Diversity, Ethics, and Personalized Medicine Research

by Kyle Brothers, MD, PhD.
Dr. Brothers serves as Assistant Professor in the Department of Pediatrics and Affiliated Faculty Member in the Institute for Bioethics, Health Policy, and Law at the School of Medicine.

There was a time when the aim of every ambitious biomedical researcher was to discover a “silver bullet.” If only we could find the right treatment, this logic went, we could cure everyone with a disease. While this approach did result in a few remarkable success stories, it became apparent over time that the best we could hope for were treatments that helped most patients.

Over the past 15 years, however, suspicion has grown that the reason no single treatment works for every patient is that we are attempting to use one-size-fits-all interventions to treat dissimilar patients with subtly dissimilar diseases. This suspicion has evolved into a whole field of research focused on dividing diseases and patient populations into smaller and smaller subgroups. Because these subgroups will contain patients with more similar individual characteristics and more similar pathophysiology, it is hoped that they will also respond more similarly to treatments. This new field – usually referred to as “personalized medicine” – focuses on discovering the biological markers that healthcare providers may one day use to separate out patients who will respond to a specific treatment. The majority of research in this area currently focuses on genetic variants to identify these patient subgroups.

In this short article I want to draw attention to a few ethical challenges having to do with race that are relevant to personalized medicine. It may not seem obvious that there is a link between personalized medicine and issues related to diversity, but in fact the connection is extremely important. There are a number of issues that I could raise. But for this short piece, I’ll focus on the way that genetic association studies, the types of research studies that are needed for personalized medicine, usually have to be performed in only one racial group at a time. This has raised problems for making sure that personalized medicine can benefit patients from all racial and ethnic groups, and draws attention to the importance of performing biomedical research in subjects from diverse backgrounds.

Genetic Association Studies and Race

Before healthcare providers can use a genetic variant to predict whether a patient will respond to a specific treatment, genetics researchers must first discover which genetic variants are more common in patients who respond to a treatment. They do this using a type of study called a “genetic association study.”

This type of study is demonstrated in Figure 1. Researchers compared how frequently genetic variant A occurred in a group of patients who had received benefit from Medication C. They compared this to the frequency of genetic variant A in patients who did not respond to Medication C. From this, they were able to see that having

(Continued on page 7)
School of Dentistry

My Honduras Experience: The Value of International Service Missions
by R. Stephen Boh, DMD, 2012 ULSOD Graduate

My grandfather was an ophthalmologist for 40 years, and he spent a large part of his career traveling around the world doing medical mission work in third world countries. He is among the men I have most admired, and I always wanted to follow in his footsteps. I had been looking for an opportunity to begin down a similar path. When I learned about the Honduras trip from Dr. Madeline Hicks, it was precisely what I had been waiting for.

We stayed at a mission house, called Mision Caribe, where volunteer groups sleep and eat meals during the evenings before going out and working on various projects during the day. The staff of the mission was incredibly gracious and hospitable. By the end of the trip, they felt like family.

The main goal and highlight of the trip was to provide dental care for the local community members of the surrounding churches that were supported by the mission. Each day, we would load up our equipment (lots of it!) in a van or school bus and make a two to three hour trek to our mission location. These drives allowed us to see the beautiful landscape of Honduras, and insight into how the people live. Once we arrived at our location, we unpacked our equipment, set up our operatories, and got to work. The need for dental care was immediately apparent, and we soon learned that many had never seen a dentist. We mainly performed basic operative, extractions, and cleanings. However, the people were extremely grateful for the work we provided. We were able to treat and relieve many who were in pain, children in severe need of care, and young people with anterior esthetic restorative needs.

The most valuable dental lessons I learned involved the sheer magnitude and complexity of the logistics of bringing dental care to remote and foreign areas. The amount of necessary tools, equipment, and materials was staggering, and the need for proper preparation was critical. I was fortunate to play a role in organizing the equipment and materials before leaving, and again on location. I learned how to set up mobile dental units by arranging tables for tools and materials, planning for sterilization methods and processes, assuring for adequate electricity and lighting, and planning for patient triage and organization. In addition, we had to repack and reload everything daily! At night, we did inventory, assessing our need for additional materials for the next day. These were all extremely valuable lessons that I will use often in future dental outreach trips at home and abroad.

