Published in final edited form as:
Semin Oncol Nurs. 2008 November ; 24(4): 254–261. doi:10.1016/j.soncn.2008.08.005.

Social and Ethical Implications of Genomics, Race, Ethnicity and Health Inequities

Vence L. Bonham, JD and
Associate Investigator, Social and Behavioral Research Branch, Division of Intramural Research, National Human Genome Research Institute, National Institutes of Health, 31 Center Drive Room B1B55, Bethesda, Maryland 20892-2070, Phone: (301)594-3973, Fax: (301)480-3066

Sarah Knerr, BA
Post-baccalaureate Intramural Research Fellow, Social and Behavioral Research Branch, Division of Intramural Research, National Human Genome Research Institute, National Institutes of Health, Bethesda, Maryland 20892-2070

Vence L. Bonham: bonhamv@mail.nih.gov

Abstract

Objectives—To review ethical, ethnic/ancestral, and societal issues of genetic and genomic information and technologies in the context of racial and ethnic health disparities.

Data sources—Research and journal articles, government reports, web sites.

Conclusion—As knowledge of human genetic variation and its link to diseases continues to grow, some see race and ethnicity well poised to serve as genetic surrogates in predicting disease etiology and treatment response. However, stereotyping and bias, in clinical interactions can be barriers to effective treatment for racial and ethnic minority patients.

Implications for nursing practice—The nursing profession has a key role in assuring that genomic healthcare does not enhance racial and ethnic health inequities. This will require utilization of new genomic knowledge and caring for each patient as an individual in a culturally and clinically appropriate manner.

Keywords

human genetics; clinical decision-making; race; health disparities; nursing

> "The public will increasingly expect that the registered nurse (RN) will use genetic and genomic information and technology when providing care." (1)

In September 2005 an independent consensus panel of nurse leaders from clinical, research, and academic settings was established to outline the minimum competencies needed to prepare the nursing workforce to deliver genetic and genomic focused nursing care. The result was the creation of essential nursing competencies for genetics and genomics. One of these core competencies is that a registered nurse should be able to identify ethical, ethnic/ancestral, and societal issues related to genetic and genomic information and technologies (1). This article

Correspondence to: Vence L. Bonham, bonhamv@mail.nih.gov.

addresses ethical, ethnic/ancestral, and societal issues of genetic and genomic information and technologies in the context of racial and ethnic health disparities and the implications for health professionals.

We are five years into what has been termed the genome era (2). In this relatively short period of time knowledge of the human genome has expanded dramatically, overturning widely held notions about genomic structure and function. The view of the genome as a static collection of genes has changed to a dynamic network model where overlapping regulatory elements, coding, and non-coding sequences are transcribed and interact in ways that have yet to be defined (3). The implementation of haplotype maps and the development of ultra high-throughput genotyping have shifted the search for gene variants associated with disease away from small case-control studies towards genome-wide association studies that can assess up to 500,000 single nucleotide polymorhpisms (SNPs), common, yet minute changes that occur in human DNA, in tens of thousands of individuals (4). As a result, the number of allelic variants associated with common disease, including cancer, has been climbing, with a burst of discoveries occurring in the past year. Notably new gene-disease associations have been identified in breast cancer (5–7), colon cancer (8–10), and prostate cancer (11–14). Often, these variants occur at different frequencies in different populations. Defining such variation, as well as differences in larger structural elements (15) and gene expression (16,17), in human populations and their implications for health has become an important focus of current genomic research. Given its significant association with health and disease, *Science Magazine* identified human genetic variation as the breakthrough of 2007(18).

Studies of human genetic variation are certainly not without their controversies, many of which result from publicity of unwarranted and unfounded conclusions about innate differences between human groups. 2007 was also a year of such controversy, precipitated by Nobel laureate Dr. James Watson's comments regarding race, genetics and intelligence. Watson stated in an interview for his book published in 2007 (19) that he is, "… 'inherently gloomy about the prospect of Africa' because 'all our social policies are based on the fact that their intelligence is the same as ours—whereas all the testing says not really"(20). His comments were widely denounced by the scientific community (21,22).

