

This case was developed by Tiffany McNair, Harvard Medical School '07 and used with permission. While the players in this case are medical students tasked with analyzing a specific case in a tutorial learning setting, the interpersonal interactions and the cultural issues may be familiar to genetic counseling. Please read the case and consider the applications to genetic counseling training and practice.

"What do you think, Michelle?"

Abstract

Michelle is first-year student deep into the fall term of medical school and is starting a new course block with yet another "new" tutorial group. The first case the group discusses involves a patient who is reluctant to participate in a clinical research project because a relative of his died in the infamous Tuskegee syphilis experiment. Michelle becomes aware that several questions about the Tuskegee study are being directed toward her and she finds herself uncomfortable by the increased attention - both in terms of the tutorial case as well as personal questions from her classmates she endures after the tutorial session ends.

"What do you think, Michelle?"

Part I

Michelle walked into her tutorial room on the first day of the new block to meet her new "team" of academic colleagues. Already several months into medical school, Michelle had become accustomed to the collaborative tutorial process, its investigative nature and the thrill of tackling complex clinical scenarios. She waved hi to the only other student in the room. Felicia, who was sitting with her hands crossed on top of the tutorial table, responded with a shy nod. As Michelle pulled up a chair and took out her binder, familiar faces from her society trickled into the small classroom. Particularly vibrant was Stephen, a 22-year-old wearing a bright green and yellow Abercrombie & Fitch T-shirt. Stephen walked in and sat at one head of the oval table.

He promptly asked, "You guys hear anything about our tutorial leader?"

Some students shook their heads. One girl said, "Don't know. What's his name again?"

A student named Lawrence replied, "Evans, I think. Ph.D., maybe."

Michelle chimed in, "Well, I guess we'll find out soon."

Nearly time to begin class, there were six students present, but the tutorial leader had not yet arrived. The team was almost complete. Though the group had only one person of color, it had a nice balance of males and females. The six first-years felt the anxiety brimming in the room. The first day of class was still accompanied by a level of uncertainty. *How would everyone work together? What would be the tutorial leader's style? How much work would be involved on a daily basis?*

As they waited in suspense, some students made small talk, a few browsed the syllabus. One student grabbed the keyboard and began checking email on the plasma screen. At exactly 8:30am a tall man walked in wearing a crisp white coat. His great stature, coupled with the

Harrison's text and a thick binder in one arm made for a rather striking presence. He grinned and closed the door.

Dr. Arthur Evans introduced himself as a Ph.D. in Cell Biology, a tenured professor for nearly 30 years, and an avid supporter of the New Pathway program. He began by emphasizing everyone's respective roles: "Remember that I am here merely to facilitate. I will not let you go too far off track, but this is your opportunity to pursue interesting directions and to explore unknown, but often fascinating territory. You are all responsible for the material and each individual's participation is crucial to establishing the best group dynamic. Any questions before we move on to the first case?"

Over the next week and a half, the students dissected "The Case of the Embarrassed Physics Teacher."¹ In the early stages of the vignette, a 30-year-old male teacher named Mr. Downey presented with a rash on his elbow and knees that had worsened over the previous months. Initially remarkable for "oval-to-round scarlet plaques" and "dry, silvery, thickened scales," the case patient indicated that a less aggravated version of the rash existed since childhood, but had spread recently. He also noted that his father suffered from something similar.

Investigative tools in hand, each student researched a different aspect of the case, anatomy of the skin to family history to potential dermatologic therapies. By the middle of the case, many of the students had presented what they each researched and the group was fast-approaching identification of the underlying pathology.

Finally, within the case it was revealed that Mr. Downey had a condition called psoriasis. The hypothetical physician in the case then described a research project on which he and his colleagues were working, and solicits the participation of the patient. Despite reassuring the physics teacher that the procedures involved in the study were harmless, Mr. Downey was still wary of participating. Lawrence read aloud the last paragraph on the page:

Mr. Downey hesitates, and says that he has concerns about participating in any study. You [the physician] assure him that you completely respect any person's feelings about this. After reflecting for a moment, Mr. Downey says, "It seems silly not to participate, if it would help learn more about the condition. My family has a rather negative history with the medical profession. I am biracial, and a great-uncle of mine died in the 'Tuskegee' mess.

