the second most common among children. It is over 10 times more prevalent in Zambia than in the U.S. Of the more than 50 million people worldwide with epilepsy, 80% of these individuals live in developing regions of the world.

Blaming the Victim

In the focus group discussions that took place at both rural and urban sites as part of the EASZ research, an enormous burden of enacted stigma aimed at women was noted. Initial discussions with traditional healers in the region revealed that when faced with a man with epilepsy, healers commonly attributed the condition to being “bewitched” because someone was jealous of the man and/or his success. In women, healers usually attributed seizures to “bad behavior” or wrongdoing. Blaming the victim is one common mechanism whereby stigma is worsened and in Zambia it begins as soon as people seek care from their local healer. Healer’s attribution usually stick with epilepsy sufferers and some even seemed to accept blame for their medical condition.

Fear of Assault and Exposure

We found that the lives of WWE are informed by fear. In traveling to participate in the focus group discussions (FGD), they worried about possible injury during a seizure, feared assault or abduction, and were concerned about broken taboos regarding exposure of others to bodily fluids. One FGD participant stated, “When I am in an attack I may be found by a stranger and I may not even be decently covered. Then everyone knows of your problem and you are shamed.” Local taboos prevent anyone except a relative in the matrilineal line from being potentially exposed to ones body fluids (urine, feces, or vomit). So women with epilepsy not only require a traveling companion to feel safe, but are limited in who could potentially assist them if they experienced a seizure. This fear of traveling was a key deterrent for health-seeking among women with epilepsy who were interviewed.

WWE also worry about the possibility of being sexually assaulted. Many women with epilepsy have been abandoned by their families and spouses. Those without a male “protector” felt themselves to be at high risk of rape, with no consequences for the perpetrator. Traditionally, if a woman is raped by a known assailant, her husband or father’s brother will seek financial retribution through the local headmen and this is seen as a strong deterrent. But without a male protector, a woman considers herself extremely open to sexual assault. Indeed, we found these fears to be all too well grounded. In a case-control study comparing women with epilepsy to women with a non-stigmatized chronic disease matched on age and source of care, we found 20.2% of WWE reported incidents of rape compared with 3.3% of the control group. The astonishingly high prevalence of rape experienced by women with epilepsy has even more sinister and far-reaching implications for individuals and communities in light of HIV rates of almost 30% among people 15-49 years of age.

Family Response and Domestic Responsibilities

The family’s response to WWE is often heart wrenching. Some family members are supportive, but many routinely rejected the individual. “If someone is bewitching you, better they should just kill you,” was what one WWE was told by an uncle shortly before he chased her from the compound. There were many reports of physical abuse, and WWE in urban settings were sometimes “sent back to the village,” ejected from their homes when their families feared the landlord would eject the entire family. “My father took care of me and protected me from my mother and brother. But since my father died . . . God has abandoned me.”

In terms of domestic responsibilities, safety issues limited what WWE could or should do. In rural settings, family members rely on one another to complete the daily chores necessary for survival, such as cutting firewood, fetching water, and growing food, and women traditionally complete the bulk of these daily tasks. Labor is divided among all members of the extended family, and the social value of an individual is in part determined by her/his ability to participate

in this unwritten agreement. But for WWE it can be risky to draw water, work over an open fire, travel into the bush for firewood, and care for small children alone. Some WWE continued these duties and lived in constant fear of seizure-related injury. Others were forced to relinquish these tasks, with great loss to their self-esteem and self worth. "This disease has caused me a lot of problems. I can't walk around freely. I can't cook because of the fire. I am not free to do things since at any time I could have an attack. I am not even free in my own home. I can't go to draw water alone. I can't bathe alone. All diseases hurt, but this one has really affected my heart."

Marital Issues and Childbearing and Rearing

WWE are significantly more likely to never marry or be divorced/widowed and never remarry. If unmarried before the onset of epilepsy, WWE were faced with limited potential partners due to gossip. "Most of my problems are due to people talking a lot about me. I would like to marry again, but whenever someone shows interest, people talk to that man, and tell him about my problem and so I haven't had any offers of marriage." A woman's status within a marriage is influenced by the *labola* or bride price that her husband had to pay for her. One WWE reported residing with an old man who frequently beat her. She had been "given" to this man by her brother who stated, "Just take her. She has no value for us."