Thus, the year of human genetic variation was not entirely about celebrating our growing understanding of the association between genetic individuality and disease but also about our need to study the social and clinical implications of such findings. It was a year where discussion of genetics and human difference at times created an uncomfortable undertone of racism. 2007 emphasized the need for addressing ethical issues surrounding genetic technologies, genetic information, race, and health inequities, all of which are essential to improve the public's health.

There is an ongoing debate surrounding conceptualizations of race. Common understandings of race conflate biology and culture and place social meaning on physical characteristics (23). Racial categories can reflect culture, history, socioeconomic, and political status, as well as ancestral geographic origin (24). That is to say, time and place, as well as legal, political and religious realities, can impact racial identity. There are multiple dimensions of racial identity: internal (self-identified), external (what others attribute to an individual), and the public presentation of an individual's sense of their racial identity. These components are fluid and context specific. Social scientists describe racial formation as a "process by which social, economic and political forces determine the content and importance of racial categories" (25). Though popular notions of race often create categories based on group similarities that are phenotypic in nature, the factors influencing racial identity are revealed to be more complex with critical examination.

Despite the fluid and socially constructed nature of racial groupings, there have been attempts to classify individuals into discrete categories throughout history. The word "race" and many of the ideas about physical and mental human difference associated with it emerged during the "age of exploration" when increasing interaction with people from different parts of the world led Europeans to begin to sort individuals into groups (26). For centuries, science has searched to group people. In 1758 Carolus Linnaeus' *Systema naturae* classified the human population into a four-race system. This model was based on geography and physical features, but also incorporated negative stereotypes (27). Linnaeus's student J.F. Bluemenbach shifted racial taxonomy from a four race system that reflected geography to a linear, five race system that ranked groups based on their putative worth (28). From this point forward studies of biological difference between the "races" were frequently coupled with pejorative and racist terms. The eugenics movement of the late 19th and early 20th centuries (29) perpetuated such division, articulating them as rooted in genetics.

Today the United States Census Bureau collects race and ethnicity information using standards set forth by the United States Office of Management and Budget (OMB). These standards are socially and politically constructed and have changed over time as conceptions of race and ethnicity have shifted (Table 1). Currently, the OMB standards include five minimum categories for race (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White) and two categories for ethnicity (Hispanic or Latino and Not Hispanic or Latino) (30). The existing guidelines, which give individuals the ability to identify with more than one racial category, arose in response to criticism that the previous system did not accurately represent the United States population, specifically the increasing proportion who identify as multiracial (31). OMB included the caveat: "The racial and ethnic categories set forth in the standards should not be interpreted as being primarily biological or genetic in reference. Race and ethnicity may be thought of in terms of social and cultural characteristics as well as ancestry" (30).

Cancer, Genomics, Race and Ethnicity

The fields of cancer research, treatment, and prevention have faced the complexities of using racial and ethnic categories to predict health related outcomes and make medical decisions. Some clinicians feel that race and ethnicity are important genetic surrogates and thus can be useful predictors of treatment regimens. In this model differences in treatment response seen between racial or ethnic groups are perceived to be due to specific inherited genotypes that vary in frequency between racial and ethnic groups (32). For example, it has been reported that African Americans treated for breast cancer experience higher rates of chemotherapy complications (33), which some researchers and clinicians have suggested is related to variation in baseline white blood cell counts between patients.

In addition to differences in inherited mutations, differences in cancer causing somatic mutations that vary with race and ethnicity can also play a role in identifying the most effective treatments for an individual patient. The anti-cancer drug gefitinib (Iressa; AstraZeneca, London, UK) has shown evidence of increasing survival for Asian-origin patients with non-small-cell lung cancer who were refractory to or intolerant of their latest chemotherapy regimen (34). Researchers have proposed that the mechanism behind increased drug responsiveness of this population is related to somatic mutations in the epidermal growth factor receptor that occur more frequently in East Asians, women, non-smokers, and patients with adenocarcinoma (35). In another example, a high prevalence of basal-like tumors associated with decreased survival have been found in young African American women with breast cancer (36). Drug regimens tailored to target basal-like tumors could be a successful treatment option for African American women with this type of breast cancer. In prostate cancer, differences in the expression profiles of immune-response genes between tumors in African American and

European American men have recently been identified, which could have implications for utilization of immunotherapy treatment (37). Still, relying on the proxies of race and ethnicity to guide clinical decisions will not be as accurate as directly assessing the genomic and environmental factors that predict treatment response and efficacy. This is the promise of personalized medicine (38).

