PERSPECTIVES IN GENETIC COUNSELING
NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.
Volume 5, Number 3, September, 1983

INFLUENCES OF ETHNICITY, CULTURE, AND RELIGION ON THE GENETIC COUNSELING PROCESS: PROCEEDINGS OF THE REGION II EDUCATION CONFERENCE, 9 MAY 1983, COLLEGE OF PHYSICIANS AND SURGEONS OF COLUMBIA UNIVERSITY, NEW YORK, NY

Niecee Singer

Effective genetic counseling can be hampered severely by subtle, unspoken barriers derived from ethnic, cultural, and religious factors. Understanding the important influence of those factors should improve the genetic counselor's ability to deal with some counseling problems. Three invited speakers, six case presentations, and discussion sessions addressed this challenging area.

Roberto Belmar, MD, Professor of Community Health, Albert Einstein Medical College, Bronx, New York, discussed "Hispanic Culture and Beliefs Regarding Genetic Disease." When he came to this country from Chile ten years ago, Dr. Belmar instituted a unique program that assigned medical students to live in Hispanic neighborhoods. Dr. Belmar presented pertinent background material and a summary of the data derived from the experiences of those students.

For Hispanics, the center of life is the family. Many of the first Spaniards to arrive in South America were men who had been in jail and were sent overseas to settle the land for Spain. The church compelled them to marry Indian women immediately; the couple was then sent to settle and defend outpost areas. The state was an oppressor, not a provider, and the family became the only unit for protection. Education, also a function of the family, was provided by the elders. Those conditions led to a distrust of everything outside the family. The concept of the "godfather" as an extension of the family is also part of the Hispanic culture. Such an individual is someone outside the family who is revered because he has the power and money necessary to improve the lot of the family.

The mother is extremely important in the Hispanic family because she controls decision making. The father is the provider; unemployment often leads to divorce because it threatens the image of the provider and is, therefore, intolerable for the Hispanic man. Elders play an essential role, as demonstrated by the fact that despite expense, Hispanics in this country will travel to their home country to confer with their elders when a crisis occurs. Thus, it is vital to involve the whole family, including the elders, in the genetic counseling process.

Spanish is a very descriptive language; the spoken word is more important than the written word. Subtle differences in words can convey totally different meanings and can even lead to misunderstandings that can jeopardize the messages we attempt to deliver. For instance, the verbs "ser" and "estar" both mean "to be," but "ser" refers to permanent conditions and "estar" to temporary ones. Using the wrong form of the verb can imply the opposite of what one intends.

Health is seen as a state of harmony between one's self and the environment. There are hot (fever, the color red) and cold (upper respiratory infection, the color blue) forces that must be in balance, and a great deal of resistance will result if a physician prescribes a cold force to cure a cold condition. Congenital disease is viewed as punishment for having broken some tradition. Therefore, it is necessary to pray to a saint to protect the family. That is a costly undertaking, with attendant fees of approximately $8000.

When an Hispanic couple comes to a genetic counselor, they test the counselor to determine if he or she understands their needs. If the counselor fails the couple will not return. That may account for the broken appointments one encounters in Hispanic populations.

The vital role of the family makes having children the most important contribution of an Hispanic woman. When medical care is poor many of the children die, and to ensure perpetuation of the family, there are no restrictions on child bearing. Instead of trying to enforce our traditional family planning methods, Dr. Belmar suggests that we provide better medical care to limit childhood deaths. Voluntary restriction of family size will then occur.

Recently, in an attempt to fill the void left by the absence of elders, elderly non-Hispanic people in the North Bronx have been paired with Hispanic families for the purpose of giving counsel and advice. It is hoped that that will benefit both groups.

Dr. Belmar's presentation provided rewarding insights into the often perplexing attitudes we encounter in genetic counseling. An appreciation of some basic concepts of Hispanic society helps make previously inexplicable attitudes understandable.

Joseph Giordano, ACSW, of the American Jewish Committee, addressed "Ethnicity and Family Therapy." He related his experiences as an American of Italian ancestry who was raised in an Irish neighborhood and now works for a Jewish organization. He is concerned about ethnicity as it relates to the acceptance of therapy. One's belief system is established very early and remains available for support during stressful experiences. During a crisis one often loses one's usual sense of identity and relies on earlier belief systems and values, such as religion or the family. Those attitudes may be conscious or unconscious. When discussing ethnicity, there is a danger of stereotyping, and one must use knowledge of the ethnic background of an individual only as a guide in treatment or counseling.

Mr. Giordano compared stressful situations in various ethnic groups. To Italians, separation from the family is the ultimate stress and can result in spiritual death. To the Jewish family, a low level of achievement is a basic cause of stress and is equated with disaster. For Puerto Ricans, lack of respect will cause profound stress.

