



HEALTH CARE IN AMERICA IS NOT THE SAME FOR EVERYONE,

# Unequal TREATMENT

by David Wilkins

*As U.S. medicine becomes patient-based and patient populations grow more diverse – culturally, ethnically, racially, and in terms of faith, lifestyle and demographics – the national institution that is medicine in America must unravel and address serious disparities in health care treatment and delivery that the Institute of Medicine has decreed as one of the nation’s “most serious health care problems.”*



## AND U-M RESEARCHERS ARE ASKING WHY

**W**hile diabetes is virtually non-existent among Arab nomads in the Egyptian desert, 40 percent of Arab immigrants in southeast Michigan are diabetic or glucose intolerant. African-Americans seeking medical help for chronic pain report more severe symptoms — greater pain intensity and severity, depression, disability and post-traumatic stress disorder — than white patients do. Native American women are less likely than women from other racial and ethnic minority groups to contract breast cancer, but more likely to die within five years when it is detected.

Why? The question is compelling, the answers complex and often unclear.

The tangled web of contributing forces to disparities in disease prevalence, health care and medical outcomes includes discrimination, acculturation, lifestyle and behavior, as well as limited access to and utilization of health care, variations in diagnosis and treatment, exposure to environmental health risks, genetic predisposition and socio-economic factors.

“Disparities in the health of — and in health care delivery to — different racial, ethnic, and socio-economic populations have existed for at least decades and prob-

ably as long as statistics have been gathered on these issues,” says David Gordon, M.D., professor of pathology and associate dean for diversity and career development. “Some gaps have lessened over the years with improvements in health care, but most remain and some may even be widening with time.

“Interestingly, medical conditions with the greatest disparities — including cardiovascular disease, obesity and related diseases, and prostate and breast cancer — are the major causes of death for the entire U.S. population,” he says. “So the opportunity is clear. Any insights on ►

how to improve health status and health care delivery in these areas should lead directly to improvements in the overall health of our country.”

The Institute of Medicine’s groundbreaking 2002 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*, concluded that:

- The most significant barriers to equitable care are factors which affect access to treatment — differences in income, lack of health insurance or reliance on publicly funded insurance, high co-payments, inadequate transportation, and a scarcity of nearby health care services.
- When limited access to care is removed from the equation, however, significant disparities in morbidity and mortality persist — suggesting bias and stereotyping play a large role.

- Minorities receive lower quality and less intensive health care and diagnostic services than whites across a wide range of medical conditions and treatment regimens.

While the important work of documenting disparities continues, medical researchers, including dozens at U-M, are digging deeper. Their goal is to understand why disparities occur. Why, after suffering a stroke, are Mexican-Americans less likely than non-Hispanic whites to take blood-thinning drugs that can reduce the risk of another stroke? Why are African-Americans four to five times more likely than other groups to develop kidney disease? Why are there often treatment delays when a woman suffers a stroke?

Understanding why these differences exist is the first step toward eliminating

them, U-M researchers say — by toppling barriers to care, rooting out bias, correcting communication lapses between doctors and patients, identifying variations in treatment, understanding biological differences, and targeting unhealthy patient behavior with carefully calibrated education.

“We need to understand the underlying reasons for these disparities in order to design interventions that are person-specific or group-specific,” says Carmen R. Green, M.D. (Residency 1992), a U-M anesthesiology professor who studies physician decision-making and disparities in pain management. “In doing so, we can improve the quality of life for all people.”

Treating patients equitably, then, does not mean treating them identically. It means, in fact, accounting for and addressing the differences that create disparities — the tendency to under-prescribe pain medication for minorities, women and the elderly, for example, or the way Westernized lifestyles and genetic predisposition combine to make Arab immigrants susceptible to diabetes.

As a fellow in the U-M Multidisciplinary Pain Center in the early 1990s, Green wondered why some patients coped better than others with unrelenting pain. She also noted variations in the care they received. “I saw differences in treatments

“Disparities have existed probably as long as statistics have been gathered on these issues.”