WWE who were married when the seizures began reported high rates of spousal abandonment. Children were often taken from them, or women were left with the children and no financial support. If the marriage had not produced children, the *labola*, if originally paid, was often reclaimed by the husband's family. For those women whose spouses remained, they were terrified of being abandoned. "I had a seizure on the way to clinic. My children had to go back to the village for help and my family had to come and collect me with a scotch cart. My husband says he won't divorce me as this problem started after we were already married, but one day he will tire of this and leave." Said another, "If others know of my condition, they may tell my husband to leave me. I didn't ask for this problem. People don't realize that I didn't ask for it. Maybe God should take my life away."

There is a basis for this fear of abandonment and isolation. "In 2001, my husband divorced me because of my seizures and my child was only 1 year old at that time and my husband took my child when he left." In addition to worrying about losing their children, WWE fear seizures during pregnancy, passing the condition on to their child, or injuring the child during a seizure. Some women began to doubt themselves. "We (WWE) should not have children. The seizures can get worse when we are pregnant and the work of being a mother can also worsen this problem." WWE can be so marginalized and isolated that they doubt their ability to care for their children. "And maybe one day I will get angry and drop my baby. What kind of mother cannot care for her own child? I don't want relations with my husband and I might hurt my own child during a fit. Maybe one day I will just find my baby dead because I threw her away."

WWE in polygamous marriages were provided less financial support (food, material goods) and reported feeling humiliated by "not being visited" by their husbands. "My husband supports me. But since he took a second wife he never lies with me. My husband's family and the second wife are afraid that she will get this condition from me. They think my condition shames the family. People tell my husband he should abandon me. Sometimes I drink."

Employment Issues

Lack of financial contribution to the family unit can have significant consequences for WWE. If abandoned by family and/or spouse, many were left with few options. WWE reported higher rates of transactional sex for survival goods, at 14.3% versus 2.2% of the control group. Job status and classification are also significantly lower for WWE: 23.7% of housewives with

epilepsy had no other job, compared with 16.6% of women in the control group. In rural settings, WWE faced safety concerns in the work they did, as they couldn't work with heights, fire, or near open bodies of water. For women who worked as paid farm laborers, productivity was decreased due to intermittent seizures and drug side effects. If they experienced a seizure at work, WWE expected to be fired, and usually were. "My marriage has changed. I don't work now and cannot bring home money like before and because of my epilepsy I can't find work . . . because my condition is known, no one will hire me." For those working in the marketplace, once their condition was "known," people would not buy their goods, possibly due to contagion fears.

Rejection by the Greater Community

The rejection WWE experience within their family units is repeated in the larger community settings. Often taunted by children, WWE reported that no one is willing to "visit" them, that children are told not to "even take water" from them. "In town there was too much talk and even the children ridiculed me there. Even the children in town disrespected me and I cried a lot. I became so sad that I could barely force myself out of bed to do my duties." During the shared midday meal that was part of each focus group discussion, some of the women wept at being included because at home they had not been allowed to "share the cooking pot" since their seizures began. "Because of the epilepsy people won't sit next to me. Even my family has rejected me."

Before conducting the EASZ study, we knew that epilepsy-associated stigma affected health-related quality of life. What the EASZ data so keenly illustrates is the extent to which *all* aspects of life are affected, for the individual and the entire community, and that the burden of stigma rests heaviest upon those already burdened by social and economic inequities. As bleak as these facts and the findings of the EASZ study and previous research are, the prognosis for solutions does suggest reason to be optimistic. In May 2007, the EASZ team will be submitting another proposal to NIH--this one for initiating a multi-pronged intervention program involving structural improvements in healthcare, a stigma reduction program with teachers, and the empowerment of women with epilepsy through education and community activism. Our aim is to improve the care received by people with the condition, benefiting overall quality of life for individuals and their communities.