There is a short pause and Dr. Evans asked if anyone has something to say.

Stephen quickly asked, "Why is this man so hesitant to join the study? What exactly is the 'Tuskegee mess?' "

Dr. Evans promptly echoed the inquiry, "Does anyone know what Tuskegee has to do with Mr. Downey's concerns?"

Lawrence answered, "I'm not sure, but I think it has something to do with health disparities. Didn't one of the speakers mention it during orientation?"

Another student responded, "Yeah, I remember reading something about Tuskegee in one of our Patient-Doctor articles a couple weeks ago."

With no definitive answer in site, everyone looked in Michelle's direction.

¹ Human Body 2003: Case 1-3.

"Do you know anything about this, Michelle?" asked Dr. Evans.

Slightly taken aback by the increased attention, Michelle cleared her throat and sat up in her seat. "Well, uh, I know a little bit about the Tuskegee syphilis experiments. There was this study in Tuskegee, Alabama—I think it lasted almost 40 years—and black men were deliberately infected with syphilis. I think the researchers wanted to see what would happen if they weren't treated."

Felicia interrupted, "Wait, I don't think they were actually *infected*. They already had syphilis, right?"

"Hmmm," Michelle hesitated, "I think you're right. The men already had syphilis." She shifted in her seat a little, and then continued, "Still, the study was incredibly unethical since the men did not know they weren't receiving treatment."

Michelle anxiously waited for someone else to continue the discussion.

One student eagerly asked, "So...do you know anyone who was involved with the Tuskegee study, Michelle? Maybe a family member?"

"Well, actually my family is from Connecticut," she responded.

Then Stephen suddenly reacted, "I can't believe they weren't treated! I guess Tuskegee explains why African-American patients are less compliant than others." Some other students nodded in agreement.

Michelle desperately looked to her tutorial leader. He stared blankly at her.

She sighed and responded, "I'm not sure Tuskegee is the only explanation for why black patients may have a less trusting relationship with their doctors. I mean, racial/ethnic health disparities have been around forever."

Felicia interjected, "Honestly, though, I just think that it was so long ago."

"Yes, but a lot of minority patients still receive unequal care today," Michelle declared.

"Well," Felicia went on, "stuff like Tuskegee doesn't happen anymore."

"Yeah," agreed one of the other students, "can we please get back to the case?"

"What do you think, Michelle?" **Part II**

"Alright, well I think we're done with this page. Good discussion today, everyone. Tomorrow we will continue to go over the mechanisms behind psoriasis and we will continue with the next few pages of the case. Is everyone clear about their assignments?" The class nodded in response. As Dr. Evans picked up the giant medical texts in preparation to leave, some of the students began to cluster around Michelle. The tutorial leader then grabbed the large binder, flashed his trademark grin, and left the tutorial room.

After Dr. Evans left, the students finished gathering their things and talked about their plans for the day. Michelle was unusually quiet as she put her books into her bag, though most of the

other students seemed not to notice. Stephen confirmed, "Ok, wait, so I'm looking up hyperplasia and you're doing the immunologic response, right, Michelle?"

"Yes," she responded dryly.

"Cool," he replied. "Oh, wait," he said as he went up to her, "You know what else I wanted to ask you though?"

Michelle cringed inside as she considered the possibilities of the next line of questioning. 'Please, no more about Tuskegee!' she thought to herself.

"Well, I've been wondering about your hair actually."

"My hair?" said Michelle.

"Yeah. You know, how does it do that?"

Abandoning her Tuskegee worries, Michelle paused for a second, "How does it do what?"

"You know... *that!*" Stephen said while he cupped his hands around his own head.

Then Lawrence walked over to Michelle and patted her head. "I was thinking about that too. It's so poofy! Did you wear it like that when you interviewed for medical school?"

Michelle wasn't quite sure what to say but she did feel a lump forming in her throat. Felicia and several other remaining students were waiting for a response, too. "Um, I don't know. This is just my hair, guys. I'm not sure what to tell you. This style is just one of many...besides, your questions are making me a little uncomfortable. I'm sure you're just curious, but I feel like I have to defend myself here...for being me."