—David Gordon, associate dean for diversity and career development

that had previously been provided or were currently being provided. I started asking why.”

A decade later, Green is a national leader in the study of disparities in the way people perceive, assess, seek help for, and are treated for pain. In a series of studies published in *Pain Medicine* (2001-03) and the *Journal of Pain* (2003), for ►

Photo: Martin Yloet



DAVID GORDON

# FROM CAUSE TO INTERVENTION

## U-M RESEARCHER LEADS INVESTIGATION OF BREAST CANCER DISPARITIES AMONG NATIVE AMERICAN WOMEN

While developing a presentation on breast cancer several years ago, Marilyn Roubidoux, M.D., an associate professor of radiology in the U-M Medical School, found a vast amount of research exploring factors which influence a woman's propensity for the disease — and little on how these underlying factors affect racial and ethnic minorities. "There were few articles about breast cancer risk factors in minority women and nothing at all on Native American women," says Roubidoux. "I thought we ought to study this in minority populations as well as Caucasians."

Roubidoux subsequently became the first investigator to review and report on Native American women's mammogram results. She has researched family history for breast cancer, breast tissue density and other risk factors among Aleut and Eskimo women in Alaska, native tribes in the southwest, and Sioux tribes in South Dakota.

From these data, Roubidoux has attempted to evaluate whether the Gail Model — a widely used screening tool for assessing breast cancer risk — is appropriate and effective for Native American women. "We don't know whether the Gail Model really fits in a native population, because it is based on research which studied white women," she says. "The same question has been raised regarding African-American women."

Her research also delves into differences within the native population. Breast cancer incidence and mortality rates are six times higher among Native American women in Alaska and the northern plains states, for example, than they are in the Southwest. Understanding the reasons for these variations — which could involve diet, smoking, lifestyle, genetics, breastfeeding and child-birth practices, and the ages at which menstruation begins and menopause occurs — could have benefits far beyond the Native American population, Roubidoux says. "The disparities between native groups might give us a clue about the factors contributing to breast cancer," she says. "Once you understand the causes you can create interventions."

Native American women are less likely than women from other racial groups to contract breast cancer, but more likely to die within five years when it is detected — which may suggest that limited access to screening is delaying diagnosis and treatment. "Findings among the native population can potentially benefit all rural or underserved women," Roubidoux says.

Photo: Martin Voet



MARILYN ROUBIDOUX



JOSEPHINE KASA-VUBU

# ADOLESCENT GIRLS AND LIFESTYLE:

## WHY SOME ARE MORE VULNERABLE THAN OTHERS TO CERTAIN DISEASES

**J**osephine Kasa-Vubu, M.D. (Residency 1988), a pediatric endocrinologist at Michigan, views health disparities through the lenses of age, gender and lifestyle. She studies the ways in which exercise or obesity can affect adolescent girls' reproductive function, bone density and other health outcomes.

"Excessive exercise, on one end of the spectrum, and inactivity and obesity on the other, can cause menstrual irregularities," she says. "There is no question that exercise is beneficial to all; however, adolescent girls are unique as they may be more vulnerable to the consequences of exercise even if they are a normal weight."

Kasa-Vubu is interested in the point at which over-training causes amenorrhea and an increased long-term risk of osteoporosis. She studies endocrine changes associated with exercise that may have an impact on bone health. But weight and exercise (or their lack) are linked, and she also studies the point where obesity triggers type 2 diabetes, impaired fertility and a long-term risk of heart disease. Her research explores why these points vary among young women and seeks to identify factors — such as body composition or pituitary hormones — which indicate whether a girl's lifestyle places her at risk of an 'energy imbalance.'

Who tolerates and benefits from intense exercise and who suffers from it? Why do some obese, inactive adolescents get diabetes while others do not? "I'm interested in the adolescent girl across the weight spectrum, from lean to overweight," she says. "What is the impact of energy balance on her menstrual cycle and her bone health, on one hand, or her risk for type 2 diabetes on the other? How does that happen? This information is particularly important at a time when more girls will need to be counseled in weight control strategies to curb the growing obesity epidemic in youth.