It was extremely gratifying to provide care for the wonderful people of Honduras. They were gracious and very appreciative of everything we did, and it felt great to help make their lives a little easier. I enjoyed experiencing an entirely different culture. The language barrier was a challenge, but by the end of the trip, I was able to communicate well enough. All in all, it was an amazing experience. I learned a ton, and look forward to the opportunity of doing in again in the future!

Taking A Bite Out Of Poor Oral Health Care

Stepping away from the confines of a college classroom, University of Louisville School of Dentistry Dental Hygiene students Jessikka Suazo and Nimet Altairi took their education and experience to the Wayside Christian Mission Center. As many dental problems can be slowed or even reversed by a proper regimen of oral hygiene and professional care, these enthusiastic students gave a lively and engaging presentation that held their audience’s undivided attention. Jessikka and Nimet quickly connected with the women in the recovery program and what followed was a lively hour of oral health care dialogue and education.
School of Medicine

Influencing Lives: Community Outreach at Nativity Academy

by Rafael Fernandez-Botran, PhD, Associate Professor, Department of Pathology and Laboratory Medicine, Acting Chair of the SOM Diversity Committee

Most of those who follow a career in science or a health-related field, could probably remember a person or persons, parents, relatives, teachers, health professionals, who at some point of our lives provided the inspiration that shaped their career choice. Whether by example, through a class or through an office visit, these persons awoke our curiosity and opened our eyes to a fascinating world of possibilities, shaping our future. But what if such inspiration would not have been there? Wouldn’t it be fair to provide now the same inspiration for others, particularly for children who are just beginning to think about their future? As part of the commitment to our community, several University of Louisville faculty and staff members from the medical, dental and nursing schools have been volunteering their time to talk to and hopefully inspire, children of 6-8th grade ages attending Nativity Academy, right here in the HSC neighborhood.

Nativity Academy, located just a couple blocks from UofL’s HSC campus, is an independent, not tuition-driven middle school serving students of academic promise selected from low income families. Most of the students, both male and female, come from African American or Hispanic backgrounds. Part of a network of 64 schools nationwide, 92% of their students graduate from high school, compared to a 55% national rate for African American and Latino students.

Several UofL faculty and staff members have made presentations about health-related careers, including Alona Pack from the Nursing School, Sherry Babbage and Liliana Rozo Gaeth from the Dental School and Mary Joshua from the Office of Diversity and Inclusion. In addition, children have heard about the numerous opportunities in biomedical research fields from several School of Medicine basic science faculty, including Irving Joshua (Physiology & Biophysics), Guillermo Rougier (Anatomical Sciences and Neurobiology) and myself (Pathology & Laboratory Medicine). If the children’s interest is any indication, we could expect several future nurses, dentist, doctors and scientists to come from this group.
School of Nursing

Teaching Cultural Diversity within the Nursing Curriculum
by Valerie McCarthy, PhD, RN, School of Nursing

“But Dr. McCarthy! How can I assess my client’s culture? She is a white Protestant lady who hasn’t ever lived anywhere except the United States. So she doesn’t have a culture!!!” Sigh. How do we make our students understand that everyone has not just one but many “cultures”? That is one of the challenges in Community Health Nursing.

The syllabus for Community Health Nursing says our course is designed to meet the competency standards for understanding cultural diversity. We try to accomplish this objective by providing students a broad exposure to a variety of social systems, cultures, and subcultures. We want our students to recognize that social and cultural systems develop out of adaptation to social, environmental and historical circumstances, and to realize that race, ethnicity, and/or gender are socially constructed. We want students to be able to question and evaluate information and assertions for relevance, bias, stereotyping, manipulation, and completeness, understanding that different cultures may hold different views of the same issues.

Awareness and appreciation of cultural diversity is one of the fundamental and critical concepts of Community Health Nursing, integrated into weekly independent learning exercises, lectures, discussions, and interactive group activities. We like to think the concept really comes alive in the community settings where clinical groups apply what they are learning in the classroom to a variety of real life experiences.