"Whoa, Michelle," said Lawrence. "Calm down, we get it." Stephen nodded in agreement.

"Ok...well...see you guys tomorrow."

"Later, Michelle." As she walked out the door, she could hear Stephen say, "So you guys want to go over psoriasis again?"

“What do you think, Michelle?”

Part III — Epilogue

The following week they started with a new case. The scenario began, “Carla Rodriguez is a 57-year-old Mexican-American woman, who presents in the emergency room with a host of cardiac problems, including sharp chest pain and difficulty breathing.” During admission, Mrs. Rodriguez’s exams eventually revealed she had suffered a myocardial infarction.

Later in the case, there was also a brief paragraph discussing how the patient’s fear about seeing a doctor had grown as she got older: “Mrs. Rodriguez explained to the ER physician that she had always experienced heart trouble. She did not see a doctor until recently, however, because she was scared to get bad news when the pain worsened.”

After the students finished reading, Dr. Evans looked probingly at the group.

Lawrence said, “Ok, guys—so we know there’s some cultural issue here.”

“Yeah, there weren’t any Mexican people in Tuskegee, right?” Stephen began.

“What do you think, Michelle?”

Guiding Questions

1. When the students first arrive, what kind of concerns might they have about the way in which tutorial will operate?
 - a. Consider these concerns in terms of student-to-student and student-to-faculty dynamics, tutorial leader style, and work expectations.
 - b. How might these concerns be impacted by the balance (or imbalance) of diverse backgrounds in the group? (Consider ethnic, gender, age, and regional ratios).
2. Dr. Evans introduces himself and his background to the students, but what are the implications of forfeiting this same opportunity for the students?
 - a. How should tutorial introductions be structured?
 - b. What is the importance of having both leaders and participants voice their expectations of tutorial?
3. Why did everyone look to Michelle for the answer about Tuskegee’s relevance to the case?
 - a. Should Dr. Evans have interrupted the inquisition of Michelle?
 - b. Is the tutorial leader required to provide the correct information or should he merely facilitate the student discussion even if the comments/questions are inappropriate and/or misconceived?
4. Why does Michelle look to Dr. Evans in desperation after Stephen’s comment on the compliance of black patients? Should Dr. Evans interject?
5. Discuss the final comment made at the end of Part I.
 - a. What exactly constitutes a tutorial case and what components qualify as critical to tutorial discussion?
 - b. Should Dr. Evans have followed up on this comment at the start of Part II?

6. What is the relationship between the Tuskegee inquisition of Michelle and the barrage of questions concerning her hair?
7. Discuss the underlying meaning of Lawrence's question, "Did you wear it like that when you interviewed for medical school?"
8. Why is Michelle uncomfortable with the questions about her hair and what is the potential impact of this post-tutorial experience on her performance within future tutorials?
9. Discuss Stephen's comment at the end of Part II. How might his actions be exclusionary?
10. What, or *who*, is being investigated in tutorial cases?
 - a. How do these investigations rely on the knowledge/experiences of minority students (Think about the final question of the case at the end of Part III)?
 - b. How can tutorial leaders facilitate a healthy dialogue that does not corner minority students, but that creates an environment for open and respectful exchange?
11. How have student attitudes about culturally competent care evolved during Part III? How is the sociocultural aspects of patient's lives being trivialized and/or mocked?
12. Why is this case entitled "The Tuskegee *Epidemic*?" Specifically, how does a limited repertoire of cultural competence history impact student and faculty approaches to and understanding of a case? of healthcare dynamics? of our patients? of **each other**?

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*After reading the case of "What do you think, Michelle?",
Consider the implications for genetic counseling training and practice.*

By: Nancy Steinberg Warren, MS, CGC

Learning Objectives:

1. Recognize racism and prejudice genetic counseling settings.
2. Identify practice changes for improving trust with clients in clinical and research settings.
3. Place value client perceptions of their own race as a framework for providing client-centered health care.

