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Original Research

What Is It Like To Be in the Minority? Ethnic and Gender Diversity in the Genetic Counseling Profession

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Increasingly, the genetic counseling profession is recognizing the need for greater ethnic and gender diversity. Recruitment and retention efforts may be enhanced by better understanding of the experience of individuals considered to be underrepresented in the profession. In this qualitative study, 8 genetic counseling students and 7 practicing genetic counselors who were ethnic minority and/or male participated in semi-structured telephone interviews regarding how they were introduced to the field, perceived career supports and barriers, their experiences within training programs and the field, and suggestions for increasing diversity. Introduction to the field tended to be *late* and *accidental*. There were several career supports (e.g., field combines science and helping others) and barriers (e.g., lack of information about the field). Participant experiences, although primarily positive, included instances of passive, unintentional discrimination; and there were internal and external pressures to be *diversity experts* and positive representatives of their *group*. Participants reported positively impacting colleagues' cultural competency and offering a different *presence* within clinical settings. Suggestions for increasing diversity and research recommendations are given.

KEY WORDS: genetic counselor diversity; ethnicity; gender; recruitment; retention; training.

The United States is becoming increasingly diverse, with ethnic minority groups representing one-third of the population (U.S. Census Bureau, 2004). However, inadequate representation of minority groups within healthcare professions is an on-going concern (Sullivan Commission, 2004; Yoder, 2001). This concern is evident in the field of genetic counseling (Oh and Lewis, 2005). The National Society of Genetic Counselors Professional Status Survey (Parrott and Manley, 2004) indicates that only 9% of practicing counselors identify themselves as belonging to an ethnic group other than Caucasian. More concerning is the fact that this percentage represents only a 3% increase over the 6% reported more than a decade ago (Uhlmann, 1992). The results of the survey also show that males are underrepresented, comprising only 5% of respondents. In order to prevent stagnant enrollment of racial and ethnic minorities that is occurring in nursing, medicine, and dentistry (Sullivan Commission, 2004), and to increase male representation, steps must be taken to increase diversity in genetic counseling. As one step towards increasing diversity, the present study was designed to explore experiences of genetic counseling students and practicing genetic counselors who identify themselves as *underrepresented in the field of genetic counseling*. The term *underrepresented individual* is used to refer to anyone from a cultural or racial/ethnic background who is not Caucasian female.

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Importance of Diversity within Health Care Professions

It is well-documented that minority groups (e.g., African Americans, Hispanics, and Native Americans) tend to be less healthy than the U.S. majority, experience greater barriers to accessing health care, and often receive a lower quality and amount of services (Greer, 1995; Kington and Nickens, 2001; Samelson *et al.*, 1994; Sullivan Commission, 2004). Research indicates that lack of minority health professionals compounds chronic racial and ethnic health disparities in the U.S. (Sullivan Commission, 2004). As genetics becomes more prominent in all health care areas, it is important that the genetic counseling field prepare adequately to address the needs of underserved populations. One way to meet these needs is to increase the representation of all ethnic/cultural groups within the profession.

Traditionally, *fairness* and *function* arguments have been used by proponents of greater diversity within health care professions (Institute of Medicine, 2001; 2003). Fairness arguments stem from the historical exclusion of minority groups from economic and professional opportunities in this country and from the fact that despite contemporary socioeconomic gains by members of ethnic minorities, children from minority backgrounds are still more likely to have multiple risk factors for school failure [e.g., living in poverty or in single-parent households, having a mother with less than 12 years of education, speaking a primary language other than English, and/or having a mother who is unmarried at the time of her child's birth (United States Department of Education, 2004)]. Fairness advocates maintain that individuals from disadvantaged backgrounds should be recognized as having additional burdens to overcome in order to attain higher education and professional status.

Function arguments are based on claims that a diverse health care workforce helps to improve access to care for minority communities and enhance trust and communication, thus lessening or even eliminating existing health disparities. One conclusion of the Sullivan Commission on minorities in healthcare (2004) is that the lack of minority health professionals may be an even greater cause of health care disparities than a persistent lack of health insurance. Indeed, it has been shown that ethnic minority health professionals tend to practice in areas of underserved populations more frequently than Caucasian health professionals (Institute of Medicine, 2003). Moreover, increased diversity promotes culturally-sensitive practice, for example, expanding the cultural and linguistic congruence of providers and their patients (Sullivan Commission, 2004; Weaver, 1998, 1999; Yoder, 2001). Function arguments further suggest that a diverse student body positively affects Caucasian students because they are exposed to differing worldviews and perceptions, thus improving their cultural competency and their delivery of health care to minority and medically underserved communities (Baker, 2000; Gurin, 2001; Kington and Nickens, 2001; Sullivan Commission, 2004; Taylor and Rust, 1999).

Although fairness and function arguments are compelling, there is no published empirical evidence indicating that individuals who are underrepresented in the genetic counseling field do or should practice in underserved areas, or that underrepresented individuals have more effective counseling relationships with individuals from underserved populations. Similarly, there are no published data demonstrating that genetic counselors who are Caucasian females have difficulty providing quality services to underserved populations. However, a limited amount of research does address the argument of function for physicians and for students in higher education settings (cf. Greer, 1995; Kingston and Nickens, 2001; Saha *et al.*, 1999; Stohs, 2003).

Some studies indicate that on average, minority physicians treat four to five times the numbers of minority patients than do Caucasian physicians, and these practice patterns are a result of physician choice (Komaromy *et al.*, 1996). Kington and Nickens (2001) investigated the impact of diversity on minority providers' practice choices, the quality of communication between minority patients and providers, and the quality of training. They found that physician supply was inversely related to the concentration of African Americans and Hispanics residing in health service areas, even after adjusting for community income levels. They concluded that African American and Hispanic physicians are more likely to provide services in minority and underserved communities, and they are more likely to treat poor (Medicaid-eligible) patients.