Study Abroad in Ghana: A Path to Cultural Competence

by Connie Currier, Renee Canady, Denise Saint Arnault

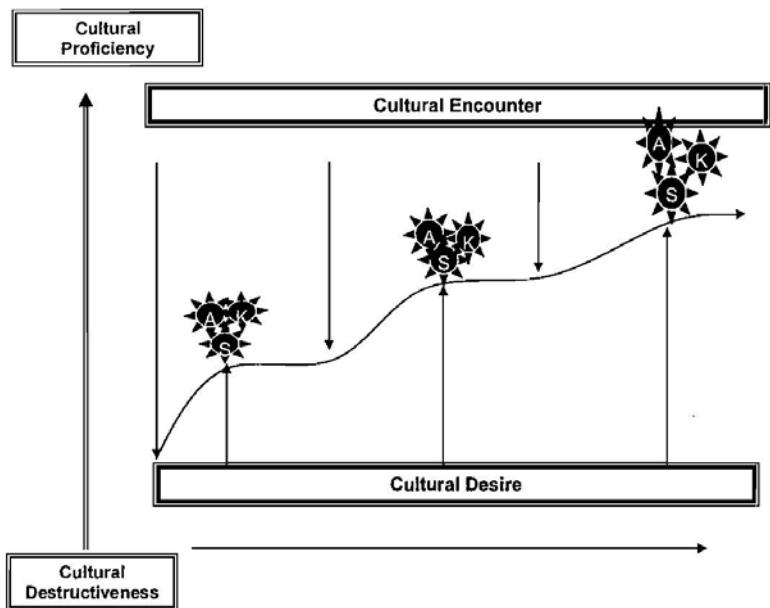
College of Nursing

As the world becomes increasingly “globalized,” U.S. health care providers need to understand health issues outside of our borders and develop skills to interact with patients in a culturally competent manner. A male physician who is culturally unaware might not understand why his repeated attempts to establish eye contact with a veiled female Muslim patient and efforts to communicate treatment options to her were met with a lowered gaze and responses from her husband. Yet understanding the cultural dynamics of this exchange is exactly what is required for the successful patient-provider relationship. Increased access to care and reduced health disparities are also directly related to cultural competence, and it is likely that health outcomes will be linked to cultural competence.

Faculty in the College of Nursing (CON)--Canady, Saint Arnault, and Vinson--have proposed a new integrative model for the development of cultural competence (CC). Though CC content can be included in theory courses and clinical experiences for students in the U.S., study abroad courses provide a unique opportunity for health professions students to develop CC. CC can be defined as the ability to use culture in the resolution of a human health need.¹ The CON CC model integrates the models proposed by Campinha-Bacote (1994) and Cross et al. (1989). In the CON model, self awareness (A), cultural knowledge (K), and cultural skills (S) are considered to be dynamically interactive. The cultural encounter is the context through which these components interact. What fuels the student toward increasing levels of competency within the context of cultural encounters is known as cultural desire. In other words, cultural desire represents the motivation of the clinician/student to proceed with the difficult work of self-reflection, study, and personal change because this work is inherently worthy and meaningful. Cultural desire is necessary prerequisite for CC, as it emerges from a spiritual or ethical imperative that provides the energy source and foundation for one’s journey towards CC.

The developmental nature of the integrative model is evident in Figure 1. The process of learning in this model is set along the X axis and movement along the developmental trajectory is set along the Y axis. The model suggests that there is movement both through time and up the continuum toward the CC outcome. As students progress along the continuum, there is the expectation of greater and more sophisticated comprehension and application across advancing levels of self awareness, cultural knowledge, and cultural skill.

Figure 1. MSU CON Cultural Competence Model



In the modified CON Model (Canady, Saint Arnault, Vinson and Currier), six intersecting aspects of the cultural encounter are proposed to increase CC. The intersecting aspects are measurable and quantifiable, and characterize the *nature of the encounter* through the following: 1) length of the encounter; 2) regularity and nature of contact with home country nationals (as opposed to host country nationals) during the encounter; 3) level of cultural immersion during the encounter, and *country characteristics* (including numbers 4-6); 4) socioeconomic congruence between the encounter site and the site of student origin, in this case the U.S. 5) cultural congruence between the encounter site and the student's country of origin, i.e. "cultural distance"; and 6) need to learn a new language. Study abroad experiences provide an ideal case for investigating the developmental process of CC attainment in nursing students. With this framework as a backdrop, the study abroad program, *Ghana: A Multidisciplinary Perspective*, lends itself particularly well to evaluating this integrative model. The potential for personal growth is greatest during those times when we are most vulnerable and uncomfortable with our circumstances, or as Mezirow (2000) would say, when we are presented with a "disorienting dilemma" that causes us to question our beliefs about the world. Therefore, exposing students to the health disparities that exist in a developing country such as Ghana, combined with the ability to critically reflect on and analyze the experience, provides a unique opportunity for personal growth that contributes to the development of CC.