Personal Reflections

- What are your first instincts about this case?
- Are there analogous situation(s) from your genetic counseling training program environment that come to mind after reading this case?
- **For program faculty and supervisors:**
 - Have you ever targeted a specific genetic counseling student as the presumed "expert" due to her/his race? If so, in what way and why? What were the results?
- **For genetic counseling students:**
 - Have you ever felt "singled out" in classes, clinic or other ways in your training program due to your race or another characteristic? If so, how? Why?
 - Describe your relationship with your genetic counseling program student peers.
 - In what ways does the genetic counseling training program environment "feel" different than and similar to your high school or college environment? Compare the demographics of these educational settings.

Definitions

Ethnicity: Social groups sharing cultural roots, history, beliefs, practices, and/or sense of identity.

Prejudice: A preconceived judgment or opinion, which may be based on limited information and/or previous exposure to cultural stereotypes. Prejudice impedes interest and effectiveness in exploring individuality.

Race: Many definitions of race exist. The following table was adapted from Anderson et al., 2001 presents a daunting table (p. 431) documenting a few of the various definitions of race that have been published in the literature. These definitions range from: "race is a matter of social definition" to "race is a large population of individuals who have a significant proportion of their genes in common" to "races...designate...major migrations into the United States." The

inherent variations of this concept make reference to this concept in clinical and research settings exceptionally challenging.

Anderson notes that government-designated race assignments of a child of a white mother and a black father have “evolved” over time. Prior to 1989 the child would have been given the race of the non-white parent (black); after 1989, the child would have been assigned the race of the mother (white). Neither of these definitions are biologically based; they reflect the social nature of racial identity.

Race, as defined by the U.S. Census Bureau of the Federal Office of Management and Budget (OMB) are self-definition items in which residents choose the race or races with which they most closely identify, and indicate whether or not they are of Hispanic or Latino origin (ethnicity). The OMB defines the concept of race for the U.S. Census as not scientific or anthropological and takes into account social and cultural characteristics as well as ancestry but not primarily biological or genetic factors.

Please see the OMB website to review the current standards for data collection:
http://www.whitehouse.gov/omb/bulletins_b00-02

The Institute of Medicine report on collecting race/ethnicity data can be found at
<http://www.iom.edu/Reports/2009/RaceEthnicityData.aspx>

Racial identity development: Evolution over time of psychological implications of racial-group membership, based on a perception of a shared heritage with a particular racial group (Helms, 1990). The process of racial identity development depends on the racial group, and may include a wide and changing spectrum of immersion and aversion to his/her racial peer group over time. Ideally, the “internalized” individual will maintain connections with his/her racial peers while establishing meaningful relationships with individuals from other racial groups, who in turn respect the individual for his/her self-definition (Tatum, 1992).

Racism: A system of advantage base on race (Tatum, 1992).

Implications for Genetic Counseling

Minority clients may not trust health care providers and may not want to participate in research. Despite institutional review board guidelines for protection of human subjects in research that emerged due to past inequities like Tuskegee (Norrsgard, 2008), it is well documented that clients from racial and ethnic minority groups continue to use fewer health services, and are less satisfied with these services than clients from the majority population (Saha, 1999). Active efforts to build and maintain trusting relationships are needed to ensure minority clients receive optimal services and access to health care research studies. “Understanding and unlearning prejudice and racism is a lifelong process” (Tatum, 1992).

It is generally accepted that race is a social construct (Anderson et al., 2001), yet as we described earlier, race is commonly used as a clear-cut biological factor in research and clinical settings. Arbitrary visual classifications are not accurate or helpful. Feldman et al. (2003) state that ancestral genetic data is more useful for medical purposes than racial categories. They suggest the importance of identifying all contributions to a patient’s ancestry, including geographic, biological and social factors. Anderson et al. (2001) provide useful suggestions on

dealing with race in health care clinical practice. Race should be ascertained by self-identification. Patients may identify with one race, more than one race, or no race.

