

Ethnocultural Diversity and Genetic Counseling Training: The Challenge for a Twenty-First Century

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KEY WORDS: genetic counseling training; ethnocultural diversity.

The most recent data from the Population Census Bureau (1990) indicate that the United States is currently experiencing its greatest and most diverse ethnic migration since before World War I. As technologic abilities continue to increase, more centers are offering genetic services, especially in urban areas where new immigrants are likely to reside. Additionally, the range of genetic services that are available has also grown. Projections for the year 2000 postulate that 1 out of every 4 Americans will be a member of a non-Euro American ethnic group. It is estimated that by the next century more than half of the total United States population will be of color. This dramatic growth of diversity mandates the training of more genetic counselors who have the knowledge, skills, and awareness to effectively work with and provide services to diverse populations. In this issue of the *Journal*, Jon Weil and Ilana Mittman propose a framework for teaching genetic counseling graduate students cross-cultural issues.

While the number of immigrants and ethnic groups in the United States is rapidly growing, adequate representation from these populations in the health professions lags behind. Specifically, there is an extreme

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shortage of bicultural and bilingual genetic counselors. These professionals are critically needed because of their unique ethnocultural perspective, in that, they are likely to have experienced the complexities of patients' cultural backgrounds. This richness in cultural experience can help provide genetic counseling services that are culturally relevant and appropriate for diverse populations. The article by Stephanie Smith, Nancy Steinberg Warren, and Lavanya Misra discusses minority recruitment and ways to retain these students in genetic counseling programs. The authors present data from a survey of 15 Master's Genetic Counseling Programs on such practices.

In response to the limited numbers of bilingual/bicultural genetic counselors, some genetic service providers are recruiting "genetic assistants" from the ethnic groups they now serve. Acting as liaisons between the community, the patient and the providers, these para-professionals have facilitated the provision of culturally sensitive genetic services. However, there is still a need to train genetic counselors for effective communication with diverse patients and to address institutional and cultural barriers in the provision of services often encountered by genetic patients.

To what extent are genetic counselors being trained to provide culturally relevant genetic services? To begin to answer this question, we undertook a pilot survey in 1991 of the directors of all 15 Master degree graduate genetic counseling training programs in North America and a sample of 50 genetic counselors currently providing outreach services to diverse communities. Program descriptions, syllabi, and other educational resources were requested from the training institutions. Program directors were asked to describe current opportunities and requirements for ethnocultural or second language coursework and/or clinical experiences.

Genetic counselors were asked to comment by mail and telephone on their use of educational materials for patients from diverse backgrounds, their own training on issues of diversity, which health professionals have facilitated their work with patients from ethnocultural communities, and the methods they use to overcome language barriers.

Program directors indicated that, in general, issues of ethnocultural diversity receive relatively little coverage in the didactic coursework, but all suggested specific areas in the first year curriculum where such issues could be incorporated. The patients encountered in clinical rotations were a diverse group. On average, 35% (range = 5-50%) of patients were of middle class socioeconomic status, an average of 39% (20-70%) were working class, and an average of 26% (12-40%) were poor. The ethnocultural and racial backgrounds of the patients were also quite diverse and geographically

specific with African-American, Latinos, Asians, and White Euro-Americans constituting large percentages of counseled populations at many medical centers.

The interviews with the genetic counselors revealed that most would have preferred to have second language training placements at centers with diverse patient populations and coursework on cross-cultural counseling. The counselors reported using a wide range of educational materials that are literacy-appropriate. Roundtable discussions, cultural self-assessments, and educational workshops were mentioned as avenues for continuing education on issues of diversity. Language barriers were most commonly addressed by use of on-site and trained translators, staff members, and patients' extended family members and friends. The majority of counselors stated that students should be encouraged to learn a second language and have exposure to a wide variety of settings and patient populations in their internships and clinical placements. Recruitment of graduate students from diverse racial and ethnic backgrounds was recommended.

From our survey of program directors, we concluded that second language training cannot realistically be built into the programs. Given the significant load of prenatal counseling cases, didactic materials on ethnoculturally specific beliefs, practices, taboos and aspirations surrounding reproduction may be valuable additions to the curriculum. Materials designed to enhance understanding of ethnocultural diversity and sensitivity would be useful in many formats including videos, case studies, fictional accounts, as well as traditional academic articles. Since a very small number of faculty members are typically responsible for social issues courses, it would be feasible to reach them all quite efficiently. This could be accomplished through distribution of bibliographics and other relevant materials, national-level training seminars and workshops, and the availability of a consulting team which could provide on-site seminars and program assessments.

From the interviews of the genetic counselors, we learned that they believe ethnocultural sensitivity training of counseling students is very important but that recruitment of students from diverse backgrounds into the profession of genetic counseling is equally important.

This pilot survey suggested that the focus on issues of diversity varies from program to program and that perceptions of what is both necessary and possible to teach may be hard to reconcile. In the midst of the DNA revolution, the amount of basic science genetic counseling graduates must master is enormous and constantly growing. The addition of more sociocultural training to an already overburdened agenda creates a dilemma. Yet, many counselors believe their training and knowledge of the science was

appropriate, but that they were not provided with the tools to address the cultural differences that they are now encountering.

This discrepancy reflects more than differences of opinion. We suggest that it reflects a growing awareness of the need to incorporate cultural sensitivity training into genetic counseling graduate programs. Rayna Rapp, in this issue of the *Journal*, poignantly presents the sociocultural complexities of genetic patients' lives and the multitude of factors that affect the impact of the new technology for individuals and families.

As the accessibility to and utilization of genetic services continue to increase for immigrant and ethnic groups, it will become more important that counseling be performed in a way that is culturally sensitive and relevant, especially as a patient's individual behavior occurs not only in the immediate context of the family, but simultaneously in the larger community as well. The challenge to genetic counselors is the same that all Americans face as we enter the twenty-first century: to establish and develop respectful communication in an America in which cultural diversity is a permanent aspect of public life. These three papers introduce ideas and methods to initiate accepting this challenge.