Race and ethnicity are also used in addition to family history as indicators for genetic testing for known cancer susceptibility variants. The most widely known example of this is *BRCA 1/2* testing for breast and ovarian cancer risk. It is documented that mutations are found at higher rates in individuals with a family history of early onset breast or ovarian cancer, particularly individuals with Ashkenazi Jewish ancestry (39). Still, a recent study of the prevalence of *BRCA1* mutations in an ethnically diverse sample of breast cancer patients showed that they occurred more frequently than expected in both Hispanic and young African American women (40) highlighting the need for the consideration of the utilization of genetic testing in a more diverse population(41).

In addition to testing for genetic susceptibility, cancer screening is another area where race and ethnicity are used to target racial and ethnic groups that may benefit from screening leading to early diagnosis. For example, mortality for colorectal cancer in African American men are 2 to 3 times higher than the general population; therefore, this group may benefit from earlier and more frequent screening for this disease (42). Prostate cancer screening has been identified as one area for earlier screening of African American men. Jones and colleagues have identified nurses as having an important role in educating African American men about existing disparities related to prostate cancer (43).

Rates of cancer incidence, morbidity, and mortality differ among population groups, including groups defined using the OMB categories. Some of these differences may be explained by genetic factors, but variation in health outcomes between racial and ethnic groups may also be attributed to social determinants in health including differences in treatment. Human beings, including health professionals, make sense of the world using universal cognitive strategies that categorize people into groups. Acquired beliefs about these groups are unconsciously applied to individuals who are assigned to them. It has been shown that practitioners unconsciously make assumptions that their racial and ethnic minority patients will not understand the diagnosis or will reject certain treatment options and communicate these topics differently to them, which may lead to disparities in patient outcomes (45–46).

Healthcare providers may also unknowingly interpret symptoms differently based on the race and ethnicity of the patient, arriving at different clinical decisions and making different treatment recommendations (47,48). The influence of unconscious stereotyping on how health professionals act in clinical encounters can impact patient satisfaction and behaviors (44,49). Thus, the effectiveness of the patient-provider relationship for eliciting positive health outcomes is influenced by both the conscious and unconscious cognitive processes of both participants.

In addition to implicit processes, the patient's and provider's explicit biases and preferences can also influence health outcomes. In this way conscious stereotyping in healthcare interactions and historical distrust of the medical profession are two barriers to effective health outcomes for minority patients. Lillie-Blanton and colleagues (50) reported that differences in access and utilization of health services may also play a role in health inequities between groups. African American and Latino patients are more likely to have a hospital-based rather than an office-based healthcare provider than white patients, independent of socio-demographic factors, health status, and insurance status. This difference in provider location could be a result of geographic or socio-cultural barriers, patient preferences or both (50), but

can have implications for cost, content and quality of care, which can in turn impact patient satisfaction and outcomes (51).

Getting at the root causes of racial and ethnic health disparities and identifying interventions to counteract them will include untangling the effects of implicit and explicit bias in patient provider interactions and access to, and utilization of, healthcare service. This complexity of this process is illustrated in the field of cancer, as disparities have been documented in both risk communication and treatment (51). Blackman and Masi point to several studies that show variation in follow-up care after cancer-related screenings when comparing racial and ethnic groups (52). Notably, minority women frequently receive their mammogram results later than white women (52). Also, white women are more likely than black women to be asked about family history of breast cancer (53). Disparities in the management of cancer related pain between racial and ethnic groups (54,55) as well as in utilization of surgery and radiation (56–58) have also been found.

There is also potential for health disparities to be ameliorated or compounded by the utilization of genomic technologies and information. For example, studies have shown racial/ethnic differences in the utilization of *BRCA1/2* genetic testing among women with a family history of breast and ovarian cancer. *BRCA1/2* genetic testing is used significantly more by white women compared to black women even after adjusting for provider-recommendation (59), barriers of ascertainment and cost (60). The extent to which this difference is explained by patient preferences is unclear, but is likely influenced by multiple social factors such as concerns about abuse of genetics information and differences in knowledge about breast cancer genetics (61). Susswein and colleagues confirmed previous findings that African American women were less likely to have BRCA1/2 testing, but, interestingly, also found that African American women participating in their study were more likely to seek out testing after receiving a cancer diagnosis (60). This suggests that context also matters when exploring the utilization of genetic testing.