Ghana: A Multidisciplinary Perspective

Ghana: A Multidisciplinary Perspective, a 6-week long, summer study abroad program, was offered for the third time in summer 2006 to 15 students: 10 were nursing students, one was a premedical student, and four were students from other disciplines. Every year, the program is offered in two sessions. For the first three and one-half weeks, students take four credits of one of the following three classes: Integrated Arts and Humanities – Area Studies and Multicultural Civilizations (IAH 211A), Integrated Social Sciences – Africa: Social Science Perspectives (ISS 330A), or Journalism (JRN 490). The goal of all of these classes is to learn about Ghana's

historical, social, political, economic, and cultural environment in a historical context. For the remaining two and one-half weeks, students enroll in Health Care in Ghana (NUR 429) for 2 credits. This course provides an overview of health status indicators and determinants; major health programs and strategies; organization of the health care system; access to and payment for care; role, image and status of health care providers; and the interface between Western and traditional medicine in Ghana. Students are encouraged to compare and contrast the Ghanaian health system with that of the U.S. and, importantly, to withhold judgment--to understand that there is nothing "bad" or "wrong" with what Ghanaians believe, their beliefs are just *different*.

Nature of the Encounter

The CON model proposes that 1) the longer the study abroad program, 2) the more opportunities the student has to be immersed in the culture, and 3) the more independent time a student spends traveling and interacting with host country nationals unaccompanied by home country instructor, the more readily the student will progress along the CC developmental continuum. Students spend six weeks in Ghana--not a full semester, but longer than most MSU summer study abroad programs. While in Ghana, students reside in a guest house in the capitol, Accra. Residents of the guest house are predominately Ghanaian, and the atmosphere is informal, allowing students to interact frequently with Ghanaian residents and staff. Throughout the program, students participate in field trips that expose them to historical, social, political, and cultural experiences including visiting museums, slave castles, traditional healers, local bead makers, craft villages, traditional dancing, and more. Students also spend three days participating in a journalism internship experience.

The program concludes with students having the opportunity to live for three days in the rural village of Danfa. During this time students interview Ghanaian nationals about their beliefs and practices related to health and illness. Health disparities between urban and rural Ghana and between Ghana and the U.S. are readily apparent. Students experience firsthand life in a small, rural village, allowing them to apply what they have learned about Ghanaian health beliefs and practices to a new level of understanding. One student noted:

Today we met the fetish priestess, saw her shrine, and received a blessing from her...Upon seeing the bowls my initial thought was, "how silly, she worships bowls with bugs around them, I wonder what is in them." Soon after I felt really bad for judging this woman's religion. How is worshiping a bowl any different from worshipping a cross or a statue of the Virgin Mary?...From this experience I learned...that I need to be open to all the experiences I have here and not close myself off or dismiss other's beliefs as silly.

Students learn what "lack of access" to health care really means. While there is a health clinic in the village, there are numerous financial barriers to care. A young mother described the costs of her young daughter's recent clinic visit: 10,000 cedis for the clinic visit, 60,000 for the medicine--a total of 70,000 cedis or \$7.70--a prohibitive amount when the woman's daily income was only 10,000 cedis or \$1.10. This same mother had a cloth wrapped around her leg, providing coverage for a quarter-sized suppurating ulcer. She explained that she didn't have the money for treatment. Realizing that the mother would sacrifice her own needs to provide for those of her daughter gave the students a greater appreciation for the dynamics of "access to health care" in this family. Although the mother's treatment would cost only \$8.00, it represented 25% of her monthly income.²

Ample independent time for students to explore Ghana on their own, without the continuous supervision of their instructor, is important. This independence gives students the freedom to interact with the local people as much as possible and contributes to their understanding of the culture. On one occasion, a group of students made a weekend trip to the town of Winneba, about 75 kilometers outside of Accra. "It was a bus ride unlike any I have experienced before," said one student. "At the beginning of the bus ride, a man stood up and asked us to pray...for the safe trip of the bus and all the people on it....Ghanaians seem to have many traditions and practices that while small, do help the people to feel united and close to one another. Not to mention the fact that praying for the safe trip of a bus is one of the many prominent displays of religion here in Ghana." This experience made the student reflect upon American culture and what she described later as the lack of clear practices and traditions in the U.S. because of the blending of so many cultures. This is a common reaction among students and appears to occur repeatedly after approximately four weeks in the program. Students observe the many facets of Ghanaian language and culture and begin to question their own cultural identity: "Why don't we have any 'culture' in the U.S.? Why don't we learn special dances in school? What traditions do we have?" These queries provide a critical "teachable moment" and a wonderful opportunity for directed journaling and values clarification assignments.