One's ethnic and cultural background can determine how one deals with problems. For the so-called WASP, it is vital to work out one's own problems and maintain a stiff upper lip. The Jewish person with a problem, however, will go for help quickly and easily, and the Italian will use the network of the family rather than seek help from a professional. The movie "Ordinary People" was cited as an illustration of the problems that can occur when different cultural factors interact in therapy. A basic conflict existed between the WASP patient (the son), who was searching for self control, and the Jewish therapist, who was not interested in self control, but rather in exploring the son's feelings. Thus, the patient and therapist had conflicting goals because of their different cultural backgrounds.

If we try to understand why we do not like particular patients, most probably we would find the dislike is related to something in our and their ethnic and religious backgrounds. From the moment of birth, we have an identity that reaches back to past generations. We have a religion, are members of a particular socio-economic class and are given a name that may have religious or familial significance. Those basic influences are etched into one's being prior to conscious awareness.

According to Mr. Giordano, there is greater acceptance today of the diversity of ethnic cultures and the richness of that diversity. The myth of America as a melting pot is diminishing as ethnicity is recognized as a strength that fosters a sense of belonging. In a society that is upwardly mobile, one can experience a series of losses that produce greater vulnerability to stress. Therapy attempts to reconnect the individual with a network, because a positive ethnic identity is related to one's level of self-esteem.

Mr. Giordano suggests that an awareness of our own cultural background will promote understanding of our relationship to our patients. We also have to understand our patient's cultural background if we are to differentiate between pathologic behavior and actions that are acceptable within a particular group. Mr. Giordano's personal approach and experiences successfully identified the type of conflicts and concerns we all encounter at some time in counseling sessions.

Reverend Robert S. Smith, Director of Chaplaincy Services at SUNY at Stony Brook, has an unusual assignment; he is chaplain to the staff, rather than patients. He discussed "Religious Attitudes Toward Birth Defects and Genetic Counseling." He and several other chaplains of various faiths have been meeting regularly with members of the genetic counseling staff to discuss concerns about coping and religion. The couple or individual who comes for genetic counseling has usually experienced something profound that isolates him from others. That isolation threatens the sense of self. Psychology and medicine are not sufficient to deal with the isolation generated by genetic problems; religion, a system that tries to identify the meaning of experiences, is necessary to allay feelings of isolation.

Reverend Smith discussed the fact that pluralism is now accepted because we recognize that there are many equally acceptable ways of being human. However, three dimensions are present in all religions: intellectual, ethical, and experiential concerns. Each dimension represents a quest for a philosophy that allows one to keep living.

Reverend Smith would encourage counselors in other medical centers to address elements of religion in the genetic counseling process. Such discussions, he says, can produce beneficial insights for counselors.

The case presentations were:

"Achondroplasia in an Hispanic Family,"
Joan Weiss, MSW;
"Pompe's Disease in a Black Islam Family,"
Judy Levy, MS;
"Meckel's Syndrome in a Latter-Day Saint Family,"
Karen Greendale, MS;
"Tay-Sachs Disease in an Orthodox Jewish Family,"
Jane Schuette, MS;
"Down Syndrome in a Born-Again Christian Family,"
Phyllis Taterka, MS;
"Multiple Miscarriages in a Greek and American Family,"
Audrey Heimler, MS.

All of the cases presented were situations where the counselor had to deal with the ethnic background of the persons counseled. All recounted puzzling aspects of what should have been routine counseling sessions. Upon further investigation, the problems were attributable to long standing attitudes grounded in the patient's ethnic or religious background—attitudes that made acceptance of counseling difficult or impossible. Counselors observed that one cannot predict what the individual will do simply on the basis of religious or ethnic background. However, without an understanding of those beliefs, the counselor cannot truly know the individual.

Niecee Singer is Coordinator of Genetic Counseling, Morristown Memorial Hospital, Morristown, NJ 07960

CORRESPONDENCE

To The Editor:

At the recent NSGC meetings in Seattle several inquiries were made regarding the audiovisual materials I used in my workshops. Copies of the "Creating Community Awareness" and "Genetic Counseling" 15-minute slide/tape shows are available for the cost of reproduction and postage. This show was developed especially for young adults, for high school groups, and for use in patient waiting areas as part of the statewide public awareness activities in Ohio.

Public information efforts continue to be a high priority for the group of genetic associates, nurses, social workers, and health educators at the nine genetics centers. These "genetic educators" meet two to three times a year to share curriculum and programs for the high school and for nursing and allied health groups. The group also reviews films, videotaped instructional programs, and workshop plans for science teachers. The make-up of the group has continued to reflect the Ohio Health Department's (Maternal-Child Health Division) focus on early intervention and prevention of birth defects, developmental disabilities and genetic disorders. The commitment to include the human approach to genetics remains strong. If others are interested in these efforts, we might work together to organize a regional workshop focusing on human genetics education from elementary school through continuing education programs for professionals.