Conclusions

In this era of genomic medicine what can nurses and other health professionals do to provide the best care to each and every patient? As a first step, increased knowledge of genomics and its growing relevance for clinical practice is required. Table 2 provides a list of web resources relevant to genomics and nursing practice. A second step is to recognize and understand the complexities and challenges of genomics, race, and healthcare and their relevance to health disparities (62,63). Having this knowledge, we believe, will afford nurses the necessary skills to provide individualized personal health care to each patient; not as a black or an African American or a white or a Caucasian patient, but as a patient with a condition for which health professionals are trained to provide care. The genome era will continue to provide the nursing, medical and research communities with new information to help personalize treatment. However, we must be diligent in recognizing that genetic information is not the sole component towards true individualized care. As social scientists that study how health professionals think about race and genetics, we believe the following considerations are important to the field of oncology nursing:

Treat each patient as an individual

This statement seems elementary and self evident; in reality it is a core principle for the provision of appropriate nursing care. Do not generalize clinical response and patient behaviors based upon patient characteristics, particularly race and ethnicity. Individualized care and decision making are what is required, not generalizations and stereotypes.

Race is not a phenotype

Phenotype is the observed characteristics of an individual, produced by the interaction of genes and environment (64). Ethnicity and race are not phenotypes, but rather social categories and groupings that can correlate with genetic variation in the human population. Viewing race as a phenotype can lead to barriers to effective patient care.

Bias does not equal racism

Humans bring their bias and stereotypes to everything they do. Those biases are not necessarily intentional or destructive. Seeking to understand implicit and explicit bias presented by the health professional and the patient is one step in addressing health disparities.

The nursing profession has a key role in assuring that genomic healthcare does not enhance racial and ethnic health disparities, but rather reduces them. To achieve this goal will require further understanding of how new genomic knowledge relates to health and disease, and a willingness to care for each patient as an individual in a culturally and clinically appropriate manner. Although challenging for all health professionals, we believe nurses and the nursing profession can offer leadership in the implementation of genomics into healthcare.

Acknowledgments

We thank our colleagues including Jean Jenkins, RN, PhD, FAAN, and Dale Lea, MPH, RN, CGC, FAAN for their suggestions in preparing an early draft of this article.

Supported [in part] by the Intramural Research Program of the National Human Genome Research Institute, National Institutes of Health. The content is solely the responsibility of the authors and does not represent any position or policy of the National Human Genome Research Institute, National Institutes of Health or Department of Health and Human Services.

References

1. Consensus Panel on Genetic/Genomic Nursing Competencies. Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics. Silver Spring, Maryland: American Nurses Association; 2006. See: http://www.genome.gov/17517037
2. Collins FS, Green ED, Guttmacher AE, Guyer MS. A vision for the future of genomics research. Nature 2003;422:835–847. [PubMed: 12695777]
3. The ENCODE Project Consortium. Identification and analysis of functional elements in 1% of the human genome by the ENCODE pilot project. Nature 2007;447:799–816. [PubMed: 17571346]
4. Topol SJ, Murray SS, Frazer KA. The genomics gold rush. JAMA 2007;298:218–221. [PubMed: 17622604]
5. Easton DF, Pooley KA, Dunning AM, et al. Genome-wide association study identifies novel breast cancer susceptibility loci. Nature 2007;447:1087–1093. [PubMed: 17529967]
6. Meijers-Heijbor H, van de Ouweland A, Klijn J, Wasielewski M, et al. Low-penetrance susceptibility to breast cancer due to CHEK2(*)1100delC in non-carriers of BRCA1 or BRCA2 mutations. 2002;31:55–9.
7. Hunter DJ, Kraft P, Jacobs KB, et al. A genome-wide association study identifies alleles in *FGFR2* associated with risk of sporadic postmenopausal breast cancer. Nature Gent 2007;39:870–874.
8. Haiman CA, Le Marchand L, Yamamato J, et al. A common genetic risk factor for colorectal and prostate cancer. Nature Genet 2007;39:954–956. [PubMed: 17618282]
9. Tomlinson I, Webb E, Carajal-Carmona L, et al. A genome-wide association scan of tag SNPs identifies a susceptibility variant for colorectal cancer at 8q24.21. Nature Genet 2007;39:984–988. [PubMed: 17618284]
10. Zanke BW, Greenwood CMT, Rangrej J, et al. Genome-wide association scan identifies a colorectal cancer susceptibility locus on chromosome 8q24. Nature Genet 2007;39:989–994. [PubMed: 17618283]