Country Characteristics

The CON model proposes that students' values and perspectives are more likely to be challenged the greater the socioeconomic differences between the student's country of origin and the host country, the greater the "cultural distance" between the two countries, and the greater the need for bilingualism. If the student is required to learn a new language in the study abroad country, the more likely the student will be further propelled along the cultural competence continuum. Language is like a window to another culture, and learning a language opens doors in many unexpected ways. Although students are not required to learn another language while in Ghana since English is the official language, students learn basic greetings in Twi, a commonly spoken dialect in the southern part of the country. While traveling, students often mention how excited Ghanaians become whenever they try to speak Twi and that it is evident how proud Ghanaians are of their language. Students' efforts are often rewarded with long conversations that lead to a better understanding of both the Ghanaian people and their culture.

It is readily noted that Ghana is economically distinct from the U.S. As of 2004, the gross national income per person in Ghana was \$2,280, whereas in the U.S. it was \$39,710. While in Ghana, students are forced to live in conditions to which they are unaccustomed and they lose access to many of the daily amenities we take for granted. One student commented in her journal: "These things have made me realize how much I really take water for granted. Simply being in Ghana and going places where there is no sink or the water gets shut off at a certain time helped me to realize the luxury I have of water a little bit."

Differences in cultures have been analyzed by individualism or collectivism related to behavioral priorities and values, and along vertical or horizontal dimensions related to social structure/organization (Triandis, 1999). Based upon these criteria, the U.S. could be considered a Vertical-Individualistic society and Ghana could be considered a Horizontal-Collectivist society, making these two societies culturally "distant." Traditional, agricultural-rural cultures where individuals define themselves as part of a group, relationships are of greatest importance, and social behavior is often predicted by norms and perceived duties and obligations tend to be collectivist. Cultures that are marked by equality and a strong sense of cooperation tend to be horizontal. While conducting interviews in the village, students commented on their observations of the role of women noting that they were doing all of the cooking and cleaning, taking care of

the children, fetching the firewood, and so on, and that men did not participate in these activities. One student wrote, “it is a different culture here in Ghana, and the men and women’s roles are very different than in the U.S. It is hard to understand when you have been taught for so long about values and ways of life. I am keeping an open mind about Ghana and I hope to be able to understand the culture better.” Students observed and learned about collective village-based activities, for example community gardening efforts to support the local primary school. These experiences force students to examine their values in comparison to those of another culture. Moreover, they challenge students to form an opinion about the values and principles they live by, or want to live by, and what they truly believe to be important.

The Ghana: A Multidisciplinary Perspective study abroad program gives students tremendous insight into privilege, vulnerable groups, and how culture and socioeconomic status affect health:

Learning all that I have about when and how people seek care has changed how I look at health care. As the theme of this trip, Americans have a “just do it” mentality. Being here has shown me *that things are not always so simple*. In America you get an infection from germs, you go to the doctor, you get an antibiotic, and that is that. Here, with cultural beliefs, lack of access and resources ...getting health care is a far more complicated thing than at home.

Going to Danfa made me realize how difficult it is to change how people view healthcare or how they view being healthy. It is easy to say, well just clean up the trash, just make sure there is no standing water because that will prevent malaria, or just wash your hands. Ghanaians...have been living this way for hundreds of years and this is what they know.

Students learn that the factors that contribute to health disparities and efforts to eliminate them are, in fact, very complex. Students state they have become more adaptable, better able to converse with others, more flexible, more open-minded, and more humble as a result of studying abroad. One student said, “I have changed in many ways since coming to Ghana. One important way is a heightened sense of others and their perspective. The idea that just because we do something one way doesn’t make it the right or only way. I think this *awareness* will help me in society to deal with several viewpoints.”

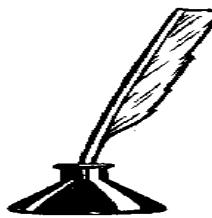
It is clear from anecdotal comments, conversations about the program, and journal notes that the Ghana study abroad program has a profound impact on students. It is a transformational learning experience that often leads to a change in students’ worldview. This cross-cultural encounter challenges students to question their values, their lifestyle, their own culture, what their home country represents, and their role in the world. The length of this program, combined with the independence it grants, and the characteristics of the host country, result in a profound and life-changing experience for students. The program forces students to consider disparities in health and health care in Ghana, in the U.S., and between the U.S. and Ghana. The facilitation of the development of CC for health professions students will ultimately benefit their future practice and their patients.

Notes

1. Adapted from James Green, 1995, 1989.
2. The woman’s treatment was paid for to thank her for participating in the group interview.