For some minority patients, having a minority physician may result in better communication, greater patient satisfaction with care, and increased use of preventive services (Greer, 1995; Kington and Nickens, 2001; Saha *et al.*, 1999). One possible explanation is that historically, some minority groups have had negative experiences with the health care

system. The genetic counseling field in particular may evoke fear of eugenics and subsequent mistrust by some underserved clients (Laskey *et al.*, 2003; Oh and Lewis, 2005). Minority mistrust could prove to be a stumbling block to the development of a productive counselor-patient relationship and may result in sub-optimal quality of care, thus perpetuating the lower health status of underserved populations. Although there are no empirical data supporting this hypothesis within genetic counseling, numerous studies have shown that Black and Hispanic patients are more likely to choose a physician of their same race due to personal preferences and also because of ability to speak the patient's language (Kington and Nickens, 2001; Komaromy *et al.*, 1996). Similarly, data from the Commonwealth Fund Minority Health Survey (Saha *et al.*, 1999) revealed that Black and Hispanic patients were more likely to rate care as excellent to very good from physicians of the concordant race. It would seem that from the patient's perspective, it is important to have health care providers who are of a similar background.

Importance of Diversity within Professional Training Programs

A growing number of studies demonstrate that diversity in higher education settings is associated with positive academic and social outcomes for students (Gurin, 2001; Legler and Stohs, 2003; Lopez *et al.*, 2003; Taylor and Rust, 1999; Yoder, 2001) For instance, Legler and Stohs (2003) found that students at diverse institutions were more likely to be involved in community and civic activities and were better able to participate in an increasingly heterogeneous and complex society. These students showed greater understanding and consideration of multiple perspectives, and they were better able to deal with conflicts that different perspectives sometimes create in order to pursue the common good. Yoder (2001) found that inclusion of ethnic minority students' viewpoints resulted in increased multicultural awareness by all students. Data demonstrating the effects of diversity on students enrolled in genetic counseling graduate programs are not available; however, it seems reasonable to assume that similar benefits would result.

Genetic Counseling Graduate Programs

In order for the genetic counseling field to more accurately reflect the nation's demographics and to meet the needs of a changing population, a greater number of individuals from ethnic or cultural groups that are underrepresented must be trained as genetic counselors. Despite growing recognition of this need, there has been limited success to date in recruiting such individuals to genetic counseling. In addition, Lega and colleagues (2005) surveyed 235 first and second year students from 27 North American genetic counseling graduate programs and found that 97% were female and 87% identified themselves as Caucasian. Of the remaining 13 percent, 3.4% were Asian/Pacific Islander, 3.4% were Bi-Racial; 2.1% were Chicano/Hispanic/Latino, 0.9% were African-American/Black; and none were Alaskan Native/American Native.

Oh and Lewis (2005) assessed 63 high school and 170 college students' awareness and perceptions of genetic counseling. Racial/ethnic minority students indicated less awareness of the profession than majority students but were equally likely to consider a genetic counseling career once they were informed about it. Nevertheless, lack of ethnic diversity in genetic counseling continues to pose challenges that need to be addressed (Warren and Johnson, 1999). These challenges are further complicated because genetic counseling training programs likely compete for the same pool of qualified applicants with other, better-known medical professions that have developed more successful recruitment strategies for underrepresented individuals (cf. Heron and Haley, 2001; Legler and Stohs, 2003; Lopez *et al.*, 2003; Thomson and Denk, 1999).

Purpose of the Present Study

One preliminary step toward increasing diversity in the genetic counseling field is to learn from experiences of current students and practicing genetic counselors who identify with a cultural or ethnic group that is underrepresented in the profession. Accordingly, we interviewed a sample consisting of 8 genetic counseling students and 7 practicing genetic counselors who identified themselves as such. Three major research questions were investigated: 1) When and how were participants introduced to genetic counseling and what supports and barriers did they encounter in their pursuit of a genetic counseling career? 2) What are/were their general experiences in their graduate program and, for practicing counselors, what are their experiences in the field? and 3) What suggestions do participants have

about increasing diversity in the genetic counseling profession?

METHODS

Participants

Participants were recruited from three sources: 1) 15 of 33 self-identified underrepresented respondents in the Lega *et al.* (2005) study who indicated a willingness to be contacted for additional studies; 2) students enrolled in genetic counseling graduate programs who were self-identified as underrepresented (n = unknown); and 3) members of the National Society of Genetic Counselors' membership committee who self-identified as underrepresented ($n = 89$).

Upon receipt of approval from a University of Minnesota Institutional Review Board, an emailed letter of invitation was sent to the 15 individuals from the Lega *et al.*, (2005) study and to the 89 individuals from the membership committee. Twelve membership committee members could not be contacted due to invalid e-mail addresses. An emailed letter of invitation was also sent to genetic counseling program directors from 27 programs in North America that were board accredited at the time of this study, with the request that the message be forwarded to all genetic counseling students within the program. The program in which the first author was enrolled was excluded because anonymity could not be guaranteed.

The letter invited all individuals who identified themselves as underrepresented to participate in a telephone interview to discuss how they learned about the field of genetic counseling, their expectations for the field, and their experience thus far. Interested participants who met the inclusion criteria were asked to e-mail the first author to schedule an interview. The final sample of 12 females and 3 males were comprised of 4 students who had participated in the Lega *et al.* (2005) study, 3 practicing counselors who participated in their study when they were students, 4 counselors and 1 student recruited from the National Society of Genetic Counselors' membership committee, and 3 students recruited via the e-mail sent to program directors.

Instrumentation

Prior to developing the interview protocol, the authors bracketed their biases regarding the research questions. These included: 1) Individuals identifying with an underrepresented racial/ethnic group would have more negative experiences within the field than would male participants; 2) Participants would have a strong support system outside of the field; 3) Current students would have a more complex acculturation process than practicing participants. We developed 24 open-ended interview questions (See Appendix) for use during the semi-structured phone interviews. These questions were based on a review of medical and mental health literature regarding diversity in health-related fields and social cognitive career and racial identity theories (e.g., Helms and Piper, 1994; Lent *et al.*, 1994). The questions address six areas: 1) demographics, 2) introduction to and expectations for the field, 3) perceived supports and barriers, 4) training experiences, 5) clinical experiences, and 6) personal opinions and suggestions about diversity and the field. Interview questions were modified to apply to either students or practicing genetic counselors. They were piloted by the first author on two genetic counselors and one genetic counseling student (one male; two individuals from underrepresented ethnic groups). Minor revisions were made based on their comments.