1. Race should be recorded in the social history, and not in the first sentence of the clinical presentation. A patient's skin color does not provide information about birthplace, language, cultural beliefs or preferences. Discussing race with patients may be useful to facilitate a more open and less biased relationship.
2. Race should not be used as a proxy for genetic variation and risk. Clinicians should seek information about the patient's family, ethnic, and geographic background, and record this information in the social or family history.
3. Race should not be used as a proxy for social class. Ask the patient about clinically useful variables such as education level, income, total wealth, occupation, housing, area of residence, marital status, type of health insurance, etc.
4. Racism and its effects on health and the patient-clinician relationship should be considered part of the clinical encounter. Racism influences health, access to health care, treatment and the quality and effectiveness of patient-physician encounters.
5. Medical researchers should adopt a more critical attitude toward their own use of racial identifiers.

All of these suggestions may be applicable to your genetic counseling practice. Gaining greater awareness of our own use of racial identifiers, thinking about why and when we use race, and hearing from clients about the role of race in facilitating and preventing their optimal health care may facilitate trust and the effectiveness of genetic counseling. Opening up these conversations with clients may be more difficult for genetic counselors, who are predominantly white (Smith et al., 2008), than for clients of minority backgrounds.

Many black families report holding frequent explicit conversations about race, privilege, discrimination, and relationships between members of different ethnic groups, while parallel conversations rarely occur in white families (Copenhaver-Johnson, 2006). However, well-meaning whites who resist acknowledging the importance or existence of race only reinforce "blindness" to the harmful effects of racism. By not making assumptions based on a client's skin color, and by providing opportunities for clients to speak openly and frankly about their experiences, fears, and priorities, we make genuine efforts to build trust.

Implications for Training

How can we prepare genetic counseling students to work effectively in a multicultural, multiracial society? Race-related content in the training program environment can be emotionally-charged and interfere with student learning. Tatum (1992) notes that powerful emotional responses such as anger, guilt, shame and despair may be evoked by issues of oppression due to racism, classism, sexism, homophobia and heterosexism, anti-Semitism, ageism, etc. However, avoiding discussion of stereotypes and feelings is counterproductive to learning. Allowing individuals to put down others with quick, funny comments for comic relief in tense situations, or to avoid self-reflection, is also counterproductive to creating a trusting environment that encourages ongoing personal growth. Tatum suggests that individuals should speak from their own experience ("I think...") rather than use generalizations ("People say..."). Experiential learning opportunities may include identifying online and real-time exhibits on racism and assigning students to reflect on and discuss how they feel.

Implications for Practice:

How may racial concordance between genetic counselors and their clients impact client satisfaction with the services they receive? How would you assess this impact?

What counseling strategies do you use to establish trust with your clients? Do you use different strategies for clients from different racial groups?

What are the consequences to the genetic counseling intake process of using race as a proxy for other factors?

Analyze how you use the words "race" and "ethnicity." Do you use the words interchangeably? Are these words listed in your clinic forms? Do you define these terms when you use them?

What situation(s) prompt you to ask clients about their race? What words do you use? How comfortable are you in asking clients about their race? Are there times or situations when you would **not** ask genetic counseling clients about their race? Why?

Are you involved in research? If so, what is the role of race in your research project(s)? Are individuals of diverse backgrounds involved in developing and implementing the research? By seeking input and involvement of African Americans in genetic research protocols, the research is more likely to correlate with community priorities and be of most benefit the minority population. How is the community involved in your research?

Are you involved in activities for increasing social justice in your community? If yes, does your genetic counseling background influence the choice of activities, or your acceptance by others?

What are "vulnerable" populations? How much and what kind of exposure do you have with vulnerable populations in your work? How much and what kind of exposure do you have to vulnerable populations outside of work?

Discussion Questions and Organizational Assessment

Which of the following question sets explore areas most needing improvement in your training environment? Identify three areas, write them down, and share your list with other individuals in your training environment. Collaborate with representatives of relevant stakeholder groups, such as students, faculty, staff, consumers and others to develop an action plan to promote change in a well-defined period of time (this semester, this year, by fall semester 2012, etc).

1. List the methods currently incorporated into the training program environment to help students explore their similarities and differences.
2. Do genetic counseling students, faculty and staff in your training program environment learn about Tuskegee? If so, what prompts this learning? Describe the learning activities. Is the learning self-directed? Is the learning required for research purposes? Is the learning discussed in an open forum?
3. Describe learning about Tuskegee in your training program environment that is focused on implications for conducting research? Also describe how the legacy of Tuskegee for clinical practice implications is addressed.

