Published in final edited form as:

Med Anthropol. 2019 April ; 38(3): 224–238. doi:10.1080/01459740.2018.1476508.

RACIALIZED RISK IN CLINICAL CARE: CLINICIAN VIGILANCE AND PATIENT RESPONSIBILITY

Hannah S. Bell,

Department of Anthropology, Michigan State University, East Lansing, United States.

Funmi Odumosu,

Department of Anthropology, Michigan State University, East Lansing, United States.

Anna C. Martinez-Hume,

Department of Anthropology, Michigan State University, East Lansing, United States.

Heather A. Howard, and

Department of Anthropology, Michigan State University, East Lansing, United States.

Linda M. Hunt

Department of Anthropology, Michigan State University, East Lansing, United States.

Abstract

Racial/ethnic identity is contingent and arbitrary, yet it is commonly used to evaluate disease risk and treatment response. Drawing on open-ended interviews with patients and clinicians in two US clinics, we explore how racialized risk is conceptualized and how it impacts patient care and experience. We found that racial/ethnic risk was a common but poorly defined construct for both patients and clinicians, who intermingled concepts of genetics, biology, behavior, and culture, while disregarding historical or structural context. We argue that racializing risk embodies social power in marked and unmarked bodies, reinforcing inequality along racial lines and undermining equitable health care.

Address correspondence to her at Department of Anthropology, Michigan State University, 655 Auditorium Drive, East Lansing, MI 48824. huntli@msu.edu.

HANNAH BELL is a research specialist in the Department of Anthropology at Michigan State University, where she earned her Master's degree in Anthropology. She has conducted research on health disparities, Medicaid expansion, and clinical interactions in diabetes care. She also has worked with various refugee-serving agencies in the United States.

FUNMI ODUMOSU is a student at Michigan State University studying kinesiology with a minor in global public health and epidemiology. She has conducted research on racialized risk in a diabetes clinic and the insurers' influence on diabetes patient treatment and management.

ANNA CHRISTINA MARTINEZ-HUME is a graduate student in Anthropology at Michigan State University. She has conducted research in the United States and Guatemala on health care delivery, exploring the relationship between intersectionality and stigmatization on health care equity for underserved groups.

HEATHER A. HOWARD is assistant professor of Anthropology at Michigan State University and the Centre for Indigenous Initiatives at the University of Toronto. Her interests are in knowledge production in social service and health care delivery organizations, community-based research, and critical analysis of health care transformation.

LINDA M. HUNT is professor of Anthropology at Michigan State University. She has conducted research in both the United States and Mexico, focusing on clinical understandings of genetic risk, chronic illness management, racial/ethnic identities in clinical contexts, health care as an industry, and health care reform.

Media Teaser:

We explore clinician and patient understandings of racial/ethnic identity as risk, and argue this concept reinforces racial inequality and undermines equitable health care.

NOTES

Keywords

United States; diabetes; genetics; race/ethnicity; risk; responsibility

I know that African American people are more prone to diabetes and hypertension than probably any other race, and a lot of that has to do with our eating habits, the types of food we've eaten in general. Yeah, we love to fry – I mean, who doesn't love fried chicken? In my culture, who doesn't love fried food, period? (Laughs) That's our staple; that's the way we would cook. ... It's very culturally oriented.

– Yvette¹, 64-year-old African American woman

I'm Caucasian. Never tend to think of it as a bad thing. ... On the other hand, it's never been used against me because of the group that I come from.

– Sarah, 54-year-old white woman

In recent years, clinical medicine has increasingly shifted its attention from primarily treating disease toward modeling and managing risk for illness, developing evidence-based protocols grounded in statistical observations of disease distribution in the general population (Bauer 2013; Bluhm and Borgerson 2011; Kreiner and Hunt 2014). Much of this research identifies race/ethnicity as risk factors for disease. This is of particular note in the US, where racial profiling by police and white nationalism appear to be on the rise, met by popular counter-racist movements such as #BlackLivesMatter. Clinicians in the US routinely take a patient's race/ethnicity to be an indicator of disease risk, invoking common assumptions about the biological and cultural characteristics of racial minorities (Byrd and Hughey 2015; Hunt Truesdell and Kreiner, 2013b). Yet "race" is a complex construct and thereby highly problematic to incorporate into medical care, as it provides a weak and ambiguous basis for clinical decision-making.

Race is a multi-faceted, constantly changing, and culturally situated concept. While race is a powerful social and cultural fact, races do not constitute biologically or genetically distinct groups (Goodman, Moses and Jones 2012; Ifekwunigwe, et al. 2017; Lewontin 1972). Rather than confirm a genetic basis for race, observation of racial differences in disease distribution reflect biological manifestations of structural inequalities that differentially impact individuals through unequal access to power, resources, and privileges (Haritigan 2013; Mukherjee 2016). Nonetheless, racial reductionism and biological determinism remain prominent in US health care, drawing simplistic racial concepts into seemingly logical explanatory models. Racial discourse in health care, however, is not neutral: in the absence of its historical and structural implications, it reflects, replicates, and upholds existing social hierarchies (Byrd and Hughey 2015; Shim 2005).

As we can see in the opening quotes from two diabetes patients who were asked if they thought their own race affected their susceptibility to diabetes, the implications of racialized risk can have different meanings for racially marked and unmarked patients. In this article, we draw on a study conducted in the diabetes and weight management clinics of a large US

¹All names have been changed to pseudonyms and identifying information has been removed.

health care system, to examine clinician and patient understandings of genetic and environmental factors impacting diabetes susceptibility and treatment. We seek to better understand how racial/ethnic concepts affect health care decisions made with and for patients at these clinics, and how patients may internalize notions of racialized risk. We argue that racializing disease risk embodies social power in marked and unmarked bodies, which affects both patients' and clinicians' notions of patient responsibility for disease occurrence and management, and has broader implications for patient well-being and equitable health care.