11. Eeles RA, Kote-Jarai Z, Giles GG, et al. Multiple newly identified loci associated with prostate cancer susceptibility. Nature Genet 2008;40:316–321. [PubMed: 18264097]
12. Robbins C, Torres JB, Hooker S, et al. Confirmation study of prostate cancer risk variations at 8q24 in African American identifies a novel risk locus. Genome Res 2007;17:1717–1722. [PubMed: 17978284]
13. Haiman CA, Patterson N, Freedman ML, et al. Multiple regions within 8q24 independently affect risk for prostate cancer. Nature Genet 2007;39:638–644. [PubMed: 17401364]
14. Zheng SL, Sun J, Wilkund F, et al. Cumulative association of five genetic variants with prostate cancer. N Engl J Med 2008;358:910–919. [PubMed: 18199855]
15. Jakobsson M, Scholz SW, Scheet P, et al. Genotype, haplotype and copy-number variation in worldwide human populations. Nature 2008;451:998–1003. [PubMed: 18288195]
16. Zhang W, Duan S, Kistner EO, et al. Evaluation of genetic variation contributing to differences in gene expression between populations. Am J Hum Genet 2008;82:631–640. [PubMed: 18313023]
17. Stranger BE, Nica AC, Forrest MS, et al. Population genomics of human gene expression. Nature Genet 2007;39:1217–1224. [PubMed: 17873874]
18. Pennisi E. Breakthrough of the year: Human Genetic Variation. Science 2007;318:1842–1843. [PubMed: 18096770]
19. Watson, JD. Avoid Boring People. New York: Alfred A. Knopf; 2007.
20. Hunt-Grubbe, C. The elementary of dear Dr. Watson. The Sunday Times. Oct 142007 [Accessed October 15, 2007]. http://entertainment.timesonline.co.uk/tol/arts_and_entertainment/books/article2630748.ece
21. The American Society of Human Genetics. ASHG Response to Recent Comments on Intellectual Ability. Policy Statement Archives. Nov2007 [Accessed March 19, 2008]. http://www.ashg.org/pages/statement_nov07.shml
22. Zerhouni, EA. Statement by Elias A. Zerhouni, M.D., Director, NIH, regarding comments attributed to Dr. James Watson. About NIH. Oct2001 [Accessed March 21, 2008]. http://www.nih.gov/about/director/10192007statement.htm
23. Holt, TC. The Problem of Race in the Twenty-first Century. Cambridge, Massachusetts: Harvard University Press; 2000.
24. Collins FS. What we do and don't know about 'race', 'ethnicity', genetics and health at the dawn of the genome era. Nature Genet 2004;36(11S):S13–S15. [PubMed: 15507997]
25. Omi, M.; Winant, H. Rethinking the Color Line: Readings in Race and Ethnicty. 2. Gallagher, Charles A., editor. New York: McGraw-Hill; 2003.
26. Race Ethnicity and Genetics Working Group. The use of racial ethnic and ancestral categories in human genetics research. Am J Hum Genet 2005;77:519–532. [PubMed: 16175499]
27. Smedley, A. Race in North America. 3. Boulder, CO: Westview Press; 2007.
28. Gould, SJ. The Mismeasure of Man. New York: W.W. Norton and Company; 1996.
29. Kevles, DJ. In the name of eugenics. New York: Knopf; 1985.
30. Office of Management and Budget. Revisions to the standards for the classification of federal data on race and ethnicity. Federal Register Notice. Oct 301997 [Accessed March 19, 2008.]. http://www.whitehouse.gov/omb/fedreg/ombdir15.html
31. Snipp MC. Racial measurement in the American census: Past practices and implications for the future. Annu Rev Sociol 2003;29:563–588.
32. Rebbeck TR, Halbert CH, Sankar P. Genetics, epidemiology and cancer disparities: Is it black and white? J Clin Oncol 2006;24:2164–2169. [PubMed: 16682735]
33. Hershman D, Weinberg ZR, Alexis K, et al. Ethnic neuropenia and treatment delay in African American women undergoing chemotherapy for early-stage breast cancer. J Natl Cancer Inst 2003;95:1545–1548. [PubMed: 14559877]
34. Thatcher N, Chang A, Parkh P, et al. Gefitinib plus best supportive care in previously treated patients with refractory advanced non-small-cell lung cancer: Results from a randomized, placebo-controlled multicenter study (Iressea Survival Evaluation in Lung Cancer). Lancet 2005;366:1527–1537. [PubMed: 16257339]

