PERSPECTIVES IN GENETIC COUNSELING

NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.

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AN EVALUATION OF THREE COMMONLY-USED COUNSELING FORMATS

Robert S. Young, Ronald J. Jorgenson, and Steven D. Shapiro

Anyone who has provided genetic counseling in a busy specialty clinic knows the difficulty of repeating the requisite information over and over again. Besides being tedious, such repetition creates a very real problem of unconscious omission of material by the counselor, reducing his or her effectiveness. In addition, some view this repetition as an inefficient use of the counselor's time.

To circumvent this problem, many clinics have turned to group counseling or audiovisual presentations as alternative methods of conveying genetic information to large numbers of people. Critics assert, however, that these methods lack the personal attention that individual counseling sessions generate and that they are consequently less effective and more poorly received by patients. To our knowledge, however, no study has objectively evaluated the relative effectiveness of and patient preference for the three commonly-used counseling methods, that is, individual, group, and audiovisual counseling formats. This communication presents a synopsis of the results of such a study.

Design of the Study

Sixty-one parents of children born with isolated (multifactorial) cleft lip with or without cleft palate (hereafter referred to as CL/P) were enrolled in the study. They were recruited from the three existing CL/P treatment teams in San Antonio. The ages of the affected children ranged from two months to 21 years, with a mean age of 7.8 years. The etiology of the CL/P was established by careful physical evaluation of the probands and by a detailed family history. Subjects were randomly assigned to one of three counseling formats: slide/tape, group, or individual counseling.

We developed a 12.5 minute, 35 mm slide-cassette tape presentation that summarized the relevant information to be presented to the counselees. This information included the population frequency of CL/P, the embryological timing of the defect, an explanation of the multifactorial etiology, presentation of empiric recurrence risks for various family members, the unavailability of prenatal diagnosis for CL/P, and a brief discussion of the range of specialists involved in treating CL/P. To maintain uniformity of content, all group and individual counseling sessions were performed by one of the investigators (RSY). Seven parents (11%) had received genetic counseling prior to being enrolled in our study.

Each subject completed three hardcopy questionnaires. The first, a precounseling questionnaire, was given just prior to counseling; it included demographic, informational, and attitudinal questions. Immediately following the slide/tape presentation and throughout the group and individual counseling sessions all questions were answered. A postcounseling questionnaire was administered to assess the efficacy of the counseling and to identify any changes in attitude toward CL/P that might have occurred through counseling. Six months later, a questionnaire identical to the postcounseling instrument was sent to each subject's home, to be completed and returned by mail. Responses to this questionnaire measured long-term information retention and attitudinal changes that might have occurred over the half-year time span.

Demographic data were compared among the three counseling groups to check for uniformity of subjects' backgrounds. A percent-correct score was calculated for each subject's responses to the informational questions in each of the three questionnaires, and F-tests were performed to identify possible differences among the mean scores of the three groups of subjects within each questionnaire. The means compared are shown in Table 1.

TABLE 1. Average percent scores of the three counseling format groups achieved in the precounseling, postcounseling, and six-month follow-up questionnaires.

	Precounseling Quiz	Postcounseling Quiz	Six-month follow-up Quiz
Slide/Tape (N=21)	29.7	80.9	61.6
Group (N=18)	30.6	83.2	67.1
Individual (N=22)	37.7	82.0	71.5
Average Score	32.9	82.0	66.8

Results

Space does not permit an extensive, question-by-question analysis of our data. Such an analysis is currently being reviewed for publication in the *Journal of Craniofacial Genetics and Developmental Biology.* Instead, we have summarized the major conclusions extracted from those data and ask that, for the present, the reader accept these conclusions at face value without benefit of scrutinizing the raw data.

First, we were unable to establish that one counseling format was superior or inferior to the others in terms of information retention. Subjects learned equally well regardless of the counseling method they received. It seems clear, therefore, that for certain counseling situations at least the more time-efficient, group or audiovisual counseling may be used without concern for reduced effectiveness. Second, as shown in Table 1, genetic counseling by any method significantly improves one's knowledge base. Third, the more efficient methods of group or audiovisual counseling are accepted by counselees as well as, or better than, individual counseling.

If a slight preference can be detected in our subjects' responses, it is for the group counseling format. Several parents assigned to this format volunteered that they enjoyed meeting and talking with other parents with similarly affected children and benefited from questions that others asked. In general, however, we learned that people truly appreciate receiving information about etiology, prognosis, and recurrence risk, and do not particularly care how

the information is provided, as long as it is presented in a clear and well-organized manner.