Procedure

The telephone interviews were conducted by the first author. They were audio taped and ranged in length from 20 to 40 min (mean = 25 min). In accordance with a semi-structured format, the interviewer asked all of the questions in approximately the same order and included occasional prompts (Patton, 1990). She took notes during the interviews and then listened to the audiotapes to verify their accuracy. Participant quotes used in this paper were transcribed verbatim from the audiotapes.

Data Analysis

The first author manually analyzed interview data, using a modified version of Consensual Qualitative Research (CQR) (Hill *et al.*, 1997). The CQR method involves inductive and cross-case analysis procedures (Patton, 1990) in which the data analyst allows themes to develop freely from the data set, rather than imposing a preexisting framework, and considers each interview question separately to compare responses across all participants. First, she independently analyzed one transcript, assigning

content to *domains* (rationally-derived topics) developed based upon her own inductive analysis process. She used these domains to independently code each transcript. On occasion throughout the coding process, she decided to add or modify a domain in order to more clearly represent the data. Her analysis resulted in 9 domains. After the 9 domains were identified, she again reviewed each transcript and determined that each one reflected these domains.

She then independently constructed *core ideas* (brief summaries of the participants' responses), within each domain for the transcripts. Next, she aggregated core ideas across the 15 interviews for each of the 9 domains in order to conduct a cross-case analysis. Then she delineated these aggregated core ideas into categories (specific content areas within each domain). The second and third authors served as auditors, independently attempting to classify responses into the initial domains and categories. Any discrepancies were discussed until consensus was reached. The auditors suggested no changes in core ideas or domains, but they did recommend some regrouping of interview content within categories and slight modification of some category names. The final coding, agreed upon by the team, consists of 9 domains and 32 categories.

RESULTS

Sample Characteristics

The sample consisted of 5 female and 3 male genetic counseling students, and 7 female practicing genetic counselors. Their ethnic backgrounds included Asian, African-American, Caucasian, Hispanic, and *other*. The sample represented all 6 National Society of Genetic Counselors' regions with respect to location of their graduate programs, and 4 regions with respect to location of the counselors' practice.

How Were Participants Introduced to the Field and What Supports and Barriers Did They Encounter?

Slightly over half of the participants were introduced to genetic counseling in college ($n = 8$), while others discovered the field after college ($n = 4$), or in high school ($n = 3$). They learned about the field from working in a setting that employed a genetic counselor ($n = 4$), through a science course ($n = 4$), an advisor ($n = 2$), a family friend ($n = 1$), a family experience with genetic counseling ($n = 1$), or web-based search ($n = 1$).

Participants identified several supports and barriers to pursuing a genetic counseling career. Their responses were grouped into 3 domains and 18 categories, shown in Table I.

Domain 1: Career Supports

This domain refers to aspects of a genetic counseling career that participants perceived as appealing, and it contains 6 categories: 1) Combines science and counseling; 2) Provides opportunities to help others; 3) Is interactive; 4) Intellectually stimulating; 5) Educational - provides opportunities to teach; and 6) Is a rapidly-growing field.

Domain 2: Career Barriers

This domain refers to aspects of pursuing a genetic counseling career that participants regarded as obstacles, and it contains 8 categories: 1) Financial - reservations about the cost of graduate school and/or a perception that the average salary of a genetic counselor is modest; 2) Lack of information - many participants reported *stumbling upon* the field and then having to persist in order to locate further information; 3) Lack of diversity - some individuals worried about finding their *niche,* and/or questioned whether the field is able to serve the needs of the general population due to its lack of diversity; 4) Limited opportunities to advance – concern that professional advancement is limited because genetic counseling is so specialized; 5) Lack of confidence - regarding one's abilities; 6) Patient homogeneity – populations served by genetic counselors lack diversity; 7) Lack of autonomy – concern that the work setting lacks autonomy; and 8) No reservations about the field.

Domain 3: Family Supports and Barriers

This domain concerns the types of encouragement and discouragement participants received from family members regarding their career decision, and it contains 4 categories: 1) Unequivocal encouragement - almost half stated that their families clearly encouraged their career choice; 2) Mixed support - some indicated their families encouraged graduate school but questioned the choice of genetic

Table I. Genetic Counseling Career and Family Supports and Barriers ($N = 15$)

Categories	Prevalence (*n*)	Participant quotes
Domain: Career Supports		
Combine science/counseling	9	S: I liked that it combined science and counseling
Help others	6	S: Getting a chance to help people in an area I was interested in. I could see myself doing this for most of my life
Interactive	6	MS: Ability to do clinical work, interact with patients
Intellectually stimulating	4	C: I wanted an area where I'd be constantly challenged and forced to grow intellectually
Educational	3	C: . . . able to teach patients and colleagues about the relevance of genetics
Rapidly growing field	2	C: The pace at which the field is growing, feeling like I'm on the cutting edge
Domain: Career Barriers		
Financial	8	S: Swallowing the fact that I'm going to graduate with tons of student loans and take a job that doesn't pay particularly well C: Cost of graduate school made me consider salary a lot more when looking into jobs, which is unfortunate since a lot of underserved areas can't afford high salaries
Lack of information		S: I just stumbled across the field by chance . . . Once I knew I was interested, I found it very difficult to gather more information C: I don't really think that I was clear on what a genetic counselor actually is, even when I was interviewing and applying
Lack of diversity	7	C: . . . the field didn't really have too many minorities . . . Trying to navigate my place and where I fit in C: We're so small and homogenous, I don't think this serves the needs of our population
Limited opportunities to advance	6	MS: It felt like I was closing doors, shutting myself off to other career areas . . . if I did this schooling I wouldn't have any other options
Lack of confidence	6	S: Wondering if I could actually cut it in graduate school . . . do practical things besides take tests well C: I feel genetic counseling is something that requires some innate personality type to do well; I wasn't sure I had that personality
Patient homogeneity	5	S: When I got to school, I found that most services are only provided to people with money. There were a lot less outreach programs than I expected C: I was surprised during clinical rotations that the majority of patients were white, mid to upper SES . . .
Lack of autonomy	2	C: It's frustrating to have this advanced degree and to really know your stuff, and then have to concede to someone else with a higher degree or get their signature on things that you prepare
No reservations	1	
Domain: Family Supports and Barriers		
Unequivocal encouragement	7	MS: My parents did want me to be a doctor but . . . since I decided to be a genetic counselor, they've been completely supportive C: . . . Both sides of my family have always been very supportive of whatever I would have wanted to do
Mixed support	3	C: First they questioned it because they didn't know what it was. After they learned, they were supportive, but they do encourage me to do genetic counseling and get a PhD
Discouragement	3	S: There's been some tension particularly with my mother because she had hopes for me going to medical school. We discussed salary and that it may not be as high as she would have expected MS: They responded: "Why would you do that? What's that? Wouldn't you rather be a doctor or lawyer?" C: My parents, family, and friends all looked at the pre-requisites I took for genetic counseling and wondered, "If I was going to take all those classes, why didn't I go to medical school. If I had the intellect and could succeed, why not choose a field with more prestige and a bigger salary?"
Tacit encouragement	2	S: They didn't really respond much. All they understood was I was going to get a master's degree, so they were happy about that . . .