35. Sequist LV, Bell DW, Lynch T, Haber DA. Molecular predictors of response to epidermal growth factor receptor antagonists in non-small-cell lung cancer. J Clin Oncol 2007;25:587–595. [PubMed: 17290067]
36. Carey LA, Perou CM, Livasy CA, et al. Race, breast cancer subtypes, and survival in the Carolina breast cancer study. JAMA 2006;295:2492–2502. [PubMed: 16757721]
37. Wallace TA, Prueitt RL, Yi M, et al. Tumor immunobiological differences in prostate cancer between African-American and European-American men. Cancer Res 2008;68:927–936. [PubMed: 18245496]
38. Guttmacher AE, Collins FS. Realizing the promise of genomics in biomedical research. JAMA 2005;294:1399–1402. [PubMed: 16174701]
39. Antoniou A, Pharoah PD, Narod S, et al. Average risks of breast and ovarian cancer associated with *BRCA1* or *BRCA2* mutations detected in case series unselected for family history: A combined analysis of 22 studies. Am J Hum Genet 2003;72:1117–1130. [PubMed: 12677558]
40. John EM, Miron A, Gong G, et al. Prevalence of pathogenic *BRCA1* mutation carriers in 5 US racial/ethnic groups. JAMA 2007;298:2869–2876. [PubMed: 18159056]
41. Huo DH, Olopade OI. Genetic testing in diverse populations: Are researchers doing enough to get out the correct message? JAMA 2007;298:2910–2911. [PubMed: 18159061]
42. Polite BN, Dignam JJ, Olopade OI. Colorectal cancer model of health disparities: Understanding morality differences in minority populations. J Clin Oncol 2006;24:2179–2187. [PubMed: 16682737]
43. Jones RA, Underwood SM, Rivers BM. Reducing prostate cancer morbidity and mortality in African American men. Clin J Oncol Nurs 2007;11:865–872. [PubMed: 18063545]
44. vanRyn M. Research on the provider contribution to race/ethnicity disparities in medical care. Med Care 2002;1(suppl 1):I140–I151.
45. Street RL, Howard G, Haidet P. Physicians' communication and perceptions of patients: Is it how they look, how they talk, or is it just the doctor? Soc Sci Med 2007;65:586–598. [PubMed: 17462801]
46. Siminoff LA, Graham GC, Gordon NH. Cancer communication patterns and the influence of patient characteristics: Disparities in information-giving and affective behaviors. Patient Educ Couns 2006;62:355–360. [PubMed: 16860520]
47. Green AR, Carney DR, Pallin DJ, et al. Implicit bias among physicians and its prediction of thrombolysis decisions for black and white patients. J Gen Intern Med 2007;22:1231–1238. [PubMed: 17594129]
48. Schulman KA, Berlin JA, Harless W, et al. The effect of race and sex on physicians' recommendations for cardiac catheterization. N Engl J Med 1999;340:618–626. [PubMed: 10029647]
49. Roter DL, Frankel RM, Hall JA, Sluyter D. The expression of emotion through nonverbal behavior in medical visits. J Gen Intern Med 2006;21(suppl 1):S28–S34. [PubMed: 16405706]
50. Lillie-Blanton M, Martinex RM, Salganicoff A. Site of medical care: Do racial and ethnic differences persist? Yale J Health Policy Law Ethics 2001;1:1–17. [PubMed: 12669318]
51. Smedley, BD.; Stith, AY.; Nelson, AR. Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Washington, DC: The National Academies Press; 2003.
52. Blackman DJ, Masi DM. Racial and ethnic disparities in breast cancer mortality: Are we doing enough to address the root causes? J Clin Oncol 2006;24:2170–2178. [PubMed: 16682736]
53. Murff HJ, Byrne D, Haas JS, et al. Race and family history assessment for breast cancer. J Gen Intern Med 2005;20:75–80. [PubMed: 15693932]
54. Anderson KO, Mendoza TR, Valero V, et al. Minority cancer patients and their providers: pain management attitudes and practices. Cancer 2000;88:1929–1938. [PubMed: 10760771]
55. Bernabei R, Gambassi G, Lapane K, et al. Management of pain in elderly patients with cancer. JAMA 1998;279:1877–1882. [PubMed: 9634258]
56. Harlan L, Brawley O, Pommerenke F, Wali P, Kramer B. Geographic, age and racial variation in the treatment of local/regional carcinoma of the prostate. J Clin Oncol 1995;13:93–100. [PubMed: 7799048]
57. Merrill RM, Merrill AV, Mayer LS. Factors associated with no surgery or radiation therapy for invasive cervical cancer in black and white women. Ethn Dis 2000;10:248–256. [PubMed: 10892832]

