PERSPECTIVES IN GENETIC COUNSELING

NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.

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This issue of *Perspectives in Genetic Counseling* reports on the first national education meeting sponsored by the National Society of Genetic Counselors, Inc. The program, "Strategies in Genetic Counseling: An Update," was comprised of presentations by invited speakers, five workshops, contributed papers, and a media and resource center.

Program chairpersons, Carolyn Bay, MS, Susan Reed, MS, and Elizabeth Thomson, RN, BSN, are to be commended for organizing a tremendously successful conference. Many members of the planning committee, reporters, and others contributed to the excellence and success of this meeting; their participation is greatly appreciated.

CONFERENCE WORKSHOPS

Members of the National Society of Genetic Counselors, with help from several other professionals and parents, presented workshops on subjects relevant to current genetic counseling practices. Sessions on group counseling for amniocentesis and family therapy were held simultaneously. Additional concurrent sessions addressed counseling methodologies, parent groups, and professional roles. After those workshops, each was summarized for the entire group of conference participants. Summaries of each workshop follow.

WORKSHOP I, GROUP COUNSELING

moderated by William Herbert, MS

The increasing number of couples referred for pre-amniocentesis counseling challenges genetic counselors to use their time efficiently while respecting the individual needs of clients. Panelists described three approaches to group counseling.

As referrals increased, Myrna Ben-Yishay, Albert Einstein College of Medicine, Bronx, New York, found herself with a case of "amniocentesis blahs." "After repeating the facts so often, I felt as if I could operate on automatic pilot," Ms. Ben-Yishay said. "Unfortunately, the patient can sense this." Group counseling with a slide-tape presentation seemed the answer. Each group sees the counselor individually for construction of the pedigree. The group, usually six individuals, then gathers for the slide show and question session that follows. Clients with special concerns are offered individual counseling following the group meeting.

Sylvia Rubin counsels clinical ward patients at Columbia Presbyterian Medical Center in New York City. Her approach to group counseling is similar to Ms. Ben-Yishay's, except that a counselor delivers the presentation. Ms. Rubin sees the sharing of common concerns and experiences as one advantage of group counseling. She adds the caution that negative feelings can be contagious.

Anne Mathews, University of Colorado Health Science Center, Denver, conducted a study comparing responses of two groups of 70 couples referred for pre-amniocentesis counseling. One group received individual counseling. Individuals in the other group first spent time with a counselor for history-taking, then joined one or two other couples in viewing a videotaped explanation of amniocentesis. Finally, group members returned to the counselor for an individual discussion session. No significant statistical difference in levels of knowledge, anxiety, or satisfaction was found between the groups. Group counseling with videotapes prevents mistakes that result from tedious repetition and provides a consistent, easily documented format that can be used by different counselors.

All panelists agreed that pre-amniocentesis counseling in a group setting conserves counselor time and energy while meeting the needs of the client.

WORKSHOP II, FAMILY THERAPY

moderated by Jodi Rucquoi, MS

Jodi Rucquoi is a genetic counselor at Yale University and a family therapist. She received her advanced training at the Ackerman Institute for Family Therapy. Ms. Rucquoi presented insights and strategies regarding family dynamics that may help facilitate the genetic counseling process.

Though there are many different methods of therapy, Ms. Rucquoi prefers an eclectic approach utilizing various therapies for each family system. An accurate assessment of a family's ability to accept genetic counseling, Ms. Rucquoi emphasized, requires that the genetic counselor remain neutral in the family system. Genetic counselors are called upon to help families work through the difficulties discussed during genetic counseling. The stress inherent in this process is decreased considerably. The family is better able to deal with bad news if the genetic counselor encourages the family members to be open and honest in expressing themselves and is attentive to their responses.

Genetic counselors rely extensively on a family pedigree for accurate interpretation and counseling. However, the family's unique cultural genotype, or genogram, is often neglected. To provide effective counseling, we must be conscious of a family's genogram.

During the discussion period, a participant noted that, while genetic counselors may find these techniques useful, most genetic counselors are not trained family therapists capable of applying these methods optimally. Ms. Rucquoi concurred, but stated that utilization of some of these techniques would likely increase counseling effectiveness. Empathy, honesty, and acceptance, key words in effective genetic counseling, also form the foundation for family therapy.

WORKSHOP III, COUNSELING STRATEGIES: CRISIS INTERVENTION AND CHRONIC DISEASE

moderated by Linda Lustig, MS

The session explored the methodologies used by three groups in different genetic counseling situations. Sean Phipps, MS, discussed the protocol used at Milwaukee Children's Hospital in dealing with parents after a stillbirth or neonatal death. He emphasized the need for personal contact with the family over an extended period of time. The grief process following a stillbirth is as necessary as it is after the death of an older child or an adult. Practical ways to make the loss a reality were suggested, such as encouraging the parents to see and touch the baby and holding a funeral or ceremony to affirm the fact that a death has occurred. Repeated family contacts provide continuing support and allow opportunities to review etiologies and recurrence risks.