Note. S: current student; MS: current male student; C: practicing genetic counselor

counseling, primarily because they did not know what it is; 3) Discouragement - some participants stated that their families discouraged their choice of genetic counseling; and 4) Tacit encouragement - some reported that their families were supportive of graduate school, but *noncommittal* about a choice of genetic counseling.

Experiences within Training Programs and the Field

Participants described a variety of positive and negative experiences that were grouped into 6 domains and 14 categories, summarized in Table II.

Domain 1: Size of Training Program

This domain refers to the impact of training program size on a student's sense of belonging, and it contains 3 categories: 1) Fosters support - a majority of participants stated that smaller programs produced *automatic friendship*, and that the amount of time spent together facilitated bonding among classmates; 2) Isolating - others reported that a small student cohort made them feel even more conspicuous, leading to a sense of exclusion or loneliness; and, 3) Difficult to diversify - one participant stated that a smaller program makes it more difficult to have a truly diverse group of students.

Domain 2: Being in the Minority

This domain refers to experiences stemming from being an underrepresented individual in genetic counseling, and it contains 4 categories: 1) Different perspective - many stated that their cultural/ethnic backgrounds allowed them to offer a different perspective and to increase awareness of cultural differences; 2) Loss of cultural identity – almost half reported some loss of cultural identity because classmates or colleagues, while not intentionally excluding them, seemed generally unaware of cultural differences and therefore did not invite participants to share these differences. A few participants described how in large professional settings their cultural identity is either ignored or is their only salient characteristic; 3) Feel different/alone - Several participants described occasions when being in the minority made them feel different/alone. These occasions often involved discussions in which classmates or colleagues dealt with cultural beliefs from a theoretical or academic viewpoint, while the participants had personal insight. One participant reported feeling directly excluded by classmates due to gender differences. 4) Work harder to belong - Several participants reported having to exert more effort to make themselves part of their training program/the field, for instance, attempting to engage classmates in conversation or social events, or striving to be involved in multiple professional activities in the National Society of Genetic Counselors.

Domain 3: Ambivalence

This domain represents participants' conflicting feelings about being underrepresented individuals, and it contains 2 categories: 1) Hesitate to voice differences - some participants, while recognizing differences between themselves and their classmates/colleagues, refrained from expressing them; and 2) Question relevance of pioneer efforts - a few participants expressed excitement over being the first from their cultural/ethnic group to be part of the field, but were conflicted about pursuing a career that may fail to meet the needs of underserved groups.

Domain 4: Pressure

This domain concerns externally and internally imposed pressure, and it contains 5 categories: 1) Patient misperceptions - over half of the participants had encountered patient inaccuracies regarding their cultural/ethnic backgrounds. For instance, some patients either expect participants to understand them better due to a perceived common cultural/ethnic background or to act in a certain manner because of their background; 2) Underrepresented individuals are diversity experts - classmates and/or colleagues may expect them to be knowledgeable about all underrepresented groups, to have greater insight regarding culturally sensitive topics, and/or to know how to increase diversity within the field. 3) Justify one's place - several participants reported self-imposed pressure to prove that they deserve to be in the field/training program. This pressure comes from a perception that others consider their cultural/ethnic background to be advantageous during the graduate admission process, or from their own belief that acceptance to a graduate program is a privilege and they must work harder to take advantage of it. Some

Table II. Experiences in Genetic Counseling Program and the Field

Categories	Prevalence (*n*)	Participant quotes
Domain: Size of Training Program (N = 15)		
Fosters support	11	S: Our class size is so small, it makes us an automatic group; I don't think anyone would be excluded because of race C: . . . with the level of comfort that you have to develop in a program that is so small, I think people are very aware of asking about differences – not just on an ethnic level, but a personal level as well to find support within your class
Isolating	4	MS: It's like I'm an outsider. There's this small group of us, and I'm always the one to be singled out or excluded . . .
Difficult to diversify	1	C: I knew going in that because the programs are so small, it's extremely difficult to have true diversity . . .
Domain: Being in the Minority (N = 15)		
Different perspective	9	S: I think that people from different backgrounds bring additional perspectives and that just adds to your knowledge base and experience . . . S: I definitely think that I add a lot to the program personally because I offer a different perspective and opinion C: I think in general I do bring a different perspective. During my rotations I served in a population that had more minority groups, so I was able to bring a different perspective as to what a patient was dealing with culturally and what was going on in their head . . .
Loss of cultural identity :	7	S: I find myself relating to them [classmates] and wondering how their culture affects their perception of things, instead of . . . them trying to understand me C: I've learned to acclimate . . . I could fit in to [classmates'] experiences and culture, but sometimes it wasn't as obvious to them that I may be different . . . they didn't even know to ask or think I would be different . . . C: . . . in large settings, like the national conference, I either lose my cultural identity or my cultural identity's all I am
Feel different/alone	6	S: . . . they [classmates] talk about things in a kind of theoretical fashion, whereas I was thinking they don't know what it's really like. It's weird to think that I'm the only one in the program that has this insight . . .
Work harder to belong	5	S: I often feel that it is my own personal effort that has allowed me to fit in with the group C: I work hard to stay involved . . . make my face known so other counselors think of me when projects come up and I can be a presence for other underrepresented counselors or students. I think if I didn't do those things, it would feel more isolating.
Domain: Ambivalence (n = 12)		
Hesitate to voice differences	5	S: . . . I feel like I might perceive things differently but . . . don't really want to be different or stick out, so I don't usually voice these differences C: At times it would have been nice if [my classmates] were more interested, but it was just easier for me to blend in rather than make a big deal out of things
Question relevance of pioneer efforts	3	C: On the one hand I feel like a pioneer; on the other, I wonder if the field is really serving the needs of the minority community in general
Domain: Pressure (N = 15)		
Patient misperceptions	8	S: I've always associated with people with a higher SES - but with my culture, I think patients assume my family might be lower SES and I can . . . understand them better MS: Patients always seem to think that I'm the doctor. It's frustrating to get the question of 'Why didn't you go to medical school?' from my patients! Like I couldn't cut it, or like genetic counseling is somehow less of a field C: [Sometimes patients from the same background] put a lot of pressure on me because they expect that I will automatically understand them or speak their language. When I can't or I ask more leading questions to learn more, I feel they get frustrated or think that I have sold out on my background because I don't know the traditional customs
Underrepresented individuals are diversity experts	6	S: I went to the NSGC diversity meeting and . . . it felt like everyone was watching me and expecting me to have a brilliant idea or solution C: My classmates seemed uncomfortable with other ethnic/ minority groups or would often follow my lead and the way I'd respond to situations. It made me feel like I was expected to have a better understanding of all minorities