RACE AND MEDICINE

As genetic science rapidly advances, the idea that genetic tests can clarify one's ancestry or predict disease risk has captured the public imagination, with large numbers of people pursuing commercial genetic testing (Boddy 2017; Lee and Mudaliar 2009). At the same time, it is widely anticipated that expanding genetic knowledge will revolutionize clinical medicine, ultimately leading to precision health care specifically tailored to each patient. However, genetically based treatments and diagnosis remain rare, and genetic testing for most common illnesses has not yet been developed. Instead, racial/ethnic identity is routinely taken in medicine to be a proxy for genetic heritage (Bonham, Callier and Royal 2016; Hunt and Kreiner 2013; Yudell, et al. 2016). For example, racial labels divested of social context are regularly invoked in research on the genetic differences found in biobank repositories (Lee 2015) and in pharmaceutical research and recommendations regarding drug response (Ahn and Park 2017; Kahn 2009).

Epidemiological research documenting racial/ethnic health inequalities in disease distribution further encourage the idea that race is clinically important. Race has consistently been identified as a risk factor for many health conditions, including heart disease, kidney disease, low birth weight, and certain cancers (Williams 2012). However, the clinical implications of these observations remain unclear, as is the case with most associations identified through observational studies. Disparate patterns of disease distribution likely reflect the combined effects of a variety of factors, including genetic, behavioral, and environmental characteristics, amplified by socioeconomic inequalities ensuing from the long-term impacts of systemic racism (Duster 2015; Gravlee 2009; Krieger 2008). Recent research suggests these effects may have intergenerational impact through processes of epigenetics, wherein behavioral and environmental factors are inscribed into gene expression (Mulligan 2016; Thayer and Kuzawa 2015).

Thus, correlations between racial identities and health indicators reflect deeply complex relationships between environment, behavior, and genetics (Ackerman, et al. 2016; Gravlee 2009; Hughey and Byrd 2015). While racial/ethnic identity may be relevant to health, racial differences in disease incidence and health outcomes are not reducible to genetic, biological, behavioral, or cultural attributes, but instead reflect the impact of long histories of race-based social inequities in all of these domains.

Belying this complexity, race remains prevalent in clinical medicine as a simplified concept, reified through research, clinical guidelines, public health efforts, and finally through

clinical assumptions and clinical decision-making that directly affect patients (Hunt et al. 2013b; Lee 2015). As an example of racialized risk, we turn now to type 2 diabetes, a condition widely believed to carry a much higher burden for racial/ethnic minorities than for whites.

DIABETES AND RACIALIZED RISK

Diabetes diagnoses have been growing at an alarming rate: in 2015 in the US, 29 million people had been diagnosed with the disease and 86 million were classified as “living with prediabetes” (CDC 2016). While genetic heritage is likely a major factor in diabetes development—more than 40 genetic variants have been associated with type 2 diabetes—there are currently no clinically accepted genetic tests for diabetes susceptibility (Vassy and Meigs 2012). In place of genetic testing, extra vigilance is recommended for “at risk” groups, particularly racial/ethnic minorities.

The most recent American Diabetes Association (ADA) clinical guidelines identify certain racial/ethnic groups (African American, Native American, Hispanic/Latino, and Asian American) as at high risk for developing type 2 diabetes (ADA 2017a, 2017b). These guidelines recommend screening at a younger age and more frequently for these groups, and more aggressive prescribing of medications for them. Noting that racial/ethnic minorities may face socioeconomic challenges, it is also recommended that medication dosages be adjusted around food availability, and that patients be referred to free medication programs and diabetes literacy programs. Such recommendations mirror a simplistic approach to treating race as a fixed set of biological and behavioral characteristics that can be addressed at the individual level.

Long ago Goodman (2000) pointed out the limitations of such reductionism, using the example of high diabetes incidence among Native Americans. Rather than take this as evidence of genetically innate characteristics of the group, he noted that dietary changes toward sugar-sweetened beverages and fast foods had resulted in similar rates of diabetes among genetically unrelated groups. Nonetheless, while lifestyle changes of this sort, when occurring across a population, may help explain group differences in diabetes risk, it is problematic to extrapolate these observations to explain diabetes etiology for individuals, because it would presume homogeneous lifestyle and behavioral patterns for group members (Byrd and Hughey 2015; Kaufman and Cooper 2010). Instead, the role that race/ethnicity may play in the etiology and progression of diabetes—itself a complicated and multifaceted phenomenon—reflects an intricate interrelationship between environment, behavioral, and genetic factors.

One is left with an uneasy question: Are differential clinical guidelines for minority patients inviting clinicians to invoke biological determinism and racial stereotypes in making diabetes management decisions for minority patients?

WHAT IT MEANS TO BE RISK-FREE

Implementing more vigilant screening and aggressive treatment per ADA guidelines has no doubt been undertaken with the best of intentions, designed to improve outcomes for

minority groups suffering disproportionately from disease burden. However, the consequences of labeling some groups of patients as inherently “at risk” have not been carefully considered, or they have been dismissed by those prioritizing narrowly construed benefits above the potential unintended consequences. Invoking racial identity in clinical care constructs opposing categorizations, designating minority group members as living in bodies marked for disease and whites as having unmarked, neutral bodies. This model implies that whites are not only less susceptible, but also better able to control their disease state and more equipped to care for themselves and make lifestyle changes (c.f. Altman 2006; Hartigan 1997; Walley 2017).

This is not innocuous. Promoting the idea that one’s race determines one’s risk may not only reflect, but also engender racially based power inequities. Disregarding structural inequalities underling health disparities, and instead presuming inherent biological and behavior characteristics drive the observed patterns, may ultimately disarm the disempowered, reifying hegemonic processes that have created and upheld these risk groups in the first place (Glick Schiller 1992; Goddard and Myers 2017). A high-risk designation can also undermine patients’ sense of their own ability to impact their health, transforming an active patient into a passive one (Finkler 2003).

By considering the ways racialized risk is assigned to and embodied by patients, we can begin to understand the implications of treating race as a risk status in clinical medicine. We will explore clinician and patient ideas of race/ethnicity, risk, and responsibility in the context of type 2 diabetes, to better understand how these notions are conceptualized and applied by clinicians, and the impact this has on patients.