The opportunity to meet with many of you in Seattle has left me re-fueled and refreshed. The challenge of our work is clear, and the commitment and enthusiasm of our colleagues continues in our work to improve the quality of life for our patients and the children of the future.

Maureen H. Clark
Children's Hospital
Columbus, OH 43205

NSGC NEWS

NSGC Annual Business Meeting

Date: Monday, 31 October 1983
Time: 8:00 pm - 10:00 pm
Location: Omni Hotel, Norfolk, Virginia

The business meeting has been scheduled during the free evening at the ASHG meeting to allow adequate time for discussion from the floor by the membership. Any member who wishes to propose an item for the agenda should contact Virginia Corson, president, at the following address:

CMSC 1001
Johns Hopkins Hospital
Baltimore, MD 21205

1983 NSGC Education Conference

The 1983 NSGC Education Conference was held on 17, 18 June 1983 in Seattle, WA. Approximately 200 participants attended the meeting, titled "Strategies in Genetic Counseling: Clinical Investigation Studies." Evaluation forms and informal discussions with conference participants indicated that most were pleased with the informational content and with the chance to socialize with colleagues. A limited number of programs are still available.

Most of the conference was recorded on cassette tapes by Audio-State Educational Services, Inc. Please see the flyer enclosed with this issue of *Perspectives* for information on purchasing tapes of individual sessions or of the entire meeting. The conference committee is exploring the possibility of publishing the conference proceedings; specific information will be available in the next few months. Comments concerning publication of those proceedings should be addressed to: Beth Fine, Children's Memorial Hospital, 8301 Dodge Street, Omaha, NE 68114, (402) 390-5488. Copies of the program are available from Beth Fine or from: Melanie Ito, Medical Genetics, RG-20, University of Washington, Seattle, WA 98195, (206) 543-1234.

A Report from the NSGC Board of Directors

The NSGC Board of Directors met in Seattle during the annual national education meeting. Reports indicate that several projects are nearing completion and new projects are expected to begin in the near future.

The *ad hoc* continuing education committee has reviewed two NSGC educational programs (one regional meeting and the 1983 national education meeting) and two programs sponsored by other institutions. The committee continues to review NSGC-sponsored educational programs to determine whether they comply with established continuing education guidelines; continuing education units are not being awarded at this time.

The membership committee continues to streamline application procedures and has implemented many changes that have resulted in more efficient reviews. The NSGC *Membership Directory* will be updated; a revised informational brochure about the NSGC is planned.

The committee is preparing a final version of a document that describes the roles of genetic counselors. That material will be used to reply to requests for information about professional opportunities in genetic counseling. Copies will be provided to the executive office of the American Society of Human Genetics and to the National Center for Education in Maternal and Child Health (formerly the National Clearinghouse for Human Genetic Diseases).

The second professional status survey has been distributed to 380 NSGC members (319 full members and 61 associate members). A report of the results will be presented by the professional issues committee in the fall.

MEETINGS

"Coping with Genetic Disorders: A Workshop for Clergy, Parents and Health Professionals" will be held on 21 October 1983 in Washington, DC under the leadership of John C. Fletcher, PhD. Requests for additional information and registration materials should be addressed to: Linda Kramer, The Alban Institute, Inc., Mt. St. Alban, Washington, DC 20016.

The Office of Continuing Medical Education of the University of Michigan Medical School is sponsoring a course titled "Michigan Short Stature Symposium" on 3 December 1983 at The Towsley Center, Ann Arbor, MI. For more information call or write: Office of Continuing Medical Education, The Towsley Center, Box 057, University of Michigan Medical School, Ann Arbor, MI 48109, (313) 763-1400.

The first annual meeting of the Middle Atlantic Regional Human Genetics Network (MARGIN) will be held in Williamsburg, VA, 1-3 December 1983, in conjunction with the Region IX meeting of the American Association of Mental Deficiency (AAMD). The meeting sponsors are MARGIN and AAMD. For registration information contact: Gale Gardiner, West Virginia Genetics Center, Section of Medical Genetics, Department of Pediatrics, School of Medicine, Medical Center, Morgantown, WV 26506, (304) 293-4451.

POSITIONS AVAILABLE

Assistant Professor in Pediatric Genetics: Applicants must have MD in genetics, with a two-year genetic fellowship. Duties will include participation in teaching of medical students, housestaff, and fellows. This individual will be expected to do attending duties on the wards, to participate in genetics clinics, and to develop an independent research program in the area of dysmorphology and/or human cytogenetics. The recruiting deadline is 1 November 1983; the anticipated starting date is 1 January 1984. Send application to: Jaime Frias, MD, Department of Pediatrics, University of Florida, Box J-296, JHMHC, Gainesville, FL 32510. AN EQUAL EMPLOYMENT/AFFIRMATIVE ACTION EMPLOYER.