"Girls who over-train typically don't realize they have crossed a line to a place where exercise can be detrimental," she says. But at the other end of the spectrum, the perception of physical activity can also be a problem, and parents of Kasa-Vubu's obese adolescent patients often don't view their daughters as sedentary and overweight. "As I started recruiting for my study, I noted that adolescent girls, in general, are very interested in their health, nutrition and exercise. I had mothers inquire about the study and wonder how and why their daughter's menstrual cycle was affected by training," she says. "But we need a better way to guide them through this process. There's not a one-size-fits-all solution."

example, she and colleagues found that physicians are more likely to prescribe optimal pain treatment for men who have metastatic prostate cancer or postoperative pain after a prostatectomy than they are for women who have metastatic breast cancer or postoperative pain after a myomectomy.

In other recent studies, Green concluded that African-Americans across the age continuum are in significantly greater distress than white Americans when they initially seek medical help for pain. Further research is needed, she says, to understand the reasons behind this disparity. Possible causes include ineffective doctor-patient communications, differences in pain tolerance, variable health insurance and financial status, and physicians being less aggressive in providing minorities with pain medications and referrals for specialized pain care. African-Americans in Green's studies generally were covered by health insurance — but they were more likely than whites to be covered by Medicaid or Medicare and also were more likely to say medical care for chronic pain was a significant financial burden.

Green recently led a multidisciplinary team of researchers from around the country, including the U-M School of Public Health, which conducted an unprecedented review of research on factors contributing to racial and ethnic disparities in pain treatment. In a paper published in the September 2003 edition of *Pain Medicine*, they concluded that racial and ethnic disparities exist in pain perception, assessment and treatment in all medical settings and for all types of pain. They cited one study, for example, which found that white patients arriving in the emergency room with a broken leg were twice as likely as Hispanics to receive pain medication — and the disparity was not explained by the severity of the injury or the patients' gender, primary language, insurance status, or suspected intoxication. Little is known also about the pain experiences of other indigenous people.

Green and her co-authors explored the interwoven collection of causes that may contribute to these types of disparities, some of which involve patient attitudes and doctor-patient communication. Patients with serious medical conditions often under-report the severity of their pain, a phenomenon which directly

affects the level of care delivered. This tendency may be more pronounced among minorities for several reasons. Many Hispanic and African-American patients adopt a stoic outlook, research suggests, and subscribe to the belief that pain is an inevitable part of a serious disease and must be accepted. Minorities also may tend to rely on alternative and complementary treatments, prefer to take analgesics only when pain is severe,

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and have a heightened fear of potential adverse effects of opioid drugs, including addiction, developing tolerance and intolerable side effects.

Studies also have found that minority patients may be less involved than non-minorities in decision-making about their treatment — although they participate more actively when their doctor shares their ethnic background — and that minorities are referred less frequently for specialized care.

Caregiver decision-making can be another factor. Health care providers have not widely employed consistent protocols and guidelines for treating many painful conditions, including back pain, cancer pain, and sickle cell anemia. As a result, clinical decisions are idiosyncratic and widely variable, which may contribute to less than optimal pain care in general, and disparities in care for racial and ethnic minorities in particular.

Access to health services also plays a significant role in pain treatment. It has been shown — notably in a study conducted by researchers from the Mount Sinai School of Medicine and published in the *New England Journal of Medicine* in April 2000 — that pharmacies in pre-

dominantly minority communities in New York City were less likely than pharmacies in white neighborhoods to maintain an adequate stock of opioid analgesics for the treatment of severe pain. In a study presented at a meeting of the American Pain Society in May 2004, Green and her colleagues replicated and extended this study across the state of Michigan and found that pharmacies in minority neighborhoods were less likely to stock opioid analgesics as well. These studies provide examples of the ways in which certain areas are under-served.