Community groups in recent semesters have focused on various populations and settings: low-income older adults in residential housing; grade school children in Louisville’s West End and in the historic Portland community; men, women and children who are homeless, encountered in emergency and transitional housing, day centers, and health clinics; and among immigrants at Churchill Downs, in a rural family health center, or in a vaccination clinic initiated by a member of the SON faculty.

Of course, like many courses, getting our message across to students in a way they really understand can be a challenge, as the student above so clearly illustrated for me not long ago. What is sometimes lost in translation when we are talking about various cultural groups is that “culture” is a much broader concept than just the ethnic heritage that shapes a client’s perceptions of health or the language a client speaks in a clinic or community center.

In talking with students about culture in various community settings I explain that culture is the way we see ourselves, our relationships with others, and our understanding of the world based on the beliefs, values, attitudes and practices we learned growing up. We all learn things as we grow up, whether that is in China or Afghanistan, or in a Hispanic family in Los Angeles, or in rural areas in Africa or Alabama. As children we learn about religion and morality and about the proper gender roles for men and women. We learn about respecting the wisdom and accumulated knowledge of older adults or that old people are a burden on society, draining assets needed by the succeeding generation. We learn about the value of being on time, maintaining personal space, making eye contact, or what foods should be served when someone is sick.

We learn that what shapes our beliefs, values, attitudes and practices is influenced by whether we

(Continued on page 8)
Public Health and Information Sciences

Third Annual International Food Festival: A Celebration of Culture and Diversity
by Naureen Malik, MPH Student and Member of the Diversity Committee and Irma N. Ramos, M.D., Assistant Professor and Acting Chair of the SPHIS Diversity Committee

Culture is the lens through which we see and experience life. The richness of our cultural diversity is manifested through the set of beliefs, customs, artistic expressions, foods and music that place us within unique groups, in other words, the inner voices that define who we are as individuals and populations. Indeed, increasing knowledge of other cultures empowers us to become more open-minded, tolerant and sensitive to others and to better understand the world around us.

The Diversity Committee of the School of Public Health and Information Sciences (SPHIS) in collaboration with its Student Government Association held the 3rd Annual International Food Festival on November 12, 2013. The main goal of this event was to foster an environment where faculty, students and staff experience and “taste” the different cultures represented in the School. A secondary goal was to create an opportunity for students to become better acquainted with each other and with the faculty and staff of the School. We are fortunate to have individuals from multiple continents making our population richly diverse and powerful in many ways.

Students, faculty and staff donated food and drink selections representative of their countries of origin. Delights in the category of foods included Cuban delicacies, Mexican tamales, New Orleans style gumbo, and various rice dishes from several native countries in Africa including, Pilau and Mandazi from Tanzania, and Jollof from Ghana. The amazing virgin Piña Colada from Puerto Rico was the main drink offered to participants. To top it all, an authentic dessert from Pakistan called Halwa plus others were offered to those with a sweet tooth! In addition, participants enjoyed music from all over the world and a beautiful power point presentation with faces, places and wonders of the world. To keep the group engaged, educational games were sponsored during the activity, including a challenging game to test general knowledge on flags and countries of the World. Another fun game involved guessing the number of candies placed inside a Mexican “Pinata”. Great prizes were handed out to winners in each category. Everyone seemed to enjoy the activity and most participants were astonished with the level of energy, enthusiasm, interest and diversity represented at the SPHIS.

A special thanks to all who contributed to the success of the activity and especially to those who joined in the celebration!
First Steps Paramedical Program. The students are enrolled in a dual credit six-credit hour Emergency Medical Technician (EMT) class that meets on the Health Sciences Campus of Madisonville Community College (MCC) this fall.

This unique program was created through the collaboration of Baptist Health Madisonville, Madisonville Community College, West Area Health Education Center and Hopkins County Schools, along with support from the Medical Center Ambulance Service in Madisonville. According to MCC’s Chief Academic Affairs Officer Dr. Deborah Cox, “This program is built on the successful First Steps Nursing program that has offered local high school students, who are selected on a competitive basis, a college medical pathway. The First Steps Paramedical students have an excellent instructor in Justin Cardwell.”