Jobs Hot-Line: The NSGC has established a jobs hot-line to keep track of positions available and genetic counselors who are seeking new positions and to minimize the delay in alerting members to new openings. This service will supplement the announcement of jobs in *Perspectives*. If you would like to post an opening or be kept informed of positions available contact: Linda Nicholson, A.I. DuPont Institute, Wilmington, DE, (302) 651-4117, Monday, Thursday, or Friday, 9 am - 5 pm.

Genetic Counselor: A position is available within a large OB/GYN private practice group affiliated with Harvard Medical School. The practice includes many high risk pregnancies and is associated with and located in a tertiary urban teaching diagnostic center of the hospital and in the general genetics clinic of a neighboring pediatric hospital. Candidate must be board eligible/certified by the American Board of Medical Genetics. Salary commensurate with experience. Send resume to: Dr. Samuel A. Latt, Chief, Division of Genetics, Children's Hospital, 300 Longwood Avenue, Boston, MA 02115.

Genetic Associate: A position is available 1 October 1983 in the Department of OB/GYN, Center for the Developmentally Disabled, University of South Dakota School of Medicine. A master's degree in human genetics or genetic counseling is required. Duties will include public education, workshops for professionals and paraprofessionals in health fields, participation in birth defects clinic, and clinical research. Send resume and two letters of reference to: Virginia P. Johnson, MD, Center for the Developmentally Disabled, School of Medicine, University of South Dakota, Vermillion, SD 57069, (605) 677-5311.

Book Review

Children Born with Sex Chromosome Aneuploidy: Follow-up Studies, Edited by Donald A. Stewart, March of Dimes Birth Defects Foundation, New York, Alan R. Liss, Inc., 1982, 251 pages, $54.00; Reviewed by Lynn Godmilow.

This volume reports on the third international meeting of investigators from nine centers that are conducting on-going studies of children identified at birth as having X or Y chromosome aneuploidy. The book begins with a concise, helpful summary of the investigators' conclusions about each of the syndromes that were studied. The balance of the book is comprised of nine reports—one from each center—that describe the specific studies in detail.

The Denver study, which still involves 61 cooperating patients, is impressive in its scope and depth. The study explores physical, intellectual, and psychological parameters, and there is a particularly useful discussion of the impact of the study on the participating families.

The Edinburgh investigators are following 67 children and their families. Their data on the intellectual problems of females with XXX syndrome are of particular interest.

The Danish study of 25 youngsters is extremely thorough and compares each of the affected children to his or her normal sibs and to other controls. Of significance is the investigators' report that I.Q. scores have improved since the last testing. Danes are continuing to offer newborn screening to all prospective parents in one particular part of the country and have a 95% acceptance rate from the families in that area.

The Toronto study of 53 children is lengthy and detailed, and includes much data on the sex hormone status of the affected children. There is some very unusual and interesting research reported here on brain development and total finger ridge count as reflections of early biological growth.

The Japanese study is an anthropometric one of 11 patients with 45,XO and seven patients with 47, XYY. There are no data in this chapter on any parameters other than physical growth.

The Winnipeg group performed physical and psychological investigations on 19 children. Their results indicate a relatively benign course for the XYY group, some behavior problems with the XXY group, and significant problems of intellect and behavior for the XXX group.

The Boston group investigated the relationship between XXY's and XYY's in terms of development. The report dealt specifically with the XYY group of 13 boys and suggests difficulties with processing, storing, retreiving, and producing linguistic information. Most of those children were said to have significant learning disabilities.

The New Haven group identified 10 children who have sex chromosome aneuploidy. All of the children studied to date have mild to moderate impairment of cognitive ability when compared to controls with fullscale I.Q.'s from 55 to 98. Each child has demonstrable learning disabilities. Physical characteristics, particularly height, differed from the controls. The New Haven researchers also stressed the importance of this type of collaborative data in developing accurate and statistically meaningful information for use in counseling for a sex chromosome anomaly detected prenatally.

The final chapter is a timely and cogent discussion of the legal and ethical issues involved in neonatal chromosome screening and prenatal chromosome diagnosis.

This book is required reading for all genetic counselors and clinical geneticists involved in counseling for sex chromosome aneuploidy. It is of even greater importance to those involved in prenatal chromosome studies; it offers the only extant compilation of prospective studies about those problems. This book belongs in the library of every genetic counselor. Its cost, while high, is not prohibitive.

Send all mailing address changes to:
Ann C.M. Smith, NSGC Membership List,
Genetic Services, The Children's Hospital,
1056 East 19th Avenue, Denver, CO 80218.

[redacted]