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Challenges to Identifying Best Decisions

by Celia E. Willis, Ph.D., R.N.
College of Nursing

Patient choice is receiving increased attention as a means of improving quality and outcomes of health care. Patient-centered decision supports are being tested to foster patients becoming well-informed and proactive users of health services. Initial efforts are underway to define the quality criteria to evaluate these tools, such as the IPDAS criteria mentioned by Holmes-Rovner, but these criteria lack “best” choices criteria. Holmes-Rovner identifies several key issues as potential barriers to identifying an individually-best decision: ethical debates about patient autonomy, difficulty in measuring personal values, and effective approaches to providing information with “pathways” to aid patients to make well-informed, best decisions.

Several challenges to identifying best decisions can be highlighted.

One issue is that there is often debate about the extent to which a best choice truly can be identified for an individual based on the gaps in existing research knowledge. This is particularly so for populations in which health interventions have not necessarily been well-researched, including populations for which marked health disparities exist. In this type of situation, it may be premature to recommend a best choice. However, best choices should be identified where they do exist. Where patients, health care providers, and the scientific evidence are strongly in agreement about what would be best to do, choices may be “easier” and not require formal decision support approaches.

A second issue is the urgent need (highlighted in the current evidence-based practice movement) for developing and testing translation models to guide the interpretation of scientific evidence for use in decision-making. The need for good translation, including making the central “take home” points of evidence understandable and usable, can apply to both clinicians and their patients. Holmes-Rovner addresses this issue as the proliferation of information and choices which can overwhelm decision makers and result in sub-optimal choices. Early versions of patient-focused decision supports have tended to be overly-complex, text- and number-dense, and not necessarily well-matched to the information preferences, literacy, cultural, and health constraints of a number of individuals. To make a meaningful impact with the populations that are often in the most need of empowerment in making choices, there is a need to “de-complexify” decision supports as appropriate to better match what individuals can and prefer to handle, to foster greater ease of use with less cognitive burden. Indeed *less can be more*.

A third issue is that the boundaries between informing and persuading are not always clear-cut. What should be the criteria for identifying a best choice for an individual, especially if the

situation appears almost too close to call? Formal decision analysis approaches have often been advocated as a means of sifting through complex decisions to arrive at a rational best choice option. However, decision analysis is only as useful as the data that inform the model, and cannot resolve some of the fundamental ethical questions about the extent to which patient autonomy should determine the choices that are made.



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Patient Choice, Rationality, and Cost-Effectiveness

by Tom Tomlinson, Ph.D.

Dr. Holmes-Rovner's discussion raises important questions about the relationships among empowering patient choice, enhancing patients' understanding of their options using decision support aids, and encouraging a more cost-effective health care system.

She's surely right to point out that we can draw no simple line from increased patient understanding, to more rational patient choice, to greater patient autonomy, to lower health care costs. A large part of the reason is that there are different kinds of "rationality" at work in each of these contexts. The rationality of cost-effectiveness aims to maximize aggregate population benefits against aggregate cost. The rationality of individual choice is focused on maximizing individual utility, the net of my gains and losses. A choice may often be rational for me, but at odds with what's most socially desirable. And the rational autonomous choice is something more than utility maximizing, since it aims to make the choice most consistent with those values and goals I hold dear. Most of us (sociopaths and economists excluded) are not mere utility maximizers. We care about more than our own self-interest, and often make fully autonomous choices that leave us worse off.

She's also right to be skeptical of the impact that enhanced patient understanding will have on cost-effectiveness. Any reduction in cost from greater patient understanding requires that patients' goals and values regarding treatment are often different than those that motivate their physicians' recommendations; and that the patients' goals and values tend to favor less resource use. There's not much reason to believe either of these is generally true, which is not to say they're never true. No doubt they partly explain the particular contexts in which patient involvement in choice has had an impact: hysterectomy; prostate screening and treatment; and the choice between mastectomy and lumpectomy. The impact of these decisions on sexuality and self-image is felt much differently by patients than by their doctors, and prioritized differently in deciding what choice is best.

The great bulk of medical treatment decisions are not like this, however. Most of the time, my priorities and my doctor's coincide. When they do, I'm not going to make any more cost-effective a choice than my doctor. And when they do I won't have much interest in exercising my autonomous choice, either. This is not to disparage the importance of respecting patient autonomy; it's only to focus its relevance. Respecting and enabling autonomy is most important where patient and doctor are most likely to reach different conclusions. The "failures" of patient decision aids may be just as important as their "successes" in mapping the geography of patient

autonomy. When we know better where to invest our efforts, and what to pass by, we will be more successful at both reducing costs through enhanced patient understanding and at empowering patient autonomy where it really matters.