THE STUDY

We conducted a study of diabetes management in 2014–2015 in two specialty clinics of a large US health care system. The clinics were in a Midwest US city of about 100,000 people with a racial mix typical for this part of the country -- about 60 percent white, 25 percent African American, and 12 percent Hispanic. With about 80 percent white patients, the clinics reflect common bias in referral patterns from primary care to specialty clinics. To address our research question, we oversampled minorities, resulting in a sample of about 63 percent white patients, and the rest minority—closer to the city’s demographics than the clinics’ (see Table 1).

These clinics—a Diabetes Services Clinic and a Weight Services Clinic—offer intensive and focused care to diabetes patients, requiring frequent and sustained interactions, thus providing enhanced opportunity to examine ways racial concepts may be incorporated into clinical practice. We employed a multi-faceted approach including participant observations of clinic activities and type 2 diabetes consultations. We interviewed all clinicians whose consultations we had observed, as well as many of the support staff. The patients we interviewed were recruited from observed consultations. We also asked patients for permission to review their medical records, from which we later abstracted information about medications, labs, insurance status, and clinician notes.

We observed 122 clinical consultations and interviewed 19 practitioners, including physicians, physician assistants, nurses, dietitians, and medical assistants (see Table 2). We also interviewed 52 patients and reviewed the clinic's medical records for 51 of them, focusing especially on the notes pertaining to the visits we had observed (again, see Table 1).

Interviews were open-ended, lasted about one hour, and were audio recorded and transcribed. Clinician interviews explored understandings of the causes of diabetes and criteria applied in diagnosis and treatment. We also asked specifically about the role they felt genetics, family history, and race play in diabetes etiology and management. Patient interviews focused on diabetes and weight management, care experiences, and concepts of genetic risk, race, and family history. Following IRB-approved protocols, all study participants gave informed consent for each phase of the study. In gaining informed consent, we avoided directly raising the topic of race, describing the study as exploring how group identity, genetic risk, and individual responsibility are understood in the context of diabetes management.

All interview transcripts and observational notes were coded into an NVivo (NVivo 2012) database. We developed a nested coding strategy which evolved throughout the project, capturing answers to specific questions and broader themes emerging through the course of analysis, toward capturing a nuanced understanding of subjects' everyday use of complex constructs such as genetics, race, risk, ancestry, and culture. Our review of interrater reliability exceeded 95 percent. Because we did not observe explicit conversations about race in the course of daily clinic life, to understand how race is understood and invoked in this clinical context for the present analysis, we focus primarily on the clinician and patient interviews.

PATIENTS' VIEWS OF RACE AND RISK

When we asked patients if race/ethnicity can affect what diseases a person may get, 71 percent (37/52) believed this to be true. Most named African Americans, Hispanics/Latinos, and Native Americans as more at risk, mentioning health concerns such as diabetes, high blood pressure, weight issues, and strokes. Only four (8 percent, 4/52) indicated whites or Asians might be at risk, citing conditions such as Tay-Sachs, bone loss, stroke, and heart problems. There were also a few (17 percent, 9/52) who said although they had heard that race/ethnicity affects disease susceptibility, they didn't believe this was true.

While patients generally agreed that racial/ethnic identity could affect risk for disease, when asked an open-ended question about what they thought might cause diabetes, specifically, only two (4 percent, 2/52) mentioned race/ethnicity. Instead, most (69 percent, 36/52) mentioned genes, heredity, family history, or some combination of these, as causes of diabetes. Many also named dietary factors (60 percent, 31/52) or inactivity or obesity (44 percent, 23/52).

When we asked patients if they thought their own race/ethnicity might affect their health, we began to see stark differences in responses between individuals of different racial/ethnic groups. Only a few (9 percent, 3/33) white patients said this was the case, while most (68

percent, 13/19) minority patients said that it did—with 80 percent (8/10) of African Americans, 66 percent (4/6) of Hispanic/Latinos, and 33 percent (1/3) of mixed-race patients stating this belief. While racially marked patients had internalized the idea that their race may put them at risk for disease, they did so in complex ways, offering multifaceted explanations associating their race with their own family heritage, genes, dietary preferences, and other aspects of their families' lives. The concepts of genetic and behavioral heritage were often intermixed in these discussions. Most (65 percent, 34/52) said that family history and genetic heritage are essentially the same thing, identifying the combined effect of biological inheritance, family habits, and diet as contributing factors.

Looking more closely at the responses of the African American patients, all but two (75 percent, 6/8) attributed their own racial/ethnic risk primarily to preferred foods. "Fried foods," "fatty foods," "soul food," "greasy pork," and being "meat-and-potato people" were some ways African American patients characterized their cultural foods. One patient, Denise, a 42-year-old African American former state employee who had diabetes for nearly twenty years, said:

African Americans, maybe some Hispanic cultures, tend to develop diabetes. I don't know exactly what it is in us that does it, but I just think it's more prevalent in those type of cultures. ... It's our diet. We come from families of rich foods and fried foods. Food is a big thing in some of these cultures. They're not always the healthiest foods. ... I'm sure there's something else within us, but what that is, I don't know.

Like Denise, patients frequently related their race to both cultural and biological factors. We saw some group differences in the emphasis placed on these factors, with African Americans emphasizing family history or genetics and Latinos focusing more on their ethnic diet and related weight gain. Few (6 percent, 2/33) white patients thought their diabetes had anything to do with their race and more often blamed diabetes on personal lifestyle choices and their individual family history or genetics, without relating these to racial identity.

When asked if clinicians had ever discussed their race/ethnicity in relation to their health, only a few patients (12 percent, 6/52) said they had. For example, Elaine, a 56-year-old African American woman, told us:

[My primary care doctor is] always talking about: "Either you're going to lose weight, or you're going to die." ... I think that he, in a kind of funny way, is trying to tell you that, "You're black and you need to try to eat better." You know? He's African American but I think he's trying to let us know we need to eat right.

Though her clinician didn't mention her race directly, Elaine understood him to be insinuating that her unhealthy dietary choices were race-based. This affected her conception of her poor health, which she attributed to her race, diet, and weight gain.

Others reported having had more direct racial conversations with clinicians. For example, Grace, a 51-year-old African American patient, said that over time, she had been told by several doctors that being black put her at higher risk:

I have had different doctors tell me that blacks—that we have high blood pressure and we have sickle cell. ... One doctor was checking my feet and my legs, that's when he told me I had neuropathy. That doctor went OFF on me. ... He's like, "First you're going to have high blood pressure, then you're going to have heart disease, and then you're going to not be able to walk, and then we're going to have to cut your foot off, and then we're going to have to cut your leg off, and then you're going to die if you don't take care of yourself!"