4. What strategies can be used in the genetic counseling training environment to create a safe forum for open discussion of interpersonal interactions, biases and assumptions? Whose responsibility is it to set this tone?
5. What resources (lectures, assignments, articles, experiential learning, self-directed learning, case-specific, etc) are used in your training environment to increase understanding of the role of race in health care?
6. How racially diverse are the students, faculty, supervisors and staff in your training program environment? Who sits on the program's admissions committee? What efforts are made to recruit students from diverse backgrounds?
7. How racially diverse are the clients seeking services in your genetics center, and your institution? How racially diverse is your community? What differences do you note in the racial composition of these respective settings?
8. When is it appropriate to explore the backgrounds of students, faculty, supervisors and others in your training program environment? What questions and strategies may be useful to facilitate this exploration process?
9. What strategies are used in your genetic counseling training program to promote respectful communication among students, faculty, supervisors and staff? How are these strategies evaluated?

Teaching Tools and Resources:

Implicit Association Test. Web-based self-evaluation tests to assist exploration of assumptions and stereotypes about race, religion and other parameters of diversity. Suitable for students and professionals.

<https://implicit.harvard.edu/implicit/demo/>

James, Kara. (2007). **Tutorial on Race, Ethnicity and Health Care.** Sponsored by the Kaiser Family Foundation. <http://www.kaiseredu.org/tutorials/REHealthcare/player.html>.

Excellent presentation on health disparities pertaining to different racial groups.

Miss Evers' Boys. DVD. HBO Home video.

True story of the US Government's 1932 Tuskegee Syphilis Experiments, in which a group of black test subjects were allowed to die, despite a cure having been developed.

Following viewing of the movie, ask students to journal their thoughts about racism and genetic counseling.

Norrgard, Karen. Human subjects and diagnostic genetic testing. (2008). *Nature Education*, 1(1).

<http://www.nature.com/scitable/topicpage/Human-Subjects-and-Diagnostic-Genetic-Testing>

Race, Genetics and Health Care: What We Know and What It Means for Your Clients. National Coalition for Health Professional Education in Genetics (NCHPEG), April 20, 2006.

90 Minute taped television broadcast intended to teach primary care providers and other interested individuals about race, genetics and health care. Request a DVD and/or view the program online at www.nchpeg.org Also available: 14 frequently asked questions and answers about race, genetics and health care developed by Lynn Jorde and Steve Olson.

Race: Are We So Different? Online exhibit by the American Anthropological Association. <http://www.understandingrace.org>

Work with your community to bring in this exhibit to a museum nearby. Attending the exhibit raises awareness and increases knowledge and sensitivity of health care providers, students and the lay public on the history of racism in the US and commonly held stereotypes.

Race Matters Toolkit

<http://www.aecf.org/KnowledgeCenter/PublicationsSeries/RaceMatters.aspx>

This toolkit is designed to help decision-makers, advocates, and elected officials provide equitable opportunities for all. The approach described in the toolkit deals specifically with policies and practices that contribute to inequitable outcomes for children, families, and communities. The toolkit presents a specific point of view on addressing unequal opportunities by race. It includes checklists on organizational self-assessment and other helpful handouts, such as how to talk about race in the workplace.

Race: the Power of an Illusion. California Newsreel's 3-part documentary about race, science and history. http://www.pbs.org/race/000_General/000_00-Home.htm

Help students learn more about race and become more aware of the stereotypes they hold. "To get beyond racism we must first take account of race. Until we address the legacy of past discrimination and confront the historical meanings of race, the dream of equality will remain out of reach" (Justice Harry Blackmun).

Racial Equity Tools

<http://www.racialequitytools.org>

A website designed to support people and groups who are working for inclusion, racial equity and social justice. The site includes ideas, strategies and tips, as well as a clearinghouse of resources and links from many sources.

Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. (2002). Institute of Medicine. <http://www.iom.edu/?id=16740>

IOM study to assess the extent of disparities in the types and quality of health services received by U.S. racial and ethnic minorities and non-minorities; explore factors that may contribute to inequities in care; and recommend policies and practices to eliminate these inequities. The report found that a consistent body of research demonstrates significant variation in the rates of medical procedures by race, even when insurance status, income, age, and severity of conditions are comparable. This research indicates that U.S. racial and ethnic minorities are less likely to receive even routine medical procedures and experience a lower quality of health services. The committee's recommendations for reducing racial and ethnic disparities in health care include increasing awareness about disparities among the general public, health care providers, insurance companies, and policy-makers.

Wynia, Matthew. (2003). *Race, Trust, and Tuskegee: Professional Ethics, Broken Trust and Health Disparities.* American Medical Association.

www.ama-assn.org/ama1/pub/upload/mm/369/nih-coprraceandtrust.ppt

Slide presentation on how health care providers can undermine or gain trust from minority clients.

Additional Reading:

Delinsky, Barbara. (2007). *Family Tree.* Broadway Books, Random House, New York.

References:

Anderson, M. R., Moscou, S., Fulchon, C., & Neuspiel, D. R. (2001). The Role of Race in the Clinical Presentation. *Journal of Family Medicine, 33* (6), 430- 434.

Copenhaver-Johnson, J. (2006). Talking to children about race. *Childhood Education, 83*, 12-22.

Fairchild, A. L., & Bayer, R. (1999). Uses and Abuses of Tuskegee. *Science, 284* (5416), 919-921.

Feldman, M. W., Lewontin, R. C., & King, M. C. (2003). Race: A genetic melting pot. *Nature, 424* (6947), 374.

Gamble, V. N. (1997). Under the Shadow of Tuskegee: African Americans and Health Care. *American Journal of Public Health, 87* (11), 1773-1778.

Johnson, R. L., Saha, S., Arbelaez, J. J., Beach, M. C., & Cooper, L. A. (2004). Racial and Ethnic Differences in Patient Perceptions of Bias and Cultural Competence in Health Care. *Journal of General Internal Medicine, 19* (2), 101-110.

Office of Management and Budget. (1997). Retrieved June 8, 2009, from Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity Web site: <http://www.whitehouse.gov/omb/fedreg/ombdir15.html>

- Parker, L. S., Alvarez, H. K., The Legacy of the Tuskegee Syphilis Study. Retrieved June 8, 2009, Web site: <http://www.asph.org/UserFiles/Module2.pdf>
- Smith, M., Freivogel, M.E., & Parrot, S. (2008), National Society of Genetic Counselors, Inc. Professional Status Survey 2008.
- Somnath, S., Komaromy, M., Koepsell, T.D., & Bindman, A.B. (1999). Patient-Physician Racial Concordance and the Perceived Quality of Use of Health Care. *Archives of Internal Medicine*, 159 (9), 997-1004.
- South-Paul, J.E. (2001). Racism in the Examination Room: Myths, Realities, and Consequences . *Journal of Family Medicine*. 33 (6), 473-475.
- Tatum, B.D. (1992). Talking about race, learning about racism: The application of racial identity development theory in the classroom. *Harvard Educational Review*. 62, 1-24.
- Telfair, J., & Nash, K.B. (1996). African American Culture. In N. L. Fisher (Eds.), *Cultural and Ethnic Diversity: A Guide for Genetics Professionals* (36-59). Baltimore, Maryland: Johns Hopkins University Press.
- Watts, R.J. (2003). Race Consciousness and the Health of African Americans. *Online Journal of Issues in Nursing*, 8, from <http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Volume82003/No1Jan2003/RaceandHealth.aspx>

Disclaimer

The purpose of the Genetic Counseling Cultural Competence Toolkit (GCCCT) is to improve the delivery of culturally responsive, client-centered genetic counseling to diverse populations and to reduce health disparities. The GCCCT is an educational resource; any suggestions do not define the standards of clinical or educational practice. All cases and scenarios are hypothetical. The JEMF, NSGC and Nancy Steinberg Warren, MS, CGC will not be liable for any medical or psychosocial applications connected with the use of or reliance upon any information obtained from this website or associated links and resources.

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