



## Family Matters

Elizabeth Ahmann, ScD, RN

# The Meaning of Race in Healthcare and Research - Part 2 Current Controversies and Emerging Research

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The state of race today is complex and challenging. An article published in the preceding issue of this journal examined the history of race and its impact on health care. This article further examines the issue of race and health care as concerns arise regarding the relevance of genetics to health disparities. Pediatric nurses must examine the literature on race, as well as our own assumptions, and be clear about when and why we use racial categories and what they really mean.

Major debates are taking place about the relevance of genetics to health disparities. The weight of research thus far leans in the direction suggesting that race is an unscientific social category, and that genetic difference fails to adequately explain health differences. There is substantial evidence that racial and ethnic health disparities are strongly associated with social factors, such as lack of access to resources, and also racial discrimination. Yet, while race appears to be a social construction, inequalities still persist amongst racialized groups, so it is premature for health care providers to abandon the concept of race altogether. Pediatric nurses must examine the literature on race, as well as our own assumptions, and be clear about when and why we use racial categories and what they really mean.

### Controversies Regarding Race

In addition to racial disparities in access to health care, in the United States there are wide disparities between the actual health of most minority groups and whites along almost all indicators. Simply put, African Americans, Native Americans, and Latinos are generally in poorer health than their white counterparts. This has contributed to some important debates, including whether racial health disparities are due to genetic or social factors, and whether race should be considered a factor in health care practice and research.

### Are Racial Health Disparities Due to Genetic or Social Factors?

Many social scientists have long disputed any genetic basis for race, viewing it as a social, not biological entity. For example, in 1998, the Executive Board of the

American Anthropological Association issued its Statement on "Race," which asserted that race is a social construction, lacking scientific meaning, and that it has been used as a justification for human exploitation. Regarding racial inequality, they state:

Given what we know about the capacity of normal humans to achieve and function within any culture, we conclude that present-day inequalities between so-called 'racial' groups are not consequences of their biological inheritance but products of historical and contemporary social, economic, educational, and political circumstances. (American Anthropological Association, 1998, p. 3)

Ample research since their statement continues to support the influence of social, rather than genetic, causes as the source of most of the major health disparities between minorities and whites (Goodman, 2000; Krieger, 2003; Ren, Amick, & Williams, 1999; Williams, 2001; Williams & Collins, 2004).

At the same time, the belief in a genetic basis for race persists among some influential scientists. For example, it is recognized that minority populations have more difficulty finding unrelated stem cell donor matches, and differences in HLA types have been found between racial groups (Mori, Beatty, Graves, Boucher, & Milford, 1997; Beatty, Mori, & Milford, 1995).

Occasionally, the differences in perspective are public. Two articles taking opposing positions on this topic appeared in the March 20, 2003 issue of the *New England Journal of Medicine*. Burchard and colleagues (2003) maintained that race and ethnicity are important categories of analysis because of genetic differences in diseases among these groups. They gave examples of genetic mutations that are more frequent in particular ethnic groups, such as Ashkenazi Jews and the Amish. Countering their attribution of these genetic differences to race, Cooper, Kaufman & Ward (2003) pointed out that not all populations racially categorized as "white" are at risk for these genetic mutations. For example, "persons of Jewish descent," not all persons racially classified as "whites," share a risk of Tay-Sachs disease. The frequency of cystic fibrosis varies widely within Europe, and thalassemia occurs in a variety of populations distributed from Italy to Thailand (Cooper, Kaufman & Ward, 2003).

Cooper and colleagues' (2003) position on the lack of genetic precision in our racial categories is supported by a

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variety of research. Population biologists point out that there is more genetic diversity *within* the standard racial categories than between them (Barbujani, Maggini, Minch, & Cavalli-Sforza, 1997; Lewontin, Rose, & Kamin, 1984). While research shows that certain genetic propensities may be more or less present in what we call racial groups, these propensities don't neatly correspond to racial categories. Rather, they reflect natural selection in response to environmental factors, such as the sickle cell allele, which appears to have evolved as a protective factor in areas with endemic malaria, and is found in Africa, southern Europe, and parts of the Middle East and South Asia (Bowman & Murray, 1990; Garte, 2002).

In addition, mixing of the "races" has occurred since peoples of different origins first encountered each other on U.S. soil (Williamson, 1995). Recent genetic studies estimate that African Americans get a wide range of from only 20% to as much as 100% of their genes from West Africa, and that about 30% of Americans who think of themselves as white have some non-European ancestry (Bamshad & Olson, 2003). Thus, prevalent racial categories don't correspond neatly to homogeneous population groups.