Martha Pleasant, Director of the West Area Health Education Center at Baptist Health Madisonville, adds, “This was a very exciting development that offered these students a great career and college pathway into the emergency medical services field. After students complete their courses, they are prepared to take their National Registry of Emergency Medical Technician Examination required to work as an EMT and to enter the MCC paramedical program with six college credits already completed.”

“This new program is a product of the ongoing partnership between the district and local institutions seeking to provide creative pathways to our students as they leave high school,” stated Linda Zellich, Hopkins County Schools Superintendent. “The partners in this program worked hard last year to put this program together, not the least of which was to reduce the costs for this class from over $1,000 to under $100 to make it affordable to all students.”

The current First Steps Paramedical students will complete the program in February.
genetic variant A seems to greatly increase the chances that a patient will respond to the medication. If they are able to replicate this finding in additional studies, doctors might one day test patients for genetic variant A before deciding whether to prescribe Medication C.

While this may sound straightforward in principle, there is often a “catch.” Not all genetic differences affect our risk for developing a condition or responding to a treatment. In fact, our genomes differ at thousands of different locations. Some of these differences influence our risk for developing a disease, some influence things like how tall we will be, and some have absolutely no measurable effect on us – they are “neutral”. Even though we are all different in this way, two persons with ancestors from the same continent (such as Africa or Europe) share many of the same variants. Some of these are important for health, others are neutral.

Imagine what would happen, then, if researchers used a genetic association study to look for a genetic variant that is associated with risk for developing diabetes, since it is twice as common in patients with diabetes compared with patients who do not have diabetes.

But there is a catch! Because diabetes is more common in black patients, it turns out that black patients ended up being overrepresented in the sample of patients who have diabetes. Figure 2B breaks down the frequency of genetic variant B by race. It turns out that this genetic variant is much more common in black patients than it is in white patients, but these frequencies have nothing to do with risk for developing diabetes. We might infer that genetic variant B emerged in ancestral populations in Africa, and is therefore only found in patients who have ancestors from Africa. But it is perfectly possible that this variation is neutral – it has absolutely no effect on diabetes risk or other characteristics that people might develop.

Separate but Equal?

We can see from the example in Figure 2 that genetic ancestry can be a confounder for genetic association studies. In fact, this phenomenon is so important that genetics researchers usually have to separate out research subjects according to their genetic ancestry. For researchers in the United States, this means that scientists interested in finding genetic associations for diabetes or for a response to a medication need to perform a study once in patients with African ancestry and again in patients with European ancestry.

This approach would be largely unproblematic were it not for a number of “real-world” limitations that make it difficult for researchers to perform every genetic association study in every genetic ancestry group. There are greater
numbers of persons in the US whose genetic ancestry is primarily from Europe compared with other genetic ancestry groups. And in certain areas, including a few where many genetics researchers work, this majority is particularly large.

The disparity in population sizes creates problems, since large sample sizes are needed for these types of studies. The examples I provided in Figures 1 and 2 involved only twenty research subjects each. But in real genetic association studies researchers may need to recruit 100, 1000, or even 2000 research subjects in order to identify a genetic association. And a large percentage of these participants must have a particular disease of interest. Because of this and a number of other factors, genetic association studies in the US have been performed disproportionately with patients from the largest ancestry group – those with European ancestry. In fact, a group of researchers reported in 2010 that between 50 and 60% of all genetic association studies performed with National Institutes of Health (NIH) funding in the previous 5 years involved persons of European ancestry only.

My concern about this matter is perhaps all too obvious. If it is true that personalized medicine is going to lead to better medical care, then disparities between the groups that are being studied could lead to disparities in the benefits minority groups receive from this research. Research findings generated from studies involved only patients of European ancestry are not as relevant for patients from different ancestry groups. If researchers tend to discover primarily those variants that are important for patient of European ancestry, then patients with African ancestry, or Native American ancestry, or Asian ancestry may not reap the same benefits of this research.