Cynthia Powell, MS, shared insights into the special needs of families affected by a chronic disease with variable expression, such as neurofibromatosis. In addition to providing facts and recurrent risks, the counselor in this situation is called upon to help families deal with problems arising from the variability of clinical findings, guilt feelings of affected parents, and the decision of when and what to tell affected children. Individuals with neurofibromatosis have a 25% chance of developing moderate to severe complications at some point in their lifetime. This constant threat of potentially severe involvement and that of psychological trauma due to disfigurement create a pressing need for emotional support. Variability of expression can also result in serious guilt feelings, as in the case of a previously undiagnosed individual who has a more severely affected child. The problems of when and how much to tell children and of providing information they can understand without frightening them were also discussed. The role of the counselor in providing emotional support, accurate information, and coordinated care was stressed. The potential benefits of parent groups in providing support and practical advice from others with similar problems were recognized.

The final genetic counseling situation considered was that of a chronic, progressive disease. Peggy Blatner, MS, discussed her experience with the Muscular Dystrophy Association clinics in New York City. The benefits of a team approach to care and support for these families were described. Multiple genetic counseling sessions, before and after a diagnosis is made, are important. This is essential in cases of progressive disorders in order to allow the family time to accept the diagnosis and its implications at their own pace. The genetic counselor should help parents to avoid placing blame and should involve the father in the counseling, particularly in the case of X-linked conditions.

While these counselors work with very different patient groups and clinical situations, a number of common strategies and patient needs were apparent. The need for the counselor to recognize and deal with parental guilt and grief, whether it results from the death of a child or the transmission of a genetic condition, was strongly emphasized by all panelists. The importance of ongoing emotional support and the therapeutic benefits of parent groups were mentioned several times, both during individual presentations and in the ensuing discussion. The group discussion period, although brief, allowed a number of participants to discuss similarities and differences in their techniques for dealing with these very difficult counseling situations.

WORKSHOP IV, ORGANIZATION AND FUNCTION OF PARENT GROUPS

moderated by Eileen Fagan, LCSW

> "Nothing, I suspect, is more astonishing in any man's life than the discovery that there do exist people very, very like himself." *C.S. Lewis*

This quote is on the cover of the brochure published by Take Heart, an organization formed to help support parents of children with congenital heart defects. Take Heart shares common goals with other parent and support groups; two members from the group, Marsha Reese and Gretchen Carter were on this panel. The workshop drew from the experiences of several mothers and professionals who have had experience with successful and unsuccessful groups.

Marsha, Gretchen, and four other parents from a cardiac clinic were brought together by a cardiac nurse. After observing other support groups and establishing their own needs, interests, and goals, they published a brochure. Six to twenty parents keep the group going. They stress the quality of the group's activities, rather than the quantity of members. The needs of the group have changed in the past five years. Educational meetings, speakers, and social meetings have been arranged to stimulate old members; information is reviewed for new members. They also try to avoid placing undue demands on the leaders by encouraging new individuals to become involved.

A similar group, Heart to Heart, exists in Iowa City, Iowa. Janet Williams, RN, MA, PNP, at the University of Iowa, presented outlines of the range of experience among this and other parent groups in Iowa. Parents with Empty Arms is a group for parents who have experienced an infant's death. The Association for Glycogen Storage Disease has nearly as many professionals as families. Pilot Parents is a support group for parents of handicapped children. Some groups are successful because of professional support or because of the dynamic personality of the parent who organized the group. Others have been less successful for several reasons: Parents become militant, promoting a hidden agenda of personal advocacy in the name of the organization; parents feel they have nothing to offer and thus cannot help; or there is a lack of trust between agencies and professionals.

Ronnie Kline of San Diego, who says she felt like the only person in the world with a defective child, helped organize Reach-Out for families of children with undiagnosed or rare conditions. In many instances, the prognosis for a child was unknown and therefore unpredictable. Often, "at every doctor's visit they found something else was wrong." The group offered peer counseling—with crisis intervention—in conjunction with regular meetings that included invited speakers and potluck meals. A newsletter with anecdotes, hints, and family letters was established. Newspapers, television coverage, and contacts with professionals served as mechanisms to encourage potential members. As helpful as professionals might be, the group felt someone who shared their unique problems, even with the variety of issues represented, was a tremendous help. After its initial success, however, membership in Reach-Out declined. After a family crisis passed, members dropped out, perhaps because they were better able to cope with their situation. New members did not appear, increasing the burden for those who remained. The panelists felt failure to sustain the group reflected a lack of professional support. It is possible that these professionals did not inform new parents about the group because they were threatened by the peer counseling and concerned about hidden agendas.