Though extreme, this outburst illustrates the types of cautionary rhetoric several African American patients told us they had heard from doctors, and the excess vigilance they appeared to be subjected to.

In contrast, only two white patients said their clinicians mentioned race to them, and one said he had brought it up himself because he was curious about it. Another, Sarah, the 54-year-old white woman quoted at the beginning of this article, reiterated several times that being white exempted her from health risks related to race/ethnicity:

I think I'm fortunate that I'm Caucasian. And I'm a certain age, and I've always had health care because my dad was a factory worker. So I don't think I fall into any of the categories where they would say, "There's a high rate of blah, blah, blah." I haven't had any of those factors that come into play for the most part.

When we asked patients if they thought clinicians take race/ethnicity into account when giving care, nearly half (48 percent, 25/52) said they did. Many thought their clinicians were applying insights based on scientific studies, while others were concerned about stereotypic assumptions.

In clinical observations, we rarely saw race addressed directly, but it was often clearly in the background of the interaction. During discussions of eating habits, the conversation often focused on the patient's ethnic diet. For example, one Hispanic patient lamented to his clinician that he would have to give up Mexican food to follow a diabetes diet. The clinician reassured him he wouldn't necessarily have to, and referred him to a nutrition class to learn to manage his food choices. The same clinician later told us in passing that diabetes is "really common" in the Hispanic population.

CLINICAL APPLICATIONS OF RACE/ETHNICITY

When we asked clinicians if knowing a person's race impacted how they cared for a patient, most clinicians (79 percent, 15/19) said it did. However, they cited a diverse set of reasons for taking race into consideration. Many mentioned biological factors, saying, for example, that African Americans are often insulin resistant and more susceptible to hypertension and kidney disease. As Ms Norbury, a physician assistant, put it: "African-Americans have a much higher risk of kidney disease from diabetes. So [we're] trying to really work on getting blood sugars down to help prevent kidney disease, and also making sure that they're getting their annual kidney screenings, and things like that."

Clinicians also often cited behavioral factors as relevant in health care for racial/ethnic group members, noting group food preferences that may lead to being overweight or that compete

with recommended dietary changes. Clinicians reported various ways they may alter care in response to a patient's race, such as requiring more frequent screening for "at-risk" patients or recommending different medications or more aggressive dosages for some races than others.

Asked if racial identity was the same as genetic risk, most clinicians (68 percent, 13/19) said they were essentially the same, and in providing specific examples of genetically based disease risk, they invariably identified racial/ethnic minorities—African Americans, Hispanics/Latinos, and Native Americans. There was no distinction in this view by training: Physicians, nurse practitioners, and medical assistants alike spoke of race in terms that intermingled genetics and behavior. As a nurse practitioner, Ms Nolan, put it: "I can't tease it out because if you're African American, some of that's genetic. ... So does it make a difference? I'm sure it does. But it's also what you eat, how you eat it, who you eat it with, how you care for your babies, and so on." Likewise, Ms Ward, a fitness specialist, told us: "When you look at family history from a medical standpoint, you're looking at their genetic traits as well as their cultural traits. Same thing when you look at race and ethnicity. ... So it's hard to separate the two sometimes."

For the most part, clinicians used the term "culture" to refer to food choices, asserting that minorities, specifically African Americans and Hispanics/Latinos, tend to eat unhealthy foods and need to be taught to make better choices. As Dr Cooper, an endocrinologist, explained:

Certain ethnic populations eat certain foods. ... I don't want to stereotype either, but if you truly look at differences in cultures, Hispanic people tend to eat more white rice and flour tortillas and corn, and things like high-carb meals, whereas other populations like Japanese or Asian, they might eat rice. ... They're more vegetarian-based and lean protein-based.

CLINICIAN ASSUMPTIONS ABOUT THE LIVES OF RACIAL/ETHNIC MINORITIES

A few clinicians (21 percent, 4/19) raised socio-economic status as a factor impacting the health of minority patients. As one dietitian, Ms Torres, stated: "Those who are economically challenged or don't have good access to food are at higher risk." Such discussions were uniformly framed in individual terms, without reference to historical and structural inequalities that might impact a minority group as a whole. Several clinicians extended their assumptions about minority patients' personal socio-economic circumstances beyond diet, to broad conjectures about all kinds of behaviors. For example, Mr Steward is a behavioral counselor working with diabetic weight management patients. When we asked if some people are more at-risk for these conditions than others he said: "People from the South—especially African Americans—tend to eat really fattening stuff, and it's just habit, I guess. Hispanics tend to eat very heavy. They can eat really well, but there's a lot of—you know, tamales are filled with lard and cornmeal. It's pretty brutal."

Mr Steward considered race/ethnicity determinative of diet. He went on to explain how race might influence how he assessed and responded to patients:

Say I meet an African-American woman who's single. It's sad to say that I often don't assume that there is a strong male figure in the family constellation. And that's just based on experience. I think about her likely having multiple stresses in her life. You know, health, and finances, and legal issues—and a lack of access to the kind of resources she needs. And it's often trying to persuade them to set better boundaries with people in their lives. Because the ones that are healthier are often the ones who have learned that lesson and figured out how to say “no” to people or how to cut ties with people who are toxic or just absolutely drowning them and their perpetual need. So it's more what I'm looking for, I guess, than treating them differently. It's more kind of seeing a story and, “Oh, I've seen this before. And here is what might help them.”

While few clinicians articulated so much detail about minority patients, many used race/ethnicity not only as a clue to genetics or culture, but to invoke stereotyping assumptions about the life of racially marked patients that may drive their approach to caring for them. Several clinicians said that years in practice had taught them to expect certain patterns with different racial/ethnic groups. They felt they needed to be especially assertive about diet changes with patients from these groups.