Health Care Ethics and Ethics and Development

by Fred Gifford, Ph.D.

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This academic year marks the second year of MSU's Graduate Specialization in Ethics and Development. This specialization is housed in the Department of Philosophy, but draws both faculty and graduate students from departments across the University.

Via courses (including a new course, PHL 452, Ethics and Development), participation in brown bag discussions and other activities, M.A. and Ph.D. students are able to address collaboratively and in a philosophically sophisticated manner the difficult ethical issues that arise in the course of social, economic, political, and cultural development within an increasingly inter-connected global context.

Central questions include: What is development? What should be its goals? What obligations tie rich and poor countries? How should we handle problems of foreign aid, economic liberalization and gender equity, and agricultural biotechnology? These are related to more general moral questions concerning human rights, autonomy, community, identity, and justice.

Clearly, there are many reasons for those associated with the Center (and students of bioethics) to be interested in this. Not only is this another interdisciplinary endeavor concerned with ethical issues arising from real world decisions, but the subject matters are themselves connected.

For instance, topics of our brown bag discussions have included: AIDS research in Africa, the practice of developed countries hiring away nurses and other health care professionals from developing nations and, most recently, the proposal to carry out randomized "trials" to assess the effectiveness of aid programs (a topic that connects with both the ethics of randomized clinical trials and controversies concerning "evidence based medicine").

The study of ethics and development will contribute to the understanding of and evaluations of health care systems in developing nations (a central topic of the "Ethics and History of Development and Health Care in Costa Rica" Study Abroad program) as well as to such topics as medical research in developing countries, the role of the pharmaceutical industry, and the importance of traditional medicine and indigenous knowledge. It will also fit well with bioethics' increased interest in public health. More broadly, of course, health and health care are important indicators of and causal factors for a nation's development, and various social factors, such as income level (and, it is claimed, even inequality per se) are causal factors for health.

For further information, see <https://www.msu.edu/~phl/EandDWebsite/index.htm> or contact the Specialization's director, Fred Gifford (gifford@msu.edu).



Report on the National Undergraduate Bioethics Conference

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About 135 people attended the 10th Annual National Undergraduate Bioethics Conference held at Michigan State University on March 23-24, 2007. The program featured papers by undergraduate students from 17 universities and colleges. Topics included Health Disparities, HIV/AIDS, End of Life Care, Organ Allocation, Environmental Ethics, Ethics of Embryos, Genetic Ethics and Political Legal Issues.

Another feature of the conference was an ethics bowl demonstration organized by students from Tuskegee University National Center for Bioethics in Research and Health Care. They led conference participants in two interactive rounds of a mock ethics bowl.

The keynote speaker was Dr. Daniel Callahan of the Hastings Center who talked on "Taming the Monster: Medical Technology." Dr. Howard Brody, formerly of MSU and now at the University of Texas Medical Branch in Houston talked about the pharmaceutical industry. Dr. Paul Root Wolpe, president of the American Society for Bioethics and Humanities, explored the privacy and terrorism implications of brain imaging. Dr. Gerald Schatz of the MSU Center for Ethics in Health and the Life Sciences spoke on International Law.

A special guest was Alexee Deep Conroy currently an attorney in New York City who had helped organize the first Conference at Princeton University. She presented a brief history of the conference which has been organized by students at the University of Virginia, Emory, Boston College, Texas A&M, University of Pennsylvania, University of Michigan, and Notre Dame University.

The Co-Chairs of this year's conference were Christina Harvey, a senior majoring in interdisciplinary social science health studies and Rebecca Cotter, a senior majoring in human biology. Other students from the MSU Undergraduate Bioethics Society who greatly contributed to the conference were Eric Reuff, Anjali Rohatgi, Gopi Patel, Sara Lake, Kevin Chen, Melissa Diller, Raj Mayak, Heather Peplinski, Nora Hung, and Nickolaus Fulbright.



News & Announcements

P. Sean Brotherton

- Spoke on “The Withering State? Socialist Entrepreneurs, Medicalized Citizenship, and the Struggle for Capital in 21st Cuba” at Disjunctive States: Crisis and Historicity in Cuba and Haiti Conference, University of Chicago (April).
- Gave invited talk “Macroeconomic Change, Emergent Capital, and the Biopolitics of Health in ‘Special Period’ Cuba” for the Center for Ethics and Humanities in the Life Sciences (CEHLS), Brown Bag Series, MSU (April).
- Presented “Machinations of the State: Shifting Ideologies, Emergent Capital, and Expanding Therapeutic Itineraries in ‘Special Period’ Cuba” in a Festschrift in honor of Margaret Lock at the Canadian Anthropology Society and American Ethnological Society Conference, Toronto (May). Invited to give this same talk to McGill University’s Department of Anthropology, Montreal (March).