One suggestion for overcoming problems with professionals was for parents and professionals to become better acquainted. Members of successful groups felt that working closely with professionals who make referrals established credibility and was an important element in group success. Formal presentations, informal social gatherings, and contacting interested professionals all contributed to the success of these groups. Brochures and newsletters, left in offices to be distributed, allowed families to call the group when they wanted to make contact. A balance of professional and parental input appears to be critical. Identifying and encouraging a strong parent leader through professional input generally seemed to work well. However, leadership needed to be shared so that one member did not become exhausted or overwhelmed.

The importance of an ongoing assessment of the needs and expectations of group members was stressed, as was the flexibility to address changing priorities. At various times, frequency of meetings and formats changed to accommodate different needs of the members, for example, those who wanted only occasional telephone contact, those wanting formal meetings with educational programs, and those wanting social contact and support without feeling they would have to share their feelings.

Comparisons among affected individuals did not seem to be a problem with group members, as they generally were glad for those who were doing well. Some found a measure of strength in knowing "there was always someone worse." Parents of children with better prognoses or for whom therapy was available appeared to need the group less. These people, however, might share in the leadership.

Genetic counselors can utilize the resources these groups offer our clients. By getting to know the group leaders and providing information about such groups to our families, genetic counseling services can be expanded by providing families with new sources for practical information, reassurance, encouragement, concern, emotional support, and hope.

WORKSHOP V, PROFESSIONAL ROLES AND ISSUES moderated by Ann C.M. Smith, MA, and Luba Djurdjinovic, MS

A rapidly increasing number of genetics centers now have genetic counselors on their staff. While 80% of genetic counselors remain employed in the traditional hospital setting, an increasing number are expanding these roles and achieving goals that reflect their personal and professional aspirations. Because there is as yet no firmly established ladder of advancement for genetic counselors, this expansion of roles has included movement into other areas of service.

The six panelists were:

Kermit Anderson, MA, a genetic counselor who has a part-time association with Human Genetics Update Service, a private educational consulting firm providing workshops and information for health care providers.

Debra Cheyovich, MS, MPH, a genetic associate who is currently enrolled in a doctoral program in public health. She discussed how her interests in public health and genetics combine to enhance her primary interest, the broad delivery of genetic services.

Luba Djurdjinovic, MS, project director of the Genetic Risk Scoring Program at Planned Parenthood, who initiated a program for identifying pregnant women at risk and for subsequent risk assessment. She is also a consultant for Planned Parenthood Federation of America.

Karen Greendale, MA, a genetic associate with the National Clearinghouse for Human Genetic Diseases, who handles inquiries from professional and public audiences and abstracts materials for inclusion in the NCHGD catalogue and bibliography series.

Nicole Lovera, MS, genetic disease program specialist in the California Department of Public Health, who administers the sickle cell program in California.

Ann C.M. Smith, MA, a genetic counselor who coordinates the Regional Genetic Counseling Program in Colorado, Wyoming, and Nebraska, but devotes most of her time to the administrative duties of the program.

Although the paths the six panelists have taken are quite different, they have come across similar difficulties. All cited the fact that, as one moves up in the traditional hospital setting or away from it, there is little or no patient contact. For many, this means losing touch with that which first brought them to the field of genetic counseling. The six panelists also said a sense of loneliness accompanied the loss of professional support systems when they left centers where other genetic counselors were employed.

Those in private endeavors spoke of the high risk of failure, which is so common with small businesses. Resistance from the community, which often does not understand the purpose and function of genetic counseling, is a formidable obstacle that requires great strength and self-confidence to overcome. Finally, large, established bureaucratic systems, and the consequent inability to provide timely delivery of services, were described as problems common to those working in government agencies.

Despite these drawbacks, the panelists agreed that moving into and developing new roles is a challenge that provides excitement, gratification, and opportunities for increased financial rewards.

Workshop Reports: I, Theresa Hadro, GA; II, Gayle Mosher, MS; III, Bonnie Leonard, MS; IV, Debra Collins, MS; V, Helen Travers, MS

INVITED SPEAKERS

Experts from fields other than genetics were invited to speak to conference participants. The topics of these lectures included "Brief Psychotherapy Methodologies," a presentation of the "Training Series on Family Dynamics," "Family Therapy Methodologies," and "Legal Issues in Genetic Counseling." Summaries of these presentations follow.

Brief Psychotherapy Methodologies

Lynn Segal of the Mental Research Institute in Palo Alto, California discussed a model of problem solving that has evolved at the institute over the past 13 years. The goal of this protocol is to shorten the length of treatment while providing more than crisis intervention or stop-gap psychotherapy; ten sessions are the maximum permitted.