Table II. Continued

Categories	Prevalence (*n*)	Participant quotes
Justify one's place	6	S: In the back of my mind I always wondered if I was only offered an interview because of my race MS: I do feel that I was given the opportunity to interview at more schools because I am male C: Other I wonder, maybe we [minority patients and I] are the same, but why was I given this privilege to be here? What's so special about me? I better not mess this up
Represent one's ethnic group	6	S:I feel like I need to do more for patients that are from the same cultural group as me, like I need to go the extra mile C: Sometimes it feels like the whole [diversity] cause is completely on my shoulders and I'm expected to bear the problem alone or with the few other minority counselors C: When any minority issues came up, I felt like I had the weight on my shoulders to educate people and to be a good spokesperson . . . . I felt like I had to present myself in a certain way, to eliminate stereotypes . . . and then when any ethical discussion came up I felt like I had to eliminate any stereotypes in regards to minority communities. I didn't expect that added pressure to be placed on my shoulders
Peer misperceptions	5	S: One professor said to me, "I think that you are very quiet because of your culture" and a supervisor said, "You need to take more control of the sessions . . . I think you have this problem because of how your family communicates with you, because of your background." MS: A lot of the girls [sic] see things as since I'm a guy I was let in. So they set lower expectations for me and don't expect me to do well MS: The people who interviewed me seemed to indicate that gender might be an obstacle. I almost felt like they were trying to deter me from the field MS: There are certain preconceived notions like, "He's a guy, he'll need more help with the feeling stuff." Professors/supervisors seem to expect that I'll know more of the medical/hard science stuff. Some of the professors or the male MDs still ask why I don't go to medical school
Domain: Interacting with Others of Similar Background is Helpful (N = 15)		
No separate categories		S: One of my supervisors was from the same ethnic group as me. It was nice to see someone that looked like me. It made me feel at ease C: It was nice when I interviewed and saw that someone like me was already in the program. I figured, "She fits in, so I probably will, too" MS: It is really helpful to have him [my roommate, who is not in the program] around to sometimes just do *guy* things. It's nice to talk about concrete things versus how I feel about things. He maintains my masculine sanity
Domain: Underrepresented Status Builds Trust/Rapport (n = 10)		
No Separate Categories		S: If I have a patient from the same cultural group as me, I can relate to them through our common experiences. I'm more comfortable and they're more comfortable MS: I feel that I might be able to understand what the father is going through better than some females would . . . C: . . . I think that when [minority] patients are able to walk into a clinic and see someone who looks like they do, they automatically think that I will understand them or watch out for them. I think they perceive that we are similar, so from their perspective the fact that we're both minorities is somewhat of a bonding quality

Note. S: genetic counseling student; C: practicing genetic counselor; MS: male student.

expressed frustration about having to justify their place when they were born and raised in the United States the same as majority students. 4) Represent one's ethnic group - Some participants felt pressure to make a greater impact during counseling sessions with patients from the same cultural/ethnic group, or to act in certain ways in group settings in order to minimize negative stereotypes associated with their ethnic/cultural group. 5) Peer misperceptions – Sometimes classmates, supervisors, or colleagues

have made inaccurate assumptions, for example, attributing individual character traits to ethnic background. All three male participants indicated that their peers labeled them with certain gender stereotypes.

Domain 5: Interacting with Others of Similar Backgrounds is Helpful

Almost every participant who had classmates who were also underrepresented reported a sense of relief at not being *the only one*, and several reported a desire to interact with other underrepresented individuals because of familiarity, being able to be themselves, and being with others going through the same experience. There were no separate categories.

Domain 6: Underrepresented Status Builds Trust/Rapport

This domain concerns beliefs that the patient-provider relationship is more open and honest when ethnic or culture backgrounds are concordant. There are no separate categories.

Personal Opinions Regarding Diversity and Genetic Counseling

Participants offered 8 possible reasons for the lack of diversity within the field and they provided several suggestions to increase diversity.

Reasons for Lack of Diversity

Over half of the participants ($n = 8$) commented that *genetic counseling is unknown* to underrepresented individuals and their families due to a lack of information (e.g., "In certain cultures parents like to have a name that they know ... they know what a doctor is and they don't know what a genetic counselor is"). The field might also lack appeal because of *differing worldviews* ($n = 7$); that is, some groups may not value genetic counseling services (e.g., "... the model of genetic testing doesn't seem to apply to minority communities who as a whole are concerned with faith, spiritual beliefs, low socioeconomic status, and everyday survival"). Salary may be another factor ($n = 7$); cultural expectations of males as providers conflict with the average genetic counselor salary, and underrepresented individuals may have a lower socioeconomic status and be deterred by the salary base (e.g., "... people tend to weigh salary as a factor especially for people that don't have a husband or someone else to rely on for an income... I think the genetic counseling salary is looked at as an upper-middle class supplement to a male income").