Green and her colleagues recommend improved training for health care providers and education for patients. Patients can benefit, they say, by seeking treatment, from information on how to discuss their pain with their doctor, and also from realistic expectations of treatment. Patients who expect pain relief and are willing to take appropriate analgesics may elicit more responsive pain management from their health care providers who, in turn, need to educate themselves regarding pain assessment and treatment and to be willing to listen to as well as elicit patients' pain complaints. The team of researchers also called for increased participation of minority subjects in biomedical research, increased federal funding for the study of health care disparities in vulnerable populations, and increased funding for minority researchers.

Pain, Green says, has an enormous impact on sufferers' productivity, personal relationships and enjoyment of life — and these burdens now fall disproportionately upon minorities. "Pain is one of the top reasons patients visit their physicians and it's the No. 1 reason for disability," she says. "The suffering, the impact on quality of life — it's huge, and we are a better country than this."

The issues raised in Green's research mirror, to a large degree, the agenda of the U-M Medical School's Office of Diversity and Career Development, established in 2002 to create a "workforce and new methodology that will improve the health of minority and disadvantaged populations."

The breadth of the office's focus is unusual among academic medical centers. Pipeline programs encourage talented grade school, high school and college ►

students from historically disadvantaged and under-represented populations to pursue careers in the sciences, health services and biomedical professions. “Our overarching mission is to coordinate medical school efforts to identify and nurture those individuals from groups which are ‘under-represented in medicine’ as well as individuals from the majority population who will work to eliminate these health disparities,” Gordon says.

Recruiting, retaining, and supporting career development for outstanding faculty, staff and students from under-represented groups and diverse backgrounds is critical to that mission. According to Gordon, “Professionals who are under-represented in medicine are more likely to serve disadvantaged populations.”

Gordon’s team also coordinates staffing to programs that support health care disparities research. “We have programs to promote increased networking among those investigators doing health disparities work and to promote increased interactions with our local communities concerning these unmet medical needs,” he says.

These responsibilities commonly are spread among several departments within a medical school, but U-M’s concerted, integrated approach is intended to promote knowledge sharing, synergy and diversity, and to generate momentum for initiatives that target disparities in health care.

The Minority Health Research Program, a key collaboration between the General Clinical Research Center and the Program for Multicultural Health, fosters disparities research within the U-M Health System and works to increase the participation of minority and historically underserved populations in U-M clinical research studies. “This program,” Gordon says, “has two main goals: to provide educa-

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CARMEN R. GREEN

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tional contacts between our clinical research investigators and surrounding minority communities, and to promote increased inclusion of minorities in our clinical research studies. This makes our investigators better able to include such research participants, while at the same time addressing some of the health information and care needs of our local communities.”

Recruiting minorities for clinical trials, Gordon explains, often requires investigators to overcome not only cultural barriers but also patients’ suspicion that they are being exploited by a health care system which is otherwise unconcerned with their day-to-day medical needs.

“Our investigators need help with explaining how their research is addressing the unmet health needs these communities face,” Gordon says. “Many of our investigators don’t even know how to begin such dialogues. So we’ve established a community advisory board composed of individuals interested in the health needs of our local minority communities. This provides investigators with a ready audience who will honestly critique their research plans, ask representative questions, and provide them with advice on who to contact and what to emphasize or change to better appeal to potential trial subjects.”

Researchers from U-M and Wayne State traversed this challenging terrain expertly for a study of diabetes prevalence among Arab-American immigrants in southeast Michigan.

William Herman, M.D. (Residency 1982), a professor of internal medicine in the U-M Medical School as well as a U-M School of Public Health professor of epidemiology, investigated diabetes rates among Arabs residing in Egypt in the early 1990s. He

found diabetes was virtually non-existent among Bedouin tribes dwelling in the desert, while prevalence climbed to 5 percent in rural villages, 10 percent among low-income people living in cities, and 20 percent among urban-dwellers with higher incomes. The variations, Herman says, appeared to result from lifestyle factors influenced by changing socio-economic status — increased ►

# TRUST AND UNDERSTANDING IN NUECES COUNTY

## ACCULTURATION'S TOLL ON THE MEXICAN-AMERICAN POPULATION

**N**ueces County in southern Texas is geographically isolated and its population is evenly split between Mexican-Americans and non-Hispanic whites, making it an ideal laboratory for the research of Lewis Morgenstern (M.D. 1990), associate professor of neurology, emergency medicine and neurosurgery, and director of the U-M Stroke Program. Morgenstern is the principal investigator of BASIC, or Brain Attack Surveillance in Corpus Christi, a 10-year study, now half completed, exploring disparities in stroke treatment, prevention and medical outcomes.