Therapy becomes necessary when someone is in distress about a personal situation or one that concerns someone else, an unsatisfactory situation is persisting, or something that is desired is not happening. The individual or family has tried to solve the problem on their own without success. The therapist in this type of setting does not attempt to define the problem.

The presumption in brief psychotherapy is that the individual wants to resolve the problem but is not using the right approach. Thus, the therapeutic intervention is aimed at intervening in the method of problem solving used by the client. The sessions focus on stopping a nonproductive approach; however, it is not necessary that the therapist substitute a more productive solution. Clients are asked what brought them in, what they have done so far, and what they want from the sessions. They may be asked to fantasize about what they expect from therapy.

An example of the altered approach to a problem was given as an illustration. A man has trouble meeting women because he feels extremely nervous when he approaches an unfamiliar woman. He anticipates being awkward, and it becomes a self-fulfilling prophecy. In this situation, the client might be advised to explain his awkwardness at the outset—in a sense, to advertise the problem.

Once the client is given suggestions about a new approach, the change can be rapid. There is no long termination process when ten or fewer sessions have been completed.

Training Series on Family Dynamics

This series is a sequence of nine videotapes packaged with a trainer's manual. The program was designed and presented by Andrew Selig, MWS, ScD, a specialist in developmental disabilities.

The videotapes were designed to assist an instructor; they are not self-instructional. Only short segments of three separate tapes were shown, making it difficult to critique the entire series. A five-minute segment of the first 30-minute tape shows a husband and wife in direct confrontation over the strain placed on their marriage by their handicapped child, Jimmy. The scene is in the couple's bedroom, presumably late in the evening. The father returns home late after having a few drinks with his friends; his wife, in hair curlers, is angry at his absence from the family. He tries to engage her in sex play, fails, and says, "All you ever talk about is Jimmy," and then adds, "I'd like my wife to act like a wife." He accuses her of climbing a mountain and trying to plant a flag, comparing her to the mother of Christ.

The second tape, "An Introduction to Family Dynamics," illustrates interviews with families selected to show relationships in families with handicapped children. One mother is convinced that if she puts in enough hours she will correct her son's problem. Another scene presents an interview with a child with Down syndrome who declares in a touching manner that her condition is not her fault.

The tapes could be useful to students, but their usefulness to practicing genetic counselors may be limited. Genetic counselors are not unaware of problems such as those presented in the tapes, but they do need to refine the skills required to deal with such problems. Since the tapes require the presence of an instructor, their use might be costly to small groups.

Family Therapy Methodologies

Catherine Bond, MA, is a licensed marriage and family counselor and Director of the Action Seminar for Progress, a consulting firm in Santa Monica, California. Ms. Bond's methodologies in family therapy have been powerfully influenced by the teaching of two family therapists, Salvador Minuchin and Virginia Satir. The purpose of her presentation was to discuss and explore Minuchin's and Satir's approaches to family therapy.

Both therapists view the family as a system and the relationships or interactions among its members as the client. The goal in therapy is to restructure the relationships to allow growth and to mitigate pain, not to change people. Minuchin is concerned with a therapy of transformation, and his style uses confrontation and humor. He sees the therapist as an observer of the system, who discerns the family's rules of communication and then determines how to intervene. Intervention involves a challenge to the family's organization and to its perceptions of the problem and of reality. Ms. Bond cited Minuchin's view of the double bind in family rules on communication: "We can't talk about that," and, "We can't talk about the fact that we can't talk about that."

Satir is concerned with a therapy of education. Her style is warmer and more accepting, but she also uses humor to point out discrepancies. As a teacher of communications, she has formulated a theory of family communications based on the origins of family behaviors and interactions in previous generations. One diagnostic tool is the elicitation of a family map, which aids the therapist in visualizing the origins of family rules.

Family rules can be categorized into three areas: power (who controls money, makes decisions, manages information); self-esteem (how one is able to feel good about oneself in the family); and maleness and femaleness (how each relates to the other). The therapist then reflects those rules for the family in a nonjudgmental and positive fashion to enable conflicts and destructive beliefs to be identified. When members are experiencing low self-esteem and high anxiety, they tend to revert to stances learned in their families of origin—the blamer, the placater, the computer, and the distractor. These are the elements in the "stress ballet." Each negates an essential part of communication: self, other, or context. Ms. Bond graphically illustrated the four stances and engaged the audience in role play groups.

Intervention is, in part, a matter of inviting family members to assume new stances or roles in an environment where members feel safe to take this kind of risk. Family members are helped to identify the positive aspects of the old roles and to build on them with new behaviors. Ms. Bond closed by citing Satir's five freedoms. Understanding these freedoms begins the process of enhancing one's self-esteem:

The freedom to see and hear what is here instead of what should be, was, or will be.
The freedom to say what one feels and thinks, instead of what one should.
The freedom to feel what one feels, instead of what one ought.
The freedom to ask for what one wants, instead of always waiting for permission.
The freedom to take risks in one's own behalf, instead of choosing to be only secure and not rocking the boat.