The field may not be viewed as one that *gives back to the community* ($n = 6$), for example, to the extent that *genetic counseling* is closely linked to *abortion*, it may signal a breakdown in community. Similarly, there might be negative connotations associated with the field ($n = 6$). For instance, *genetic counseling* might connote an emotionally-based profession, thus dissuading some men from pursuing the career, and it might evoke images of eugenics. Another reason, mentioned only by students ($n = 5$), is that genetic counseling *lacks job prestige*. Finally, a general *lack of underrepresented individuals in all branches of science* might make it difficult for the genetic counseling field to compete for applicants with other, well-known areas of science ($n = 2$), and being a genetic counselor represents a *position of privilege* ($n = 2$) (e.g., "... now they are trying to pass it [genetic counseling field] off to women of color in the community, and it's really hard because these women do not have the power to do these things").

Suggestions to Increase Diversity

Suggestions included: *increasing awareness of the field* through outreach efforts in local high schools and/or colleges, targeting regions known to have a large proportion of underrepresented individuals; *increasing professional involvement of* underrepresented individuals who are currently in the field, as their presence at large gatherings would instill a feeling of comfort; *expanding genetic counseling services to underserved areas* to increase exposure of the genetic counseling field, increase cultural competency of genetic counselors, and help eliminate health disparities; *developing recruitment materials* that clearly describe the role of genetic counselors, how the field contributes to society, and the role of underrepresented individuals currently in the field; providing *financial support* (e.g., scholarships, lower tuition, higher salaries); *providing mentors* from a similar background; *conducting more research* on the topic; increasing *positive media attention*; and

providing *counselor shadowing* opportunities to high school and college students.

DISCUSSION

In the present study, 8 genetic counseling students and 7 practicing genetic counselors who self-identified as underrepresented described how they discovered the field, career supports and barriers, positive and negative experiences in the field, and suggestions about increasing diversity. Major themes are discussed next.

Introduction to the Field Occurs Late and Usually is Accidental

A majority of participants first discovered genetic counseling either in college or after completing an undergraduate degree, and many learned about it *by chance*, in a science course, from a co-worker who was a genetic counselor, or from an academic advisor. Unfortunately, many of the student participants reported that their college advisors were discouraging because the advisors lacked knowledge about the field. One strategy the National Society of Genetic Counselors employs to increase diversity involves *culturally friendly* career posters and brochures targeted to high school and college students (National Society of Genetic Counselors, 2005). None of the participants reported encountering these materials, suggesting that at present, there is no widespread vehicle that effectively promotes the profession to underrepresented individuals.

There are Both Supports and Barriers to Pursuing a Career in Genetic Counseling

Career Supports

The participants identified several attractive aspects of a genetic counseling career, including its combination of science and counseling; opportunities to help people, have personable interactions, and educate others; its intellectual stimulation; and how rapidly the field is growing. These perceptions are quite similar to those identified in a recent survey of genetic counseling students (Lega *et al.*, 2005), suggesting that underrepresented individuals are not drawn to the field for unique reasons.

Career Barriers

The participants identified several obstacles to a genetic counseling career. Most prevalent was the difficulty obtaining information. There is no way to determine how many individuals abandon pursuit of the field because of this barrier. Similar concerns were expressed over a decade ago in a phone survey of ethnically diverse genetic counselors (Smith *et al.*, 1993). However, in the present study, lack of information was more prevalent for practicing counselors than for students, suggesting that accessibility of information might be improving.

Similar to respondents in the Lega *et al.* (2005) study, many participants expressed concerns about salaries. They also mentioned the high cost of graduate school. Research in the medical field suggests that finances often pose a greater deterrent for ethnic minorities because their families lack experience with significant debt and/or they lack resources to cope with financial burdens (Cregler *et al.*, 1994; Gabard *et al.*, 1997).

All three male students and some of the practicing counselors expressed anxiety about how they actually *fit into* the field. No female students made comments classified within this category. Since the males had spent most of their lives in the majority vis a vis their gender, their more recent minority status as graduate students might be more distressing than for the female student participants who have a history of being in the minority because of their ethnicity. The anxiety expressed by the practicing counselors might partly be explained by their extended experience of being a minority in a field that lacks diversity, or perhaps the struggle to *fit in* intensifies as one matures professionally.

Another barrier concerns a lack of personal confidence, mentioned only by female participants. In dentistry, ethnic/racial minorities more often cite a lack of confidence as a reason for discontinuing their program/practice than do majority individuals (Lopez *et al.*, 2003). Studies that assess determinants of personal confidence might aid in developing recruitment and retention interventions.

Other barriers included lack of diversity in patient populations, lack of autonomy, and concerns about inability to advance in one's career. These barriers likely vary in the degree to which they are based in fact versus perception and in the extent to which they are unique for underrepresented individuals. In our experience, lack of autonomy is a common perception among genetic counselors, regardless of

their cultural identity. Similarly, inability to advance in one's career may be a common perception both for minority and majority individuals, and it may be prevalent for anyone who pursues a specialized degree. Lack of patient diversity is a verifiable fact and it may constitute a more significant barrier for underrepresented individuals. Several participants described their shock and disappointment upon realizing that the same populations underserved in health care remain underserved in genetic counseling.

Family Supports and Barriers

Numerous studies have shown that family support is associated with behavioral and attitudinal indices of school engagement and with aspirations for career success, expectations for attaining career goals, and the importance of work in one's future (e.g., Baker, 2000; Erwin *et al.*, 2004; Kenny *et al.*, 2003). Although the majority of participants reported unequivocal family acceptance of their choice to enter the field, they often had to clarify what a genetic counselor is and does. A few reported that their family members were ambivalent about their choice, and/or actively encouraged them to investigate other careers with greater name recognition and a stronger salary base. Understandably, many underrepresented individuals who are discouraged by their families from pursuing genetic counseling may choose different career paths.

Training Programs and in-the-Field Experiences are Complex and Nuanced

Almost every participant reported primarily positive experiences and denied purposeful exclusion or discrimination due to their underrepresented status. Not unexpectedly, however, their experiences in a vastly homogenous field are mixed.

Size and Homogeneity of Settings

For most, the small size of training programs and use of a *cohort model* foster a shared, interactive learning experience in a *family-like* atmosphere. In addition, the presence of peers from a similar ethnic/cultural background provided relief and comfort. A few participants described their training experiences as *isolating* and *lonely*. Most were from larger training programs (≥ 16 students), and they were more likely to be male. Many participants reported feeling conspicuous in larger settings, such as professional conferences, perhaps because larger settings magnify differences between underrepresented individuals and the majority. Size and homogeneity of settings likely interact with intrapersonal variables such as ethnicity, gender, and personality characteristics, and additional research is needed to investigate the relative influence of these variables on feelings of inclusion and comfort.