BASIC strives to ascertain the incidence of stroke among Mexican-Americans and the risk factors contributing to it. The goal is to gain insights that will lead to more effective stroke-prevention initiatives. “The effort to reduce stroke’s impact on the Hispanic population must mean more than simply translating brochures into Spanish,” Morgenstern says. “We must look at the role that acculturation plays, especially issues of understanding and trust of the health care system.”

In Nueces County, BASIC has found that Mexican-Americans who suffered strokes were younger, less educated, and had lower income than white stroke victims. They also were more likely to have diabetes and less likely to have atrial fibrillation, conditions which increase risk of stroke. The two populations had similar rates of alcohol use and smoking and were equally likely to have visited a doctor in the previous year.

Mexican-Americans were less likely than whites to be taking blood-thinning medication that can reduce the risk of a second stroke. They also expressed less confidence in their ability to prevent stroke, more distrust of the health care system, and more concern that money impedes their access to care.

These findings, Morgenstern says, suggest stroke prevention efforts targeting Mexican-Americans should emphasize the importance of reducing risk factors and address socio-economic issues. They also must overcome mistrust of the medical establishment and possible fatalistic beliefs held by some Hispanic populations — potentially by engaging the trusted family physician and churches in educational efforts.

The ramifications of Morgenstern’s work are enormous: Hispanics are the largest minority population in the United States and Mexican-Americans are the largest sub-group within this growing population. “For the country as a whole, stroke in Hispanics is a huge economic and social burden,” he says. “I don’t think we recognize the impact this is going to have. By the middle of this century, it’s going to be astronomical.”

Photo: Martin Voet



LEWIS MORGENSTERN

# CHRONIC RENAL DISEASE AND AFRICAN-AMERICANS

U-M PARTICIPATES IN NATIONWIDE STUDY OF ALL ASPECTS OF DISEASE, INCLUDING DISPARITIES

Photo: Martin Voet



AKINLOLU OJO

Akinlolu Ojo, M.D., Ph.D., an associate professor of internal medicine at Michigan, will spend five years monitoring 500 Detroit-area patients as part of a multi-center clinical trial documenting all aspects of chronic renal disease — including racial disparities. The Chronic Renal Insufficiency Cohort Study will examine genetic, demographic, environmental, behavioral, nutritional and quality-of-life factors affecting patients with kidney disease. It also will explore their access to and utilization of health resources. The study, which will follow 3,000 patients nationwide, is funded by the National Institutes of Health and involves researchers at Case Western Reserve University, Johns Hopkins, Tulane, the University of Illinois, the University of Pennsylvania and Kaiser Permanente, in addition to the U-M.

More than 10 million Americans have chronic renal disease — and it is four to five times more likely to afflict African-Americans than other groups. Ojo and his colleagues at U-M have formed a unique alliance with investigators in the Detroit area to ensure that 150-250 African-Americans are recruited for the project, which began in September 2001 and is scheduled for completion in 2008. Researchers will monitor patients' renal function and cardiovascular health, and patients whose condition progresses to end-stage renal disease will be tracked as they undergo dialysis and kidney transplants. "One of the most difficult and unfortunate things about loss of kidney function is that patients don't notice anything until the kidney function gets quite low, almost to the point of no return," Ojo says.

Disparities in healthcare have long been of interest to Ojo. Early in his career, he and colleagues at Texas A&M University conducted a study that found socio-economic factors — income, education, employment, and insurance status — created barriers to kidney transplantation. In another project, he investigated why African-American men have lower survival rates following kidney transplants than non-Hispanic whites — and found evidence that large out-of-pocket costs made it difficult for some patients to maintain a steady supply of crucial transplant medications. "This was an attempt to determine whether non-compliant behavior was a function of financial hardship," Ojo says. "Patients who are left with a substantial amount of out-of-pocket payments for transplant medications are more likely to lose their transplants prematurely."