Ms. Bond's presentation was sensitive and dynamic. She was successful in making the participants aware of how these conceptualizations can apply in their own families. However, many were left at a loss regarding application to genetic counseling.

Legal Issues in Genetic Counseling

Roger Dworkin, JD, University of Indiana School of Law, addressed two major issues that have implications for genetic counselors. Professor Dworkin first discussed the concepts of obligation and liability in the genetic counseling situation. Team members retain responsibility for the information they give to families, although the clinic director is also liable.

Professor Dworkin identified the various persons who might claim to have suffered a loss due to misinformation presented in genetic counseling; for example, parents who abort a healthy fetus, parents who bear an affected child, affected children themselves, and siblings of affected children. Parents who are misinformed of their risk and go on to bear an affected child may be able to recover very large awards for both economic and emotional loss. He also discussed the current understanding of the professional's obligation to inform relatives of their at-risk status. He feels that nationwide standards for adequate genetic counseling will evolve one case at a time.

Professor Dworkin also reviewed the current legal status of the sterilization of incompetent individuals. In the court's view, procreation is a fundamental right. Traditionally, the court does not have the authority to deprive anyone of that right without a specific statute; typical statutes apply only to institutionalized persons. Recent cases relevant to this issue suggest some broadening of the availability of sterilization for the non-institutionalized.

Reporters for Invited Speakers: Brief Psychotherapy, Kathleen O'Connor, MPS; Training Series on Family Dynamics, Rosalie Goldberg, MS; Family Therapy, Lisa Glinski, MS; Legal Issues, Karen Greendale, MA.

MEDIA AND RESOURCE CENTER

The Media and Resource Center was assembled by the genetic counselors from the New Jersey Medical School and by the March of Dimes Birth Defects Foundation. Information regarding birth defects, genetic disorders, the genetic counseling process, and prenatal diagnosis was displayed at the center.

The information was presented in several different modes. Tables and wall posters exhibited pamphlets, fact sheets, and booklets published by many national disease-oriented organizations, for example, Muscular Dystrophy Association, Osteogenesis Imperfecta Foundation, Cystic Fibrosis Foundation, and the National Foundation for Jewish Genetic Diseases. Also available for review were publications from the Department of Health and Human Services, the March of Dimes, and several pediatric, genetic, and state health departments. Literature on conditions such as Down syndrome, cleft lip and palate, sickle cell anemia, PKU, and mental retardation was also presented. Copies of several publications and order forms for others were available.

Slide-tape presentations were available for viewing at the media center. Several of the slide shows reviewed genetic counseling for amniocentesis. A program produced by the Prenatal Diagnosis Laboratory of New York City, titled "What Every Pregnant Woman Should Know," and Baylor College of Medicine's "Genetic Amniocentesis" were available in both English and Spanish. Similar slide-tape presentations on amniocentesis were contributed by genetics professionals from the Albert Einstein College of Medicine and the University of Texas Health Sciences Center. An interesting audiovisual program, "Still a Woman, Still a Man," alerts viewers to an often neglected subject: handicapped adults and their feelings about sexuality. "From Generation to Generation" (March of Dimes), a slide-tape presentation useful for general audiences and student groups, was available for viewing.

BOOK REVIEW, Linda T. Nicholson, MS, MC

Counseling in Genetics, edited by Y. Edward Hsia, Kurt Hirschhorn, Ruth L. Silverberg, and Lynn Godmilow, Alan R. Liss, Inc., New York, 347 pages, 1979, $34.

Counseling in Genetics is a collection of chapters covering all aspects of genetic counseling. The editors have solicited material from a number of well-known individuals to compile a volume that has something for everyone, from the nongeneticist MD interested in reading about genetic counseling to the person interested in biomedical ethics and legal matters.

The entire scope of genetic counseling is presented. Introductory chapters discuss the reasons for and process of genetic counseling, professionals involved in the process, and factors affecting the transmission and reception of information. There is a very comprehensive review of genetics that is probably too technical for the reader with no background in genetics.

The section covers genetic problems related to various age groups, beginning with problems related to reproduction, such as infertility, pregnancy loss, environmental insults, and problems of reproduction in persons with various syndromes. Methods of prenatal diagnosis are covered and risks outlined. Genetic problems of infants, older children, and adults are covered in separate chapters. Indications for chromosome studies and special situations including heterogeneity, multifactorial inheritance, and late onset disorders are discussed. These sections are helpful for the general reader, but do not always give enough information for the practicing counselor.