Peer Relationships

In the present study, male participants appeared to be most adversely affected by their peer relationships. One male participant stated: "[my classmates] don't even attempt to allow me to be a part of the group, but rather assume that we are so different it is not worth it." It is unclear if a similar disparity exists among practicing genetic counselors, as all of the male participants in this study were students. Some participants sought out organizations or environments where they were guaranteed to interact with others from a similar ethnic/cultural group, especially the males, who expressed a need to *do masculine things*.

Acculturation

Participants described a personally challenging and on-going process of becoming part of the genetic counseling field. Although recognizing that their perspectives were valuable and helped to increase cultural sensitivity, they at times withheld their opinions because they did not wish to *stand out* as differing from the majority. Over half of the practicing counselors reported struggling to maintain a balance regarding their cultural identity because they continually felt as if their cultural differences were either ignored completely or were their sole identifying characteristic. Further complications involve questions about the degree to which the profession's goals meet the needs of their cultural communities and the pressure participants feel to act as the *bridge* between their cultural/ethnic communities and the genetic counseling field. Additional challenges include pressure from classmates, instructors, and colleagues to be *diversity experts* regarding all cultural/ethnic groups and to figure out how to increase diversity within the field. As one participant poignantly remarked, "Everyone is waiting for the *I Have a Dream* speech." Some participants were concerned that their

acceptance into their training program was at least partially due to their underrepresented status.

Many participants talked about sacrificing aspects of their own culture in order to *assimilate* to their classmates' culture. These experiences reflect ideas expressed in the article, "White Privilege: Unpacking the Invisible Knapsack" (McIntosh, 1990). According to the author, white privilege is the unacknowledged corollary to racism, consisting of everyday advantages that unconsciously go *hand in hand* with being a member of the majority group. McIntosh explains that for every instance in which white privilege allows the majority group to feel confidence, comfort, and oblivion, members of other groups likely feel insecure, uncomfortable, and alienated. Various participant comments support her contentions, for example, "Sometimes as a minority you can't help but feel, 'Am I the token minority student?' like you were accepted into the program because they needed to increase diversity . . ." A Caucasian female student would never feel as if she was accepted to a genetic counseling training program on the basis of her race (or gender).

Acculturation challenges also occurred in the clinical setting where participants have conflicts due to their *bicultural identity* (i.e., genetic counselor identity and cultural identity). In some instances, when counseling patients from a concordant cultural or ethnic background, counselors may experience resistance because they approach a session from a genetic counseling framework whereas the patients expect a *culture congruent* framework. Counselors may be perceived as *selling-out* in such situations (e.g., taking a nondirective approach that is diametrically opposed to their patients' cultural values and practices).

Nelson and colleagues (2006) describe the process of acculturation as "deeply interpersonal, involving both belonging and appreciation needs . . . on one hand [people] wished to pass so that they would be accepted. On the other hand, they wished to be fully known and accepted in spite of their background . . ." (p. 11). The obvious conflicts between these needs can lead to *acculturation stress*, or discomfort associated with adapting to new cultures that can lead to depression, anxiety, and suicidality (Nelson *et al.*, 2006). Program faculty and clinical supervisors should be alert for signs and symptoms of acculturation stress and intervene as necessary.

Despite these challenges, there are also advantages to one's underrepresented status in clinical settings. For instance, patients may view the counselor as similar and, therefore likable and trustworthy, and this *referent power* (Tajfel and Turner, 1986) positively affects the counseling process and outcome. Several participants reported greater comfort with patients of a similar ethnic/cultural background because their shared experience provides better understanding of patient feelings and perspectives.

Opinions Regarding Lack of Diversity in Genetic Counseling Reflect Career Barriers

Participants' speculations about why the field lacks diversity generally reflect their perceived career barriers. First of all, underrepresented individuals generally are unaware that genetic counseling is a viable career choice. This point is consistent with Oh and Lewis' (2005) findings that high school and college students' knowledge of genetic counseling was lower among racial/ethnic minorities and males. It is encouraging, however, that Oh and Lewis' minority students were as likely as majority students to consider genetic counseling as a career choice, suggesting that outreach efforts in high schools and colleges may help to increase diversity within the field.

Participants mentioned the importance of earning potential and that genetic counseling may be viewed as financially unattractive. Male participants discussed societal expectations to be *breadwinners*, and others discussed the fact that African Americans, Hispanics, Native Americans, and recent immigrants to the U.S. generally attempt to identify career paths that will raise their respective family's socioeconomic status. They also suggested that job prestige might be a barrier. There is some research support for this point, as studies of Asian samples have shown that cultural values about education and prestige strongly affect career choice (Hardin *et al.*, 2001; Tang *et al.*, 1999).

Participants also discussed value conflicts, for example, genetic counseling is not as relevant, and therefore not viewed as a field that *gives back* to the community, and it is associated with eugenics. One concern, possibly unique to males, is a perception that the title *genetic counselor* connotes a *female* career choice. However, Oh and Lewis' (2005) male respondents who had prior knowledge of genetic counseling reported being equally as likely as females to consider this career option. Perhaps an important distinction is that the present participants had actually committed to a career in genetic counseling, whereas Oh and Lewis' sample were merely

considering it. On a related note, all three males commented that because the genetic counseling field was founded by females, it may be based on principles that are more likely to appeal to females.

Some participants suggested that lack of diversity within the field reflects the sciences in general. This point is noteworthy given that many other well-known areas of science are implementing programs designed to increase diversity (e.g., Baker, 2000; Carline and Patterson, 2003; Erwin *et al.*, 2004; Heron and Haley, 2001; Legler and Stohs, 2003; Lewis, 1996; Lopez *et al.*, 2003; Thomson and Denk, 1999; Yates *et al.*, 2003), and they are/will be competing for the same qualified individuals.