If health differences were inherently due to race, one would expect similarities between the health of ancestral populations and the U.S.-born. In order to test this hypothesis, Cooper and colleagues (1997) assessed hypertension in West Africa, the Caribbean, and the United States. They discovered a continuum of hypertension ranging from 16% in West Africa, to 26% in the Caribbean, to 33% in the United States. They attributed this gradient to factors such as levels of obesity and sodium and potassium intake, which correlated with the prevalence of hypertension, adding strength to the argument that social and behavioral factors produce the excess hypertension found in African Americans.

Many of the recent debates about race and genetics have occurred in the context of pharmacogenetics — the use of genetic information to fine-tune drug treatment. Wilson and colleagues (2001) organized genetic material from a range of populations into clusters according to the distribution of drug-metabolizing enzymes among them. The results indicated that common racial and ethnic labels did not accurately demarcate the clusters. For example, 62% of the Ethiopians studied were in the same cluster as the majority of Ashkenazi Jews, Norwegians, and Armenians. This evidence led researchers to conclude that racial and ethnic classifications are not sufficient for predicting responses to drug treatment.

Yet, the manufacturers of the cardiac drug BiDil, a combination of two vasodilators, have obtained FDA approval for use of this drug specifically for heart failure in African Americans. It will be the first drug approved for a specific racial group. However, the data providing the basis for this racially targeted treatment have been criticized (Kahn, 2003; Cooper, Kaufman, & Ward, 2003).

As the previous overview of the research indicates, perspectives on the relationship between genetics and race are diverse and conflicting. In an issue as politically charged as race, it is most important to examine the research evidence, as complex as it might be, and to critically explore the assumptions of the authors, as well as our own assumptions and prejudices. We live in a society that takes the existence of race for granted, and this belief influences each of us, consciously or unconsciously, as we search for solutions to the problem of health disparities.

### **Should Race Be Used in Health Care and Research?**

The impreciseness of racial categories, as well as the

history of racial discrimination in the United States, has contributed to skepticism about the use of race in the clinical setting. Reasonable concerns have been raised that suggest race has been proven to be a non-scientific concept, and that its use in medicine can both be highly misleading and can reinforce an erroneous belief in the inherent biology of race (Witzig, 1996). Fullilove (1998) has argued that race should be abandoned as a variable in public health research in favor of other levels of analysis, such as place of residence, which can provide more meaningful data about social conditions influencing health. The use of race in the clinical setting in particular can lead to stereotyping and even false assumptions (Anderson, Moscou, Fulchon, & Newspiel, 2001), as demonstrated by the case study at the beginning of the companion article published in the previous issue of this journal (Tashiro, 2005). President Clinton's Cancer Panel, which convened a meeting of experts on "The Meaning of Race in Science," concluded that race, as a social and political construct, has no basis in science; that there is no genetic basis for racial classification, nor for a belief that distinct races exist; and, that racism continues to exert a powerful influence in society (Freeman, 1997).

The American Academy of Pediatrics (AAP) stops short of advocating the abandonment of the concept of race altogether, but urges that when race is used adequate justification should be provided. According to the authors of the AAP (2000) position statement on race, "Although race historically has been viewed as a biological construct, it is now known to be more accurately characterized as a social category that has changed over time and varies across societies and cultures" (p. 1349). For this reason, in order not to perpetuate erroneous stereotypes, AAP recommends that race and ethnicity be used as variables in research only when they are accurately defined and when the reasons for using them are adequately explained.

Kaplan and Bennett (2003) suggest guidelines for responsible use of race and ethnicity in health-related publications. These include stating the reason for the use of race as a variable and specifying how individuals in the study are assigned to racial categories, avoiding the use of race as a proxy for genetic variation, and avoiding any stigmatizing and/or misleading terminology (Kaplan & Bennett, 2003, pp. 2711-2713). Regarding terminology, some (e.g., Lee, Mountain, & Koenig, 2001) have advocated for the use of the term "racialized groups" instead of "race" in research using race as variable, emphasizing that race is not inherently meaningful scientifically, but rather a concept that is produced by society.