Sociological concerns are the emphasis of the next three chapters, beginning with patterns of health care and how they might affect decisions to seek genetic counseling. Cultural beliefs regarding childbearing, raising children, deviance, and stigma are enumerated and applied specifically to the genetic counseling situation. The acceptance and prevalence of various family planning methods are considered in relation to genetic counseling. Psychological and social considerations of sterilization, prenatal diagnosis, abortion, artificial insemination, and sex predetermination are thoroughly explored.

Nonmedical counseling issues are covered in the next chapters. The theory and principles of decision making are reviewed, and the counselor's role in the decision-making process is discussed. Psychosocial advocacy is covered from a psychodynamic viewpoint. The authors stress the need for a person with psychological training to facilitate interactions with the family, to help them get the information they need, and to support them throughout the decision-making process.

The wide variety of responses to the genetic counseling situation is illustrated through case studies that emphasize how differently families with different needs use the information they receive. The authors summarize the studies that have been done to measure how and to what extent information received during genetic counseling is used by clients. The following chapter outlines the process of genetic counseling in terms of its component stages. Conditions affecting the outcome of each stage and the variety of possible responses to each stage are explored.

The last three chapters cover screening, legal implications of genetic counseling, and a consumer's viewpoint of the genetic counseling process. The chapter on legal issues is especially timely and noteworthy, demonstrating just how many situations are untested in the courts.

In summary, *Counseling in Genetics* has something for everyone. It is especially useful for students inquiring about a career in genetic counseling. The cost, which is somewhat high, may discourage some genetic counselors from purchasing it for their personal use. The price and content make this volume more suitable for library acquisition.

ABSTRACTS OF CONTRIBUTED PAPERS

Use of the Media in the Expansion of Prenatal Diagnostic Services. Gary S. Frohlich, MS, North Los Angeles County Regional Center, Van Nuys, California.

If reported studies are correct, only 12% to 15% of at-risk couples in California are receiving the benefits of prenatal genetic counseling and prenatal diagnostic procedures. Recently, we have begun to use television in an attempt to provide these services to a larger population.

The efficacy of providing "wholesale" genetics information to the general public as a public health strategy will be examined. The type and appropriateness of the referrals generated by one such program, which aired on January 30, 1981, are discussed. Although the possibility exists for misinterpretation of the genetic information presented to the viewing public, our overall experience has been positive. (A videotape of the program, "Mid-Morning LA," was presented for group reaction and analysis.)

Patients' Subjective Interpretation of the Cause of Genetic Disease. Audrey Heilmer, MS, Long Island Jewish-Hillside Medical Center, New Hyde Park, New York.

One of the primary goals of genetic counseling is to provide information about the etiology of the diagnosis. This usually entails a detailed discussion of the pathogenesis of the disorder with reference to incidence, embryogenesis, genetics, and associated risk estimates. The literature includes references to factors that may serve as barriers to a patient's comprehension of the information provided during the genetic counseling interview; for example, social class, economic level, educational achievement, family size, reproductive goals, and attitudes regarding preventive medicine.

This paper discusses the significance of the patient's subjective view of the cause of a genetic disorder or birth defect with regard to the outcome of genetic counseling. Case histories are presented to illustrate patients' responses to the question, "What do you think caused this to happen?" Personal explanations reflect mystical, religious, psychological, and sociological influences.

The genetic counselor should direct her or his attention to eliciting and discussing this hidden agenda as an essential part of the genetic counseling process. Pearn has suggested that prior subjective views influence a patient's ability to interpret mathematical risks provided in genetic counseling. Unresolved prior subjective beliefs regarding the cause of a genetic disease or birth defect may similarly affect the patient's ability to comprehend and accept the medical and genetic facts and to reach an informed reproductive decision.

The Use of Family Therapy in Diet Management of Hyperlipidemia. Jodi Rucquoi, MS, Yale University, New Haven, Connecticut.

Awareness of the presence of dominant familial hyperlipidemia often occurs subsequent to the untimely death of a parent. When lipid studies identify affected offspring of the deceased, the psychological sequelae can be a hindrance to compliance with diet management. A case study is presented showing the techniques of family therapy that were utilized to facilitate the treatment of an affected boy.

A preadolescent boy and his mother were seen for six sessions, 18 months after the death of his father at age 46 following a seven-year history of arteriosclerotic heart disease with progressive ischemic myocardiopathy. In addition to working through a grief reaction, the boy was struggling to achieve individuality, and his mother was unsure about her role in his life. Food was an important issue in this family, and the boy felt as though he was being "killed with kindness." After the mother and boy were brought together in their sadness and shared loss, the strivings for independence were enhanced for both of them. The mother was able to pursue interests of her own, and the boy gained more control over his own life and his disease management.