Study Strengths and Limitations

Findings of this study are supported by the use of carefully crafted interview questions, recruitment of participants through several sources, and use of a qualitative design to generate a rich description of participant experiences. However, qualitative data are not intended to generalize to the population (Patton, 1990). The sample was limited with respect to the types of ethnic and cultural diversity represented, and none of the practicing genetic counselors were males. Individuals who may be in the minority based on other characteristics (e.g., low socioeconomic status, sexual orientation, affected with a genetic condition) may have different perspectives. Participants may have been reactive to our interview questions about strategies for increasing diversity since some reported feeling pressured to "find solutions" within their training and practice environments. Finally, several inquired about the interviewer's cultural background (Caucasian), which may have affected their trust and subsequent disclosure.

Implications for Training and Practice

The participants repeatedly stressed the value of training programs that are small and use a *cohort model*. It is important that the field remain cognizant of these strengths as demand for genetic counseling services grows. If programs respond by increasing student enrollment and/or offering part-time training (which threatens the cohort model), they may hinder recruitment and retention of underrepresented individuals.

Participants described painful experiences of trying to *fit in* and commented that this process is eased by interactions with other underrepresented individuals. Studies in medicine and dentistry have shown that underrepresented individuals are more likely to complete their training if they have a mentor at the training institution who is of a concordant race/ethnicity (Legler and Stohs, 2003; Lopez *et al.*, 2003). Training programs should strive to provide mentors within their training programs and within the field, and the profession should create opportunities for underrepresented individuals to interact with one another (sponsored activities at meetings, personal correspondence, etc.). Although mentoring currently is offered by the National Society of Genetic Counselors to genetic counseling students, many of the present participants were unaware of this service. Additional strategies to increase diversity include: providing language training to students and health professionals, assistance in test-taking and interviewing skills, recruitment of allied health professionals who desire a career change, and inclusion of diversity as a core curricular value (Sullivan Commission, 2004).

The genetic counseling profession cannot continue to rely upon *chance encounters* as a recruitment strategy. It must work to increase individual, family, and community knowledge about genetic counseling, proactively publicizing itself much earlier in an individual's career-decision making process. Materials should be developed that explain the utility, relevance, and accessibility of a genetic counseling career and the role of underrepresented individuals in genetic counseling. Middle and high school counselors and college and university career and academic advisors should be informed and provided with materials in order to serve as positive sources of information. Educating academic advisors in settings such as historically black institutions might help to increase diversity in the genetic counseling profession.

Finally, recruitment efforts must be complemented by concerted retention efforts. Both underrepresented and majority students should be engaged in a mutual acculturation process. On-going training in multiculturalism (through graduate coursework, exposure to underserved populations through clinical rotations and outreach activities continuing education, and peer supervision) is necessary to communicate that the profession is not one of *white, female privilege*. Culturally competent training should include knowledge about various groups, practitioner self-reflection and recognition of personal biases and

biases in the profession, and integration of knowledge and awareness with clinical practice (Weaver, 1998).

Research Recommendations

Further research is necessary to identify ways to increase diversity within the genetic counseling profession. Follow-up studies should be done to distinguish which of the themes identified in the present study are unique to underrepresented individuals and which are more universal experiences. The relative influences of gender versus ethnicity on one's experience warrant further study. Investigations of how genetic counseling is perceived by various groups are needed, especially vis a vis prestige, income, and values. Studies should also be done determine how underrepresented individuals *meld* their bicultural identities (genetic counselor identity and cultural identity) to achieve greater congruency in their clinical practice.

Theory-based, longitudinal studies that follow students from career consideration to career choice to post-degree practice may identify factors that predict their entry into the genetic counseling field as well as their career satisfaction and success. Research could be designed based on social cognitive career theory which focuses on the interaction of individual characteristics (e.g., self-efficacy) with various environmental supports and barriers (e.g., family support) in predicting academic and career performance and satisfaction (Lent *et al.*, 1994). Finally, program evaluations are necessary to identify effective recruitment and retention strategies. The American Board of Genetic Counselors (ABGC) should be called upon to assist in these efforts by collecting and disseminating statistics regarding the percentages of underrepresented individuals within the applicant pools for all certified genetic counseling programs.

CONCLUSIONS

Efforts to increase diversity within the genetic counseling profession have intensified over the past decade (Lega *et al.*, 2005; Punales-Morejon and Rapp, 1993; Smith *et al.*, 1993; Warren *et al.*, 2005; Wang, 2001). They must be further developed in order to move genetic counseling from a profession of white female privilege to one that represents national and global ethnic, cultural, and gender diversity.

APPENDIX: Interview Questions: Student Protocol*

Introduction to the Field

- How and when did you find out about the field of genetic counseling?
- When did you make this career choice (high school, college, work force, etc.)?
- What attracted you to the field?
- Do you have any reservations about entering the field?
- What factors did you weigh in choosing your graduate program?
- What expectations did you have for the program that you chose to attend?
- To what extent have these expectations been met?
- Was/would your choice of which graduate school to attend have been influenced if you knew that your classmates would consist of a diverse population (i.e., was the presence of other minority students a factor in your graduate program selection)? Was/would your choice have been affected if you knew that one or more of your professors and/or supervisors would have a diverse background?
- In your opinion, do you feel that you were treated differently than other students during the interview process? What about since you've been in your program?

Support/Barriers

- How did your family and friends initially respond to your choice to become a genetic counselor? How do they feel now?
- What would you say was the biggest barrier you faced to entering graduate school, if any? Do you feel that there are currently barriers you face in school?
- Who have you sought support from?
- Have you joined groups or sought activities whose participants include a diverse array of students?

Training

- Are any of your classmates from the same cultural/ethnic group as you?

- If yes, have you sought them out over your other classmates for support during grad school?
- Do you feel that your ethnic background has impacted your relationship with your classmates, instructors, and or supervisors?
- To what extent do you feel a part of your training program?
- Have there been specific times that you felt accepted?
- Have there been specific times that you felt like an outsider?
- Are there any particular things that you wish that your classmates and/or supervisors knew about your culture/ethnic group?
- How much would you say that your classmates and supervisors generally know/understand about your culture? How about now?

Clinic

- What impact do you think your ethnic background has on your clinical performance?

Suggestions

- What is your perception as to why the genetic counseling field lacks diversity?
- Do you have any suggestions of how we can better diversify our field?

*Questions were modified slightly for practicing counselor participants.

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