58. Chen AY, Halpern MT, Schrag NM, et al. Disparities and trends in sentinel lymph node biopsy among early-stage breast cancer patients (1998–2005). J Natl Cancer Inst 2008;100:462–474. [PubMed: 18364506]

59. Armstrong K, Micco E, Carney A, Stopfer J, Putt M. Racial differences in the use of *BRCA1/2* testing among women with a family history of breast or ovarian cancer. JAMA 2005;293:1729–1736. [PubMed: 15827311]

60. Susswein LR, Skrzynia C, Lange LA, et al. Increased uptake of *BRCA1/2* genetic testing among African American Women with a recent diagnosis of breast cancer. J Clin Oncol 2008;26:32–36. [PubMed: 18165638]

61. Halbert DH, Kessler LJ, Mitchell E. Genetic testing for inherited breast cancer risk in African Americans. Cancer Invest 2005;23:285–295. [PubMed: 16100940]

62. Tashiro CJ. The meaning of race in health care and research—part 1: The impact of history. Pediatr Nurs 2005;31:208–210. [PubMed: 16060585]

63. Tashiro CJ. The meaning of race in healthcare research—part 2: Current controversies and emerging research. Pediatr Nurs 2005;31:305–308. [PubMed: 16229127]

64. Jorde, LB.; Carey, JC.; White, RL. Medical Genetics Rev Ed. St. Louis, MO: Mosby; 1999.

65. Nobles M. History counts: a comparative analysis of racial/color categorization in US and Brazilian censuses. Am J Public Health 2000;90:1738–1745. [PubMed: 11076243]

Table 1

U.S. Census race categories, 1800–2000

Year	Categories
1800	Free White Males; Free White Females; All other free Persons, except Indians Not Taxed; Slaves
1810	Free White Males; Free White Females; All other free Persons, except Indians Not Taxed; Slaves
1820	Free White Males; Free White Females; Free colored persons, All other persons, except Indians Not Taxed; Slaves
1830	Free White Persons; Free Colored Persons; Slaves
1840	Free White Persons; Free Colored Persons; Slaves
1850	Black; Mulatto[a]
1860	Black; Mulatto; (Indian)[b]
1880	White; Black; Mulatto; Chinese; Indian
1890	White; Black Mulatto; Quadroon; Octoroon; Chinese; Japanese; Indian
1900	White; Black; Chinese; Japanese; Indian
1910	White; Black; Mulatto; Chinese; Japanese; Indian; Other (+ write in)
1920	White; Black; Mulatto; Indian; Chinese; Japanese; Filipino; Hindu; Korean; Other (+ write in)
1930	White; Negro; Mexican; Indian; Chinese; Japanese; Filipino; Hindu; Korean; (Other races, spell out in full)
1940	White; Negro; Indian; Chinese; Japanese; Filipino; Hindu; Korean; (Other races, spell out in full)
1950	White; Negro; Indian; Japanese; Chinese; Filipino; (Other race-spell out)
1960	White; Negro; American Indian; Japanese; Chinese; Filipino; Hawaiian; Part-Hawaiian; Aleut Eskimo, etc.
1970	White; Negro or Black; American Indian; Japanese; Chinese; Filipino; Hawaiian; Korean; Other (print race)
1980	White; Negro or Black; Japanese; Chinese; Filipino; Korean; Vietnamese; American Indian; Asian Indian; Hawaiian; Guamanian; Samoan; Eskimo; Aleut; Other (specify)
1990	White; Black or Negro; American Indian; Eskimo; Aleut; Chinese; Filipino; Hawaiian; Korean; Vietnamese; Japanese; Asian Indian; Samoan; Guamanian; Other API (Asian or Pacific Islander); Other race
2000	White; Black, African American, or Negro; American Indian or Alaska Native; Asian Indian; Chinese; Filipino; Japanese; Korean; Vietnamese; Native Hawaiian; Guamanian or Chamorro; Samoan; Other Asian (Print Race); Other Pacific Islander (Print Race); Some other race (Print Race)