---

(Continued from page 4)

Cultural Diversity in Nursing

live in an inner city, a suburb, or a rural area. It is based on the ethnic heritage of our grandparents and parents, the holidays we observe, and the foods we eat at family celebrations. We also learn by the experiences shared by our particular generation or birth cohort. The “Greatest Generation” was marked by the experience of living through the depression and two world wars. The “Baby Boom” cohort grew up in the rigid, corporate era of the 1950s, and then rejected it all in favor of the sexual revolution, civil rights, and getting in touch with one’s self. Today’s college students have been shaped by growing up with working mothers and involved fathers, parents suddenly out of work and savings lost somehow, and technology that has shrunk the word and eliminated the concept of privacy.

We teach in class that nurses are called to be aware of and sensitive to the various cultural groups’ religious beliefs, social rules, and preferred foods – and we also teach that it is called stereotyping when all members of a race or cultural group are lumped in together and labeled based on where they came from, the language they speak, their skin color, or the foods they eat. And we try to teach the way to walk what sometimes seems like a thin line between being ignorant and culturally insensitive and blithely assuming we know what life is like for a client because we can list the cultural characteristics learned in class.

What I really try to get across to my students isn’t just “coping with” the differences among the many racial, cultural or ethnic groups they will care for as nurses. I want students to learn to celebrate the diversity that enriches our world and broadens our perspectives. And most of all I want my students to see beyond diverse languages, religions, or racial identities that all human being share some of the same hopes, and dreams, and aspirations: to live healthy, happy lives; to raise our children in safety and security; to live our lives according to our own beliefs of right and wrong; and to make a difference along the way.
Upcoming Events and Announcements

- Dr. Martin Luther King Jr. Commemoration
  Date: Monday, January 20 at 1:00pm
  Location: The Playhouse

- School of Law Diversity Week Talk
  Topic: “Marriage and Parenting in LGBT Families
  Date: Tuesday, January 21 from 10:25 11:40am
  Location: School of Law Room 275, Belknap

- Human Trafficking Awareness Conference
  Date: Wednesday, January 22 from 5:30 8:00pm
  Location: The Avenue

- School of Law Diversity Week Talk
  Topic: “Diversity in Action: Legislative Initiatives
  Impacting Diverse Communities in Kentucky”
  Date: Wednesday, January 22 from 11:50am 12:50pm
  Location: School of Law Room 275, Belknap

- Center on Race and Inequality’s 5th Annual
  Martin Luther King Jr. Justice Lecture
  Topic: “1964: American Progress, Possibilities,
  and Problems
  A Project Progress Event
  Date: Thursday, January 23 at 5:30pm
  Location: Chao Auditorium, Belknap
  Contact: Dr. Ricky Jones

- J. Blaine Hudson Saturday Academy
  Topic: “Post Civil Rights, Post Race, Post
  Struggle: American Political Progress and the
  Black Community”
  A Project Progress Event
  Date: Saturday, January 25 at 11:00am
  Location: DuValle Education Center
  Contact: Dr. Ricky Jones

- Pan African Studies Spring Lecture
  Topic: “The Movement’s Outlaws: When the Civil
  Rights Movement Stood Up
  A Project Progress Event
  Date: Wednesday, February 5 at 5:30pm
  Location: Chao Auditorium, Belknap
  Contact: Dr. W.S. Tkweme

---

“Shining the Light on Global Domestic Violence”
with Mr. Donald Lassere, President and CEO, Muhammad Ali Center

HSC Campus Lunch and Learn
Sponsored by the Office of Diversity and Inclusion
Date: Friday, February 7 from 12:00-1:00pm
Location: Instructional Building B, Room 102, HSC
RSVP: Katie Leslie

All HSC faculty, staff, and students are encouraged to attend!

- Academic Cultural Engagement Social Justice
  Symposium A Project Progress Event
  Date: Friday, February 14, from 9:00am 4:00pm
  Location: Ekstrom Library, Belknap
  Contact: Katie Adamchik

- International Women’s Day
  Date: Thursday, February 27 at 11:30am