Libby Bogdan-Lovis

- Served as a faculty leader for spring break program “Broadening Perspectives on Health Care in Costa Rica.” Hosted by the International Health Central American Institute (IHCAI) a group of 18 students from MSU’s Colleges of Human Medicine and Osteopathic Medicine examined both the context and delivery of Costa Rica’s national health care system (March).

Lisa Campo Engelstein

- Presented “Androcentrism and Sexism in Medicine: Understanding Health Disparities between Women and Men” for the MSU American Medical Women’s Association, medical student chapter (March).

Len Fleck

- Delivered the Courtney M. Townsend Lecture at the University of Texas Medical Branch in Galveston titled “Shall We Talk? The Role of Community Dialogue in Bioethics/ (Moving from Destructive Dissent to Reflective Reconstruction)” (April).
- Did a workshop with medical staff at the Bay City Medical Center titled “Just Caring: Health Care Rationing and Appeals to Futility in the Hospital” (May).
- Gave a lecture to the medical staff at St. Johns Medical Center called “Just Caring: Last Chance Therapies and the Challenges of Health Care Rationing” (May).

Margaret Holmes-Rovner

- Participated in an Invitational Meeting, Improving Quality Health Care: The Role of Consumer Engagement sponsored by the Robert Wood Johnson Foundation, Washington, DC (Feb.).
- Co-authored (Olomu A, Stommel M, Prieto A, Corser W, Eagle K) paper given titled “Is Quality Improvement Sustainable? The example of American College of Cardiology’s

Guidelines Applied in Practice (GAP).” Presented at the Society For General Internal Medicine, Toronto (April).

- Gave Keynote Plenary lecture, “History of Collaboration in International Shared Decision Making Meetings: The Stories of Science in the Making” at the International Shared Decision Making Biennial Meeting, Freiburg, Germany (May).
- Presented a workshop (with co-authors D Stacey, G Elwyn, C Bennett C, K. Sepucha) “Critically Appraising the Quality of Patient Decision Aids Using the International Patient Decision Aids Standards Instrument (IPDASI),” International Shared Decision Making Biennial Meeting, Freiburg, Germany (May).
- Co-authored (Wills CE, Franklin M) paper presented “Feasibility and Outcomes Testing of a Patient-Centered Decision Support Intervention for Depression in People with Diabetes” at the International Shared Decision Making Biennial Meeting, Freiburg, Germany (May).
- Was a discussant at the Niagara Workshop, Beyond Diagnosis: Health Outcomes, Decision Making and Survivorship, Canadian Cancer Research Consortium (May).
- Published (with co-authors J Gruman, and D Rovner) “Shared Decision Making in the US--Research & Development Outpaces Delivery.” Zeitschrift für ärztliche Fortbildung und Qualität im Gesundheitswesen (Journal for Evidence and Quality in Health Care, English special issue) (May).

Ann Mongoven

- Became an interim member of Michigan Department of Community Health IRB (Feb.).
- Was a speaker on panel addressing bioethical and social issues regarding the use of plastinated bodies at the Detroit Science Center, in conjunction with the “Universe Within” plastinated bodies exhibit there (Feb.). Also, was a panelist for a CEHLS brownbag on same topic, MSU (March).
- Gave talk “Other Barriers:Disparities in Organ Donation and Transplantation” for Leaders Achieving Notable Education Greens Screens, MSU (April).

Gerald Schatz

- Presented “International Law and Informed Consent in Research on Human Beings” at the National Undergraduate Bioethics Conference, MSU (March).
- Conducted a workshop, “Handoffs and Heartaches--Problems of Continuity of Care” at the Annual Meeting, Medical Ethics Resource Network of Michigan, MSU (May).

Tom Tomlinson

- Presented “The Ethics of First Person Consent to Organ Donation,” at the Michigan Gift of Life conference, Saving More Lives Through Donation and Transplant, Brighton, MI (March).
- Gave talk “The Ethics of DNR Decisions” for the Lakeland Regional Health System, St. Joseph, MI (May).
- Spoke on “Ethics and Futility” for Foote Hospital, Jackson, MI (May).