Note. Categories are presented in the order in which they appeared on schedules.

Source. US Bureau of the Census.

[a] In 1850, free persons were enumerated on the form for “free inhabitants”; slaves were enumerated on the form designated for “slave inhabitants.” For the free schedule, the instructions told the enumerators: “In all cases where the person is white leave the space blank in the column marked ‘Color’ ”. For the slave schedule, the listed categories were black (B) or mulatto (M).

[b] Although “Indian” was not listed on the census schedule, the instructions read: “ ‘Indians’—Indians not taxed are not to be enumerated. The families of Indians who have renounced tribal rule, and who under State or Territorial laws exercise the rights of citizens, are to be enumerated. In all such cases write ‘Ind.’ opposite their names, in column 6, under heading ‘Color’.”

Table 2

Web Resources for Cancer Genomic Information

Professional Organizations	
American Academy of Family Physicians	www.aafp.org
American Academy of Nursing (AAN)	www.aannet.org
American Board of Medical Genetics (ABMG)	www.abmg.org
American College of Medical Genetics (ACMG)	www.acmg.net
American Medical Association	www.ama-assn.org/ama/pub/category/1799.html
American Nurses Association (ANA)	www.nursingworld.org
American Society of Clinical Oncology (ASCO)	www.asco.org
American Society of Human Genetics (ASHG)	www.ashg.org
International Society of Nurses in Genetics (ISONG)	www.isong.org
National Coalition for Health Professional Education in Genetics (NCHPEG)	www.nchpeg.org
National Society of Genetic Counselors, Inc. (NSGC)	www.nsgc.org
Oncology Nursing Society (ONS)	www.ons.org
Clinical Genetics Resources	
GeneTests	www.genetests.org
Human Genome Epidemiology Network (HuGENet™)	www.cdc.gov/genomics/hugenet/default.htm
INFOGENETICS	www.infogenetics.org/
Online Mendelian Inheritance in Man (OMIM)	www.ncbi.nlm.nih.gov/entrez/query.fcgI?db=OMIM
Sources for Patient Information and Referrals	
Genetics and Rare Diseases Information Center (GARD)	http://www.genome.gov/10000409
Genetic Alliance	www.geneticalliance.org
Talking Glossary	http://www.genome.gov/10002096
Family History Resources	
U.S. Surgeon General's Family History Initiative	www.hhs.gov/familyhistory
Centers for Disease Control and Prevention National Office for Public Health Genomics	http://www.cdc.gov/genomics/fHix.htm
Other Sites	
Cancer Genetics Network (CGN)	http://epi.grants.cancer.gov/CGN
National Cancer Institute (NCI)	www.cancer.gov
National Human Genome Research Institute	www.genome.gov
National Institute for Nursing Research (NINR)	www.ninr.nih.gov
Secretary's Advisory Committee on Genetics, Health and Society (SACGHS)	http://www4.od.nih.gov/oba/sacghs.htm
Thomas—U.S. Congress on the Internet	www.thomas.gov/

Source: Modified fromVasquez S, Jenkins J. *Identifying Appropriate Referrals and Resources (in press).*