Many also intermingled biological and behavioral explanations in discussing how they believe race may impact drug efficacy. Dr Jones, an endocrinologist, explained: “We're finding out some races are more sensitive to certain medications. Some races may need insulin earlier on than other races. We're just finding that out now based on the epidemiologic studies.” Similarly, Dr Cooper said that although she did not make treatment decisions based solely on race, she did consider race when prescribing:

African-American patients tend to be a little more insulin resistant. So I'm gonna be a little more aggressive as far as therapy goes for them, because I know that their sugars aren't gonna respond in the same way that it might with someone else, compared to a Caucasian, for example. ... It wouldn't be something I would know from the get-go, but in the back in of my mind I would probably know I'm gonna have to jump to insulin quicker or go to the highest dose a little sooner.

Because clinicians base some treatment decisions on racial identity, many found mixed-race patients challenging. Ms Nolan stated that the “dilution” of genetics and culture through interracial marriage made it difficult to identify a patient's race/ethnicity, complicating race-based treatment choices. She suggested that she could better select medications if she could order individual genetic testing to determine which treatment response group a patient belonged to.

RESPONSIBILITY

Of particular interest in how concepts of race/ethnicity impact clinical care is the ways patient responsibility for disease management is differentially conceived depending on racial/ethnic identity. When we asked clinicians if patients with genetic risk for diabetes had

the same level of responsibility for managing the condition as did patients without genetic risk, about half (42 percent, 8/19) said such patients needed to take added responsibility to avoid or manage the illness. Though this question preceded any specific question about race, their answers revealed that they were equating genetic risk with race/ethnicity, and illustrations they gave focused on minority patients.

For example, several clinicians indicated that high-risk patients needed to be more vigilant in caring for themselves, and should closely watch their diet and monitor their symptoms, be more frequently screened for related conditions, and generally maintain a heightened awareness of their disease status. As Ms Torres, the dietician, told us, “We know that African Americans are more at risk for high blood pressure. So although I very carefully monitor that with everyone, I also tell [African Americans] straight up, ‘You’re more at risk for this, so you need to be more careful about what you’re eating.’”

Telling patients that they are “at risk” was also seen by several clinicians as a potential motivator. They said patients knowing they are at genetic risk of developing diabetes opened an opportunity to take steps to prevent it. Dr Pohl, an endocrinologist, told us that risk can help to alert a patient, “because a lot of patients come in here and they beat themselves up, they’re negative, and they’re at wits end. ... [We tell them] we can’t alter the genetics, but we’re going to alter the environment that you’re in to give us the edge.”

Other clinicians thought that racial/ethnic risk could make it easier for patients to take less responsibility. Another endocrinologist, Dr Simmons, argued that some people would then say, “Well, it’s in my genetics, so you know, what can I do about it?” Mr Steward, the behavioral counselor, compared racialized risk with other genetic traits that patients may just accept as part of their lives “like the color of their hair or vision problems or any other genetic abnormality or problem ... instead of thinking about it as something that they can fix, cure, or be done with, it’s something that’s a lifelong struggle.”

When we asked clinicians if being at risk changed the level of responsibility the patient had for managing diabetes, nearly half (47 percent, 9/19) said that once diagnosed, everyone is equally responsible to try to manage the condition. For example, Mr Jermaine, a medical assistant and nursing student, said, “Whether you’ve had the family history or not, I think you have to manage it the same. ... It’s not like one group of the population can say, ‘Oh, I don’t have to worry about it as much.’ I think it’s serious either way.”

Patients also thought at-risk individuals should take responsibility for their health. About half (48 percent, 25/52) said that at-risk people still needed to prevent the onset of the condition, and most (65 percent, 34/52) believed that this was possible through lifestyle changes and extra vigilance. For example, Zoe, a 42-year-old mixed-race patient, believed that people with a genetic risk for diabetes could prevent it from developing by eating correctly, exercising, and not gaining weight. She said, “Once you get it, it’s up to the individual. Nobody else can take care of it but you.” Similarly, Constance, a 50-year-old African American woman, said, “You can keep it under control. It may be pushing right at the door and because of culture, because of what you were exposed to, what you eat and all those different things, it can be pushing, but I think you can make some different decisions

and hold it at bay.” Other patients were more skeptical. For example, Georgia, a 66-year-old white woman, didn’t think genetics were changeable: “If it’s genetic, it’s genetic. That’s how I’ve always thought of it.”

EMBODYING “RISK”: CARMEN’S STORY

Patients grappled with a complicated and often contradictory set of experiences and concepts, trying to internalize and act upon their own risk status. Their understandings of “being at risk” combined genetic, biological, racial, cultural, and familial concepts. The following example illustrates the challenges patients encounter in attempting to apply notions of racialized risk to their own circumstances and experiences.

Carmen, a 32-year-old Hispanic woman born and raised in the Midwest, was first diagnosed with diabetes about a year before we interviewed her. She was a stay-at-home mom with two small children, contending with both obesity and diabetes. She was in the process of trying to be accepted for bariatric surgery and had only four more pounds to lose to qualify.²

When we asked Carmen directly if she thought her race/ethnicity had affected her health issues or her ability to control them, she said: “I call that all crap.” But Carmen’s understanding of why she had developed diabetes was complicated. She said her clinicians related this to her family history and race/ethnicity, but also viewed her as responsible because she had not heeded their warnings about her weight. She rejected the idea that being Hispanic affected her susceptibility to the diseases, saying:

Diabetes doesn’t discriminate. ... I’ve heard, “Oh, you’re Mexican, so that’s why you’re big.” No, I’m big because I chose to get big. I’m big because I ate. I’m big because of me. It has nothing to do with the fact that I’m Mexican.

Yet she also thought her own racial/ethnic background did have important consequences for her health, due to her family’s dietary habits, and that it had affected her having gained weight, developing diabetes, and that it interfered with her ability to manage these conditions:

We make horrible choices in food when we have family gatherings. It isn’t cooking with healthy anything. It’s refried beans and a pig foot. It’s rice fried first before you cook it. Its taco shells dipped in grease. (Laughs) Oh yes, I blame them, too, because it’s good!