Today, in collaboration with the Gift of Life Foundation of Michigan and the NIH, Ojo is evaluating means for increasing organ donation among racial minorities. He also is a co-principal investigator for the African-American Study of Kidney and Hypertension, the first major study of kidney disease among blacks.

caloric intake, decreased physical activity, and increased obesity, for example.

A decade later and thousands of miles away, Herman and colleagues are studying diabetes among Arab immigrants in Dearborn, home to the world's largest Arabic population outside the Middle East. The team recently unearthed startling and troubling findings: 41 percent of the study subjects suffered from diabetes or other types of glucose intolerance and half the cases were previously undiagnosed.

In a paper in *Diabetes Care* in 2003, the investigators characterized their findings as a major clinical and public health problem. They surmised that contributing factors may include lack of access to and use of health care, and culturally related attitudes and beliefs including fear of uncovering medical problems. "Community-based intervention programs to prevent and treat diabetes are urgently needed," they wrote.

Subsequent research explored the impact of acculturation on Arab-Americans' propensity for diabetes. Genetic predisposition also may play a role, Herman says, a supposition supported by the fact that other ethnic groups typically do not experience such a pronounced spike in diabetes following emigration to America.

These important findings came to light largely because the researchers exercised great care and sensitivity in working with the community. "We spent a great deal of time preparing the community for the project," says Herman, who credits Wayne State University pharmacy professor and co-investigator Linda Jaber with leading this outreach effort. The team collaborated on the study with Dearborn's Arab Community Center for Economic and Social Services, formed a 16-member advisory board of local leaders, and established a committee of local physicians to ensure that participants with medical problems uncovered by the study received appropriate referrals and follow-up care.

Primary care physicians in the community were contacted and provided information about the project so they could reassure their patients who were asked to partici-

pate and be assured the visiting health care providers were not competitors.

The study questionnaire and consent form were translated into Arabic, reviewed for linguistic and cultural accuracy, and field-tested. Questions about religious beliefs and income, and a standard disclaimer describing plans to share



WILLIAM HERMAN

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*—William Herman, professor of internal medicine and health care disparities researcher*

study data with government agencies, raised concerns about confidentiality, racial profiling and investigators' motives. Immigrants recruited for the study "often were from a place where that kind of information could be used against a person," Herman points out. The questionnaire and consent form were revised.

Another obstacle was a perception in the community that research amounted to experimentation and had no direct bene-

fit to the participants or the community. Fear of uncovering a medical problem, culture that did not emphasize preventive care, and misconceptions about the seriousness of diabetes and the risks of treatment also generated reluctance to participate.

Investigators countered with an extensive media campaign that relied on the local Arabic newspaper and television and radio stations. They explained the scientific relevance of the study, discussed its methods and procedures, and shared information about the risks of diabetes and the benefits of early diagnosis and proper treatment.

Study participants who viewed the project favorably were asked to help recruit additional subjects, while people who expressed reluctance were immediately contacted by the principal investigator so questions could be answered and concerns alleviated.

The study required subjects to undergo medical testing, creating inconvenience and requiring a significant time commitment. To minimize the burden, researchers accommodated flexible scheduling for clinic visits, including weekend appointments. They also provided transportation and coordinated appointments for relatives, friends and neighbors. The clinic was equipped with a room supplied with magazines, children's books, toys, a television and a VCR.

In the end, the project's participation rate was an astonishing 87 percent. The research team had prepared the ground so well, in fact, that the study endured the tensions and suspicions spawned by the September 11 attacks, which occurred while the research was underway. Work was halted for two weeks, then resumed.

The current task, Herman says, is to better understand the causes of the community's elevated diabetes propensity and design effective interventions. "We don't have a clue whether people will want to pursue lifestyle interventions or medical interventions or both or neither," he says. "The goal is to make a difference — to recognize this problem, understand why it's occurring ... and do something about it." 