In the year prior to therapy, the boy's mean cholesterol and triglyceride levels were 187 and 178 mg/100 ml, respectively. In the year following the initiation of therapy, the means were 169 and 92 mg/100 ml. At two years, the means were 171 and 88; and at three years post therapy, the means were 166 and 101 mg/100 ml. The upper limits for an eleven-year-old male are thought to be 180 mg/100 ml for cholesterol and 130 mg/100 ml for triglyceride.

Genetic Counseling: An Evaluation. Elizabeth J. Thomson, RN, BSN, University of Iowa Hospitals and Clinics, Iowa City, Iowa.

Desirable outcomes of genetic counseling include a reduction of fear and anxiety, diminished impact of the genetic disorder on an individual or a family, and a reduction in the frequency of genetic disorders.

A questionnaire designed to evaluate these outcomes was mailed to 1,012 families who had been counseled in a large regional genetic counseling program; 573 families (56.6%) responded to the questionnaire. Results of this study suggest that a number of families are reassured by genetic counseling. In the low-risk group of families (those with < 10% risk), 30 of 250 families (12%) stated that after genetic counseling they had decided to have more children than originally planned. Similarly, findings of this study imply that genetic counseling can reduce the burden of genetic disorders. This interpretation was supported by several families who made anecdotal comments regarding the interpretation of a particular diagnosis and the supportive and follow-up counseling they had received. A reduction in the frequency of genetic disorders was also suggested by this study. Of the 116 families that fell into the high-risk group (those with ≤ 10% risk), 58 (50%) stated that after genetic counseling they had decided to have no more children, or fewer than originally planned.

From this study it is apparent that ongoing evaluation of the outcomes of genetic counseling is imperative. In addition to providing valuable information about each family, it permits evaluation of the service provided and provides suggestions for its improvement.

The Current State of Legislation Affecting Genetic Counselors. Ann Walker, MA, University of California Irvine Medical Center, Orange, California.

New legislation often affects genetic counselors. It is important for individuals involved in this profession to be familiar with these legislative issues. This paper discusses these issues and provides insight into pending legislation.

The Reaction of Families to Abnormal Results in Prenatal Diagnosis Program. Betty M. Youson, BN, DipPHN, RN, The Hospital for Sick Children, Toronto, Ontario.

Ten year's experience in interviewing couples having abnormal fetuses detected through prenatal diagnosis has enabled us to improve our counseling skills. From 1971 to 1980 inclusive, 4,565 women have been identified as being at high risk and have elected the option of prenatal diagnosis. An abnormal fetus was diagnosed in 125 woman (2.7%). Of the 125 couples, 114 (91.2%) elected to terminate their pregnancies, and 11 (8.8%) chose to carry the pregnancy to term. Couples were offered the option of genetic counseling during the decision-making period, as well as supportive counseling after reaching a decision.

We have observed recurring patterns of anxieties and questions from couples contemplating termination of their abnormal fetuses. Anticipating such reactions as part of the counseling process has made our counseling more effective for these families.

REGIONAL REPORTS

The 1981 Region II Education Conference will be held September 25-26, 1981 at the Mount Sinai School of Medicine, New York City. Conference coordinators (Judith Dichter, Rosalie Goldberg, Susan Schmerler, Amy Schonhaut, and Jane Schuette) have planned an excellent program around the theme, "New Directions in Genetic Counseling." The conference will focus on counseling methodologies and professional issues most relevant to continued professional growth. The conference is being planned in cooperation with the Division of Medical Genetics of the Department of Pediatrics and the Division of Consumer/Patient Education of the Brookdale Center for Continuous Education of the Mount Sinai School of Medicine (CUNY). Arrangements have been made to accommodate out-of-town members in the homes of members residing in the New York City area. For additional information contact:

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Region IV will hold its second annual education meeting on September 25-26, 1981 at the Amana Colonies near Iowa City, Iowa. Topics will include crisis intervention, case presentations, service provision, and research focusing on neuromuscular disorders.

Betty Youson, Toronto, Ontario reports that the Association of Genetic Counsellors of Ontario held their annual meeting on May 28, 1981. Betty is president of this organization of MDs and PhDs, genetic counselors, and other genetic services providers.

Monica Wohlferd, Iowa City, Iowa informs us that the second annual meeting of the Great Plains Clinical Genetics Society took place on April 10-11, 1981 in Columbia, Missouri. Twenty-eight clinical genetics professionals from eight midwestern states attended the meeting. The conference provided an excellent forum for discussion about recent funding cutbacks and the future of clinical genetics funding, including a discussion of federal block grants and the increasing reliance on third party reimbursement. Another part of the conference was devoted to the use of computers in clinical genetics programs.