While Carmen may seem to contradict herself, her views point to the complexity of the racial/ethnic concept and the nuanced and idiosyncratic way it can be integrated into an individual’s understanding of their own health. Carmen both accepts the idea that her family history has put her at risk, and insists that “race and ethnicity have nothing to do with it,” embracing the idea that culturally based choices have affected her health. Carmen takes up the idea of diabetes running in a family, not as a genetic predisposition but a heritage passed through family traditions and food culture. She also believes the cycle can be broken: she

²Before health insurance will cover bariatric surgery, patients must achieve a series of goals, including making significant dietary changes, adhering to an exercise regimen, and losing a certain amount of weight.

can make different choices for herself and her children: “If you’re not taking care of yourself and your kids are watching, they’re not going to take care of themselves.”

Thus, while rejecting the notion that race/ethnicity is determinative of disease, Carmen views her race/ethnicity as highly relevant in the management of her health, accepting racialized responsibility for her health problems and taking steps to rectify them. This included her pursuit of bariatric surgery, involving the removal of a portion of her stomach to force her to radically change her diet for the rest of her life. Carmen sees having the surgery as the responsible thing to do, to break the cycle of diabetes and weight issues in her family: “It’s time for me to get healthy. I have two children, and I can’t live big. Congestive heart failure is in my family. Diabetes is in my family. And cancers are in my family. And obesity is, too. And it was time for me to make a change.”

Carmen illustrates the complicated, very personal, and contradictory ways patients may wrestle with the idea of racialized risk and the responsibilities it can entail. She has converted racial risk into personally meaningful terms. While rejecting the idea of inherent racial/ethnic risk, she applies the racial/ethnic label to her family’s food habits and emphasizes her individual agency in making choices that affect her health. At the same time, by pursuing a radical surgical intervention, she hopes to revise the dietary habits her children acquire from her.

DISCUSSION

In this article, we have examined how concepts of racialized risk are integrated into managing diabetes and obesity in two clinics in the US Midwest. Instructed by practice guidelines indicating that race/ethnicity is clinically important in unspecified ways, clinicians invoked common presumptions about the genetic and cultural heritage of minority patients. Nearly all viewed racially marked patients as requiring added vigilance, greater patient responsibility, and more aggressive treatments. Of course, we are reporting on a small number of clinicians and patients from just two clinics, and our findings do not draw on a representative sample. Even so, we encountered a number of noteworthy concepts among those we interviewed.

While clinicians agreed that race/ethnicity was clinically relevant, they were vague about how and in what ways racial/ethnic identity increased the risk status of racialized patients. They combined genetic, familial, biological, behavioral, and cultural factors, while rarely mentioning that socioeconomic factors might also contribute to the health of minority patients. When they mentioned socioeconomic factors, these were uniformly presented as presumed individual attributes, stripped of broader historical and sociopolitical context.

Patients also held vague concepts of the relevance of race/ethnicity to health, conflating genetics, biology, and culture. However, their views were strikingly idiosyncratic and personal versions of how they might take control of their health in light of a family history of illness. Furthermore, patients who internalized racialized risk were nearly all of racially marked groups—African American and Hispanic/Latino. In contrast, white patients rarely considered their own race to be a factor in their disease status. Since this is consistent with

US structures of social power, this difference suggests that racialized risk is differentially embodied in marked and unmarked bodies. This in turn illustrates how structures of inequality may be reproduced in the clinical setting.

While only vaguely defined, concepts of race/ethnicity importantly impact clinical care. Minority patients were presumed by clinicians and patients alike to be more at risk and to have less control over their health than white patients, channeling blame toward minority patients for developing health problems and exhorting them to shoulder an increased burden of responsibility for managing disease (Bonham, et al. 2016; Duster 2015; Hughey and Byrd 2015). This both validates the construction of cultural others, and criticizes them for their inability to maintain their health through added vigilance and self-care (Glick Schiller 1992; Hunt and Kreiner 2011; Kaufman and Cooper 2010).

The idea that minority patients are at increased risk for certain diseases is based on epidemiological observation of the distribution of disease in the general population. When clinical medicine incorporates this concept into care, attention shifts from attending to the patient as an individual with unique circumstances (Bluhm and Borgerson 2011) to probabilistic concepts of what may pertain to an aggregate of individuals (Hunt, Castaneda, and De Voogd 2006; Lambert 2006; Rockhill 2001; Kreiner and Hunt 2014). When race/ethnicity is invoked in clinical care, population-level attributes, rooted in broad historical and social processes, are presumed to be manifest as individual biological, behavioral, and cultural characteristics of “at-risk” population group members. That disparities are shaped by socioeconomic status is neglected, and the pattern is attributed to individual biology and behaviors (Fletcher 2016), often framed as presumptive stereotypes about diet, ethnicity, and culture, for which individuals are expected to take responsibility.

Through individualizing racial risk in this way, social power becomes embodied in the risk status of individual patients. Racialized risk discourse, when taken up with no historical or structural context, plainly reflects and reproduces larger social hierarchies (Byrd and Hughey 2015; Shim 2005). Thus, racialized medicine may promote and perpetuate further disempowerment for racially marked patients, undermining their agency in managing their disease, and casting blame and stigma on them. Unmarked white patients are simply tasked with complying with clinical recommendations; those of an at-risk race/ethnicity encounter more limited expectations for self-control, greater responsibility to manage their risk, and more aggressive oversight and treatment (Bonham, et al. 2016; Hunt, Kreiner and Rodriguez-Mejia 2013a).

Using race/ethnicity to make clinical decisions should not be assumed to be harmless. Such practices can lead to unequal care and discrimination (Ifekwunigwe et al. 2017; Kaufman and Cooper 2010), stereotyping assumptions about patients’ lives (Smith-Morris 2017), exclusion of potentially helpful treatments (Acquaviva and Mintz 2010), patients developing negative perceptions of risk (Graves 2015; Hunt et al. 2006), and stigmatization and reproduction of privilege and power (Kahn 2009; Martinez-Hume et al. 2017). This frames the racial/ethnic “other” as having a risky body, which needs to be consistently checked, monitored, labeled, and treated for illness, reinforcing structural power and inequity along racial lines (Glick Schiller 1992; Hartigan 1997; Mukherjee 2016). While sometimes an

effective tool for public health campaigns (Smith-Morris 2006), invoking racialized risk in clinical care as an individual characteristic may in effect replicate the structural inequalities that underlie the very group differences the model is intended to address. If all patients—racially marked or unmarked—can be assessed and treated as individuals, rather than on the basis of the genetic or cultural characteristics presumed of their racial/ethnic group, it will open the door to what can truly be considered “personalized” and equitable medicine.