While it would seem to make intuitive sense to abandon the use of race as a variable altogether, there are some dangers to that position too. Proponents for continuing to collect data by race argue that abandoning this practice would eliminate the evidence of health differences due to persistent inequalities between racialized groups (Krieger, Williams, & Zierler, 1999). Race is a social fact in the U.S., and the routine collection of data by race began in earnest because of the Civil Rights Act, in order to identify and eliminate discrimination in housing, employment, and other areas of civic life. Without the data, evidence of discrimination would be lost. In fact, the concept of "color-blind racism" has been identified as a way of perpetuating the racial hierarchy by ignoring racial inequalities (Bonilla-Silva, 2003). In this regard, if the Institute of Medicine report on unequal treatment, discussed previously in the companion article (Tashiro, 2005), is any indication, "color-blindness" has not yet arrived in the examining room, and to pretend that it has will detract from efforts to ameliorate the social

and economic conditions producing health disparities.

One's stance toward race must by necessity be complex. As Krieger (2001) states in relationship to epidemiologic research, "considering lived experiences of racism as real but the construct of biological 'race' as spurious, social epidemiological research investigates health consequences of economic and non-economic expressions of racial discrimination" (p. 696). To paraphrase Krieger: while race is not real, racism is.

### Emerging Areas of Research

Searching for pathways to health disparities, more researchers are focusing on how racial discrimination might affect health. Two conditions that have received particular attention are hypertension (Din-Dzietham, Nembhard, Collins, & Davis, 2004; Klonoff & Landrine, 2000; Krieger & Sidney, 1996; Williams & Neighbors, 2001) and preterm labor (Dole et al., 2003; Rosenberg, Palmer, Wise, Horton, & Corwin, 2002). There are many methodological challenges inherent in this type of research, including how to operationalize discrimination. Should it be restricted to incidents in which the participant experiences overt racism, like being confronted by a racial slur? Or, should events that the participant suspects, but can't confirm, as being discriminatory, such as being passed over for a promotion, also be included? Much more research is needed to unravel the complex relationships between discrimination and health.

Increasing evidence suggests that neighborhood and community (often racially segregated) are important determinants of health. While methodologies for this research are still evolving (Diez Roux, 2001), recent studies seem to indicate a relationship between place of residence and health disparities (Browning, Cagney, & Wen, 2003; Franzini & Spears, 2003; Krieger, Chen, Waterman, Rehkopf, & Subramanian, 2003). Neighborhood segregation is associated with a decline in health-supporting resources (Williams & Collins, 2001). It certainly makes intuitive sense that living in a poorer neighborhood would put an individual at risk for poorer health. Factors detrimental to health, such as high crime and violence, lack of access to needed services, poor quality housing, and proximity to environmental hazards are disproportionately found in low income and minority neighborhoods. One good example of how the structure of a neighborhood can affect health behavior is a study that evaluated the effects of proximity to supermarkets, which found that African Americans increased their fruit and vegetable intake by 32% with each additional supermarket in their census tract (Morland, Wing, & Diez Roux, 2002). We must be aware of these kinds of statistics when we counsel patients and families to adopt healthy behaviors, the limited resources that might be available to them, and the need to advocate for more systemic solutions to health disparities.

### Implications for Pediatric Nursing

Nurses have enormous power to shape how children and families experience their encounters with the health care system. We can collude with tired stereotypes about race, either actively through our words and deeds, or passively, by not challenging unfair and hurtful practices. Or we can communicate, even under the most difficult circumstances, our respect, caring, and awareness of the gifts our diverse patients and their families bring.

Sometimes nurses and other health care providers are unaware of our biases and how our actions might be interpreted by others. That is why it is so important to maintain awareness of race, what it is and isn't, as well as its social history. It is also important for nurses to reflect on our own views of race and what we project to patients and families.

Many tools are available to help us in this process; one example of an excellent cultural competence self-assessment can be found in the March-April 2002 issue of *Pediatric Nursing* (Ahmann, 2002). Nurses also need to have many more conversations about race, as well as opportunities to directly hear the experiences of those who are racially different from ourselves. This should begin to happen at conferences, in continuing education offerings, and other venues. Structured interactive workshops can be especially helpful in increasing our understanding of ourselves and others.

The case history at the front of the companion article published in the prior issue of *Pediatric Nursing* demonstrates both how health care providers unconsciously categorize patients based on appearance and the danger of assuming risk based solely on the patient's 'racial' appearance (Tashiro, 2005). To avoid this problem, health care providers can adopt "universal ancestry precautions," meaning that no assumptions about ancestry should be based solely on appearance (Tashiro, 2003). Such precautions are becoming increasingly important with the growing complexity of families. Also important is for nurses to do our part in our own communities and work settings to address unfair treatment when we see it. Nurses must keep aware of the latest research on race and health, and use critical thinking skills to evaluate it. We must do all we can to promote respect and equality for our entire population.

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