Mary Amer, Cleveland, Ohio describes a very active statewide genetic services and education program. Each genetics center publishes newsletters that are supported by the Ohio Department of Health. Recently, a local television news program featured the amniocentesis clinic and its genetic counselors on a week-long segment of the 6 o'clock news. As a result, Marjorie Tasin, genetic counselor, was asked to appear on a local talk show. We are all learning that the mass media is an excellent vehicle for public education.

Beth A. Fine
Region IV Representative

Thirty-eight genetic counselors from Region V met April 24-25, 1981 in Houston, Texas for the second annual Region V Continuing Education Meeting. Jacqueline Hecht, Vickie Venne, Chris Gallery, and Ellen Marcus were program chairpersons.

The meeting began with a talk on dysmorphology by Dr. Charles Scott. This was followed by a presentation on infant stimulation programs and parent support groups by Tempa Weir, MS. Weir moderated a panel of three couples from her parent support group. The parents' frankness concerning their experiences with genetic counseling and with having a severely retarded child in the home was quite enlightening. The afternoon session was devoted to presentations by several Region V members of their areas of research. Educational materials developed by several clinics were shared.

The second day began with Dr. Arthur Beaudet's discussion of metabolic disorders. A film on professional burn-out followed. The afternoon session was devoted to an address by Jerome Berryman, theologian and lawyer, on the topic of death and genetics. Parents and professionals discussed stillbirth or miscarriage and the death of a child due to genetic disease.

The meeting was very well received. The chairpersons are to be congratulated for their work. The 1982 Region V meeting will be held in Salt Lake City, Utah. Dates will be announced.

Joan Scott, MS
Region V Representative

MEETINGS

National Society of Genetic Counselors, Inc.

Annual Meeting, Wednesday, October 28, 1981, 5 - 7 p.m.
Ballroom E, Loews Anatole Hotel, Dallas, Texas

1982 NSGC Professional Education Meeting

The second annual national conference is tentatively scheduled for June 1982 in Birmingham, Alabama in conjunction with the 1982 Birth Defects Conference. The theme of this meeting is "Strategies in Genetic Counseling: The Community Around Us." The purpose of the conference is to assist genetic counselors in identifying, utilizing, and working with community resources to provide families with optimal and comprehensive services. Anyone with suggestions, comments, or the desire to help should contact one of the following individuals:

Elizabeth Thomson, Iowa City, Iowa, Chairperson
Beth Fine, Omaha, Nebraska, Communications Co-Chair
Debra Collins, Kansas City, Kansas, Program Co-Chair
Debbie Timmons, Chapel Hill, North Carolina, Logistics Co-Chair
Betty Youson, Toronto, Media Center Co-Chair

POSITIONS AVAILABLE

The Genetics Center of the Southwest Biomedical Research Institute has an immediate opening for a full-time Genetics Associate. Primary responsibilities include genetic counseling, coordination and administration of clinics, and genetics education for the medical and lay communities. Applicants must have a master's degree in human genetics or genetic counseling, be board-eligible as a genetic counselor with the American Board of Medical Genetics, and be able to communicate with families in Spanish. Please submit current curriculum vitae to Richard C. Wagner, MS, Assistant Director of Clinical Genetics, The Genetics Center of the Southwest Biomedical Research Institute, Tempe, Arizona 85281.

Immediate opening for Genetics Program Clinic Coordinator in a new hospital-based program in Washington State. Graduate of genetics counseling program and proficiency in Spanish preferred. Send resume to Center for Child Health Services, Yakima Valley Memorial Hospital, 2811 Tieton Drive, Yakima, Washington 98902. An equal opportunity employer.

Genetics Counselor: Full-time position now available at the North Los Angeles County Regional Center, a private, nonprofit corporation serving developmentally disabled persons. Primary responsibilities include the establishment of satellite services, public and professional education, and amniocentesis counseling. Participation in genetics clinic, as well as program initiation and development. Please send letter of interest and curriculum vitae to Jaime D. Mejlszenkier, MD, Chief, Health Services Unit, North Los Angeles County Regional Center, 14550 Lanark Street, Panorama City, California 91402.

EDUCATION PLANNING GRANT AWARDED TO NSGC

The National Foundation for Jewish Genetic Diseases, Inc. has approved a grant to support the educational planning meeting of the board of directors of the National Society of Genetic Counselors, Inc. The educational program of the society will be addressed, including:

1. Discussion and implementation of a proposal for continuing education criteria developed by William Young, Director of Continuing Education/Public Service of the University of Illinois, and Beverly R. Rollnick, President, NSGC
2. Awarding of continuing education units to NSGC members
3. Planning of national and regional continuing education meetings
4. Publication of the proceedings of NSGC education meetings
5. Sources of funding

Publication of *Perspectives in Genetic Counseling* is supported in part by a grant from the March of Dimes Birth Defects Foundation.

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