ACKNOWLEDGMENTS

Ethics approval for the study was obtained from Michigan State University (Protocol Number: 13–659M) and from the clinical research sites under an Institutional Authorization Agreement with the university. All participants provided signed informed consent to take part in the study.

We wish to thank the clinicians, clinical staff, and patients who participated in this study, whose kind cooperation made this research possible. Allison Baker, MaryKate Bodnar, and Tan Li provided invaluable assistance with a variety of data collection, analysis, and editorial tasks.

FUNDING

This work was supported by the National Institutes of Health National Human Genome Research Institute under grant number #NIH 1 R01 HG 007060–01A1, under the supervision of Linda M. Hunt as Principle Investigator. The content of this article is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

REFERENCES

- Ackerman SL, Darling KW, Lee SSJ, Hiatt RA, and Shim JK 2016 Accounting for complexity: Gene-environment interaction research and the moral economy of quantification. *Science Technology and Human Values* 41(2):194–218.
- Acquaviva KD and Mintz M 2010 Are we teaching racial profiling? The dangers of subjective determinations of race and ethnicity in case presentations. *Academic Medicine* 85(4):702–705. [PubMed: 20354391]
- ADA (American Diabetes Association) 2017a Classification and diagnosis of diabetes. *Diabetes Care* 40 (Suppl 1):S11–S24. [PubMed: 27979889]
- ADA (American Diabetes Association) 2017b Standards of medical care in diabetes—2017. *The Journal of Clinical and Applied Research and Education* 40(S1).
- Ahn E and Park T 2017 Analysis of population-specific pharmacogenomic variants using next-generation sequencing data. *Scientific Reports* 7(1):8416. [PubMed: 28871186]
- Altman N 2006 Whiteness. *Psychoanalytic Quarterly* 75(1):45–72. [PubMed: 16482960]
- Bauer S 2013 Modeling population health: Reflections on the performativity of epidemiological techniques in the age of genomics. *Medical Anthropology Quarterly* 27(4):510–30. [PubMed: 24214880]
- Bluhm R and Borgerson K 2011 Evidence-based medicine. In *Philosophy of Medicine* Pp. 203–238. *Handbook of the Philosophy of Science*, Vol. 16 BV: Elsevier.
- Boddy J 2017; FDA approves marketing of consumer genetic tests for some conditions. NPR <http://www.npr.org/sections/health-shots/2017/04/07/522897473/fda-approves-marketing-of-consumer-genetic-tests-for-some-conditions>.
- Bonham VL, Callier SL, and Royal CD 2016 Will precision medicine move us beyond race? *New England Journal of Medicine* 374(21):2003–5. [PubMed: 27223144]
- Byrd WC and Hughey MW 2015 Biological determinism and racial essentialism: The ideological double helix of racial inequality. *Annals of the American Academy of Political and Social Science* 661(1):8–22.
- CDC (Centers for Disease Control and Prevention) 2016 Diabetes: Working to reverse the US epidemic - at a glance 2016. *Chronic Disease Prevention and Health Promotion* <https://www.cdc.gov/chronicdisease/resources/publications/aag/diabetes.htm>. Accessed April 26, 2017.

- Duster T 2015 A post-genomic surprise. The molecular reinscription of race in science, law and medicine. *British Journal of Sociology* 66(1):1–27. [PubMed: 25789799]
- Finkler K 2003 Illusions of controlling the future: risk and genetic inheritance. *Anthropology and Medicine* 10(1):51–70. [PubMed: 26867066]
- Fletcher RA 2016 “Keeping up with the cadillacs: What health insurance disparities, moral hazard, and the Cadillac Tax mean to the Patient Protection and Affordable Care Act.” *Medical Anthropology Quarterly* 30 (1):18–36. [PubMed: 25132244]
- Goddard T and Myers RR 2017 Against evidence-based oppression: Marginalized youth and the politics of risk-based assessment and intervention. *Theoretical Criminology* 21(2):151–167.
- Goodman AH 2000 Why genes don’t count (for racial differences in health). *American Journal of Public Health* 90(11):1699–1702. [PubMed: 11076233]
- Goodman AH, Moses YT and Jones JL 2012 *Race: Are we so different?* Malden, MA: Wiley-Blackwell.
- Graves JL, Jr 2015 Great is their sin: Biological determinism in the age of genomics. *Annals of the American Academy of Political and Social Science* 661(1):24–50.
- Gravlee CC 2009 How race becomes biology: Embodiment of social inequality. *American Journal of Physical Anthropology* 139(1):47–57. [PubMed: 19226645]
- Haritigan J 2013 Knowing race *In Anthropology of Race: Genes, Biology, and Culture* Hartigan J, ed. Pp. 3–19. Santa Fe: School for Advanced Research Press.
- Haritigan J 1997 Establishing the fact of whiteness. *American Anthropologist* 99(3):495–505.
- Hughey MW and Byrd WC 2015 Beautiful melodies telling me terrible things: The future of race and genetics for scholars and policy-makers. *Annals of the American Academy of Political and Social Science* 661(1):238–258.
- Hunt LM, Castaneda H, and De Voogd KB 2006 Do notions of risk inform patient choice? Lessons from a study of prenatal genetic counseling. *Medical Anthropology* 25(3):193–219. [PubMed: 16895827]
- Hunt LM and Kreiner MJ 2013 Pharmacogenetics in primary care: The promise of personalized medicine and the reality of racial profiling. *Culture Medicine and Psychiatry* 37(1):226–35.
- Hunt LM and Kreiner MJ 2011 Race and genetics: Concepts and practice in primary care. *American Journal of Physical Anthropology* 144:171–171.
- Hunt LM, Kreiner MJ, and Rodriguez-Mejia F 2013a Changing diagnostic and treatment criteria for chronic illness: A critical consideration of their impact on low-income hispanic patients. *Human Organization* 72(3):242–253. [PubMed: 25797962]
- Hunt LM, Truesdell ND, and Kreiner MJ 2013b Genes, race, and culture in clinical care: Racial profiling in the management of chronic illness. *Medical Anthropology Quarterly* 27(2):253–71. [PubMed: 23804331]
- Ifekwunigwe JO, Wagner JK, Yu JH, Harrell TM, Bamshad MJ, and Royal CD 2017 A qualitative analysis of how anthropologists interpret the race construct. *American Anthropologist* 119(3):422–434. [PubMed: 30078844]
- Kahn J 2009 Beyond Bidil: The expanding embrace of race in biomedical research and product development. *St. Louis University Journal of Health Law & Policy* 3(61):61–92.
- Kaufman JS and Cooper RS 2010 Use of racial and ethnic identity in medical evaluations and treatments *In What’s the Use of Race?: Modern Governance and the Biology of Difference* Whitmarsh I and Jones DS, eds. Pp. 187–206. Cumberland: MIT Press.
- Kreiner MJ and Hunt LM 2014 The pursuit of preventive care for chronic illness: Turning healthy people into chronic patients. *Sociology of Health and Illness* 36(6):870–884. [PubMed: 24372285]
- Krieger N 2008 Proximal, distal, and the politics of causation: What’s level got to do with it? *American Journal of Public Health* 98(2):221–30. [PubMed: 18172144]
- Lambert H 2006 Accounting for EBM: Notions of evidence in medicine. *Social Science and Medicine* 62 (11):2633–2645. [PubMed: 16387399]
- Lee SSJ and Mudaliar A 2009 Racing forward: The Genomics and Personalized Medicine Act. *Science* 323(5912):342. [PubMed: 19150830]

- Lee SSJ 2015 the biobank as political artifact: The struggle over race in categorizing genetic difference. *Annals of the American Academy of Political and Social Science* 661(1):143–159.
- Lewontin R 1972 The apportionment of human diversity. *Evolutionary Biology* 6:381–398.
- Martinez-Hume AC, Baker AM, Bell HS, Montemayor I, Elwell K, and Hunt LM 2017 “They treat you a different way:” Public insurance, stigma, and the challenge to quality health care. *Culture Medicine and Psychiatry* 41(1):161–180.
- Mukherjee R 2016 Antiracism limited: A pre-history of post-race. *Cultural Studies* 30(1):47–77.
- Mulligan CJ 2016 Early environments, stress, and the epigenetics of human health. *Annual Review of Anthropology* 45: 233–249.
- NVivo Qualitative Analysis Software 2012 Volume Version 10: QSR International Pty Ltd
- Rockhill B 2001 The privatization of risk. *American Journal of Public Health* 91 (3):365–368. [PubMed: 11236399]
- Schiller NG 1992 What’s wrong with this picture? The hegemonic construction of culture in aids research in the United States. *Medical Anthropology Quarterly* 6(3):237–254.
- Shim JK 2005 Constructing “race” across the science-lay divide: Racial formation in the epidemiology and experience of cardiovascular disease. *Social Studies of Science* 35(3):405–436.
- Smith-Morris C 2006 *Diabetes among the Pima: Stories of survival* Tucson, AZ: University of Arizona Press.
- Smith-Morris C 2017 Epidemiological placism in public health emergencies: Ebola in two Dallas neighborhoods. *Social Science & Medicine* 179:106–114. [PubMed: 28260635]
- Thayer ZM and Kuzawa CW 2015 Developmental and epigenetic responses to the environment: Mechanisms for the embodiment of health disparities in New Zealand. *American Journal of Physical Anthropology* 156:303–303.
- Vassy JL and Meigs JB 2012 Is genetic testing useful to predict type 2 diabetes? *Best Practice & Research: Clinical Endocrinology & Metabolism* 26(2):189–201. [PubMed: 22498248]
- Walley CJ 2017 Trump’s election and the “white working class”: What we missed. *American Ethnologist* 44(2):231–236.
- Williams DR 2012 Miles to go before we sleep: Racial inequities in health. *Journal of Health and Social Behavior* 53(3):279–95. [PubMed: 22940811]
- Yudell M, Roberts D, DeSalle R, and Tishkoff S 2016 Taking race out of human genetics. *Science Science and Society* 351(6273):564–5.

Table 1:

Selected Characteristics of 52 Patients Interviewed

		Total	
		N	%
Participants		52	
Clinic			
Diabetes Services Center	27	52%	
Weight Services Center	25	48%	
Sex			
Female	32	62%	
Male	20	38%	
Age	Range: 29–79	Median 59	
20–29	1	2%	
30–39	1	2%	
40–49	8	15%	
50–59	17	33%	
60–69	16	31%	
70–79	9	17%	
Race/Ethnicity			
White	33	63%	
Black/African American	10	19%	
Hispanic/Latino	6	12%	
Other/More Than One	3	6%	
Education			
High school or less	13	25%	
Some college/Assoc. deg.	27	52%	
Bachelor's Degree	9	17%	
Some grad sch./Master's deg.	3	6%	
Primary Health Insurance			
Medicare	25	48%	
Medicaid	6	12%	
Private	20	38%	
None	1	2%	
Household Income			
<\$10,000	4	8%	
\$11,000 to \$20,000	3	6%	
\$21,000 to \$50,000	18	35%	
\$51,000 to \$70,000	9	17%	

	Total	
	N	%
\$71,000 to \$90,000	5	10%
>\$90,000	9	17%
No Answer or Don't Know	4	8%

Table 2.

Selected Characteristics of 19 Clinicians Interviewed

Total		
	n	%
Participants	19	
Clinic		
Diabetes Services Center	9	47%
Weight Services Center	8	42%
Other Clinics ¹	2	11%
Sex		
Female	12	63%
Male	7	37%
Age Range: 22–74		
20–29	2	11%
30–39	5	26%
40–49	4	21%
50–59	4	21%
>60	4	21%
Race/Ethnicity		
White	16	84%
Asian	3	16%
Job Title		
Physician	6	32%
Nurse or NP	3	16%
Medical Assistant	3	16%
Physician Assistant	3	16%
Nonclinical Specialists ²	4	21%

¹ DSC-affiliated physicians, now working elsewhere.

² Behaviorist, Exercise Specialist, Dietician.

* Note: Percentages are rounded and may not always add to 100%