Summary

This study demonstrates that alternate methods of counseling are potentially as effective and as well received by the counselees as the traditional one-on-one format. For certain counseling situations, therefore, in which a well-defined set of information is to be presented to many people, alternative methods of counseling may be considered without fear of patient prejudice or decreased effectiveness. While our study concerned counseling for CL/P, such methods are certainly applicable to the preamniocentesis counseling situation, and may likely find wider application in other genetic counseling situations. For example, an audiovisual presentation might well be an effective method of explaining the etiology, prognosis, and recurrence risk for the free trisomy type of Down syndrome, another common counseling situation. That assumes, of course, that the presentation is done in a tasteful and nonthreatening manner. Such a production, because of its visual orientation, would present the many positive aspects of raising a child with Down syndrome far more effectively than any conversation between counselor and parents could and would ensure the inclusion of all relevant topics. The future of genetic counseling may well see the incorporation of a variety of new counseling methods that facilitate this important educational experience.

Robert S. Young is assistant professor and Ronald J. Jorgenson is professor of pediatric dentistry at the University of Texas Health Sciences Center at San Antonio, 78284; Steven D. Shapiro is assistant professor in the Division of Genetics, Department of Pediatrics at the Medical University of South Carolina, Charleston 29425.

BOOK REVIEW

Brothers and Sisters – A Special Part of Exceptional Families, by Thomas H. Powell and Peggy Ahrenhold Ogle, Baltimore, Paul H. Brookes Publishing Co., 1985, 226 pages, $16.95 (paperback).

Carson McCullers once defined the family as, "The we of me" (1). That phrase aptly reflects the tremendous influence a family has upon each of its members. It also reminds us of how indelible the effects of parent-child and sibling-sibling interactions are. Of course, any parent who has pored over Dr. Spock's book and other child development books already recognizes the special role that sibling-sibling interaction plays. But when one of the siblings is handicapped, that interaction has a unique quality.

In recognition of the lack of information for and about siblings of exceptional children, Thomas H. Powell and Peggy Ahrenhold Ogle have drawn on their own wealth of experience and on research publications to compile a concise guide for optimizing sibling relationships in exceptional families. The authors are educators who have worked with siblings of handicapped persons for more than seven years. They also founded the Sibling Information Network, an organization that publishes a newsletter and assists siblings in sharing information and emotions.

The book is divided into two sections. The first section, "Families and Siblings," provides background information such as a literature review, a listing of siblings' specific concerns about their handicapped brother or sister, and a thorough discussion of the unique needs of unaffected siblings. The second section, titled "Strategies to Help Siblings," emphasizes the importance of providing information to siblings about their brother's or sister's condition and suggests ways to increase their understanding. Unaffected siblings have a need to express their feelings, both negative and positive, so the authors provide detailed strategies to enhance sibling communication. Various programs and workshops are described. The second section also covers the counseling process and the counselor's role in working with siblings.

The remaining chapters discuss social interaction between siblings, the role of siblings as teachers for a handicapped brother or sister, and issues related to the school environment. The authors also describe problems related to the adult sibling, including concerns about long-term care and guardianship for the handicapped person. A brief review of genetics and the laws of heredity is included. Two helpful appendices are an annotated list of sources of information and service for siblings and parents, and a list of appropriate literature available for siblings.

This book succeeds in increasing the reader's awareness and understanding of the needs and issues confronting exceptional families, yet it is evident that more investigation is necessary in this area. Much of the research cited by Powell and Ogle is from studies on dyads of nonhandicapped siblings, and some of the studies are more than 20 years old. Conspicuously absent is any discussion of the work by Cerreto (2) at the University of Texas Medical Branch. The literature review was, at times, tedious and confusing. However, the chapter on workshop preparation and performance is superb in providing professionals with concrete strategies for working with siblings. The strategies can be followed precisely or adapted to meet one's own style and professional setting. The authors have avoided generalizing such a complex issue; rather, they stress the uniqueness of each family situation. The anecdotal stories and quotations preceding each chapter are tender and poignant. The section on counseling is very detailed, and despite its seemingly "cookbook" approach, it does provide an effective review of counseling skills, goals, and methods, something that is beneficial even to the most experienced counselor.

Professionals well versed in genetics will find the discussion on inheritance disturbing. Some statements are incomplete or inaccurate. For example, the authors state that disorders associated with chromosomal malformations are the result of "... the loss or addition of an entire chromosome"; they fail to mention that parts of chromosomes can also be involved. The authors' explanation of the probabilities of inheriting recessive and dominant conditions needs clarification. In fact, the entire genetics section needs to be rewritten, preferably by someone with training in medical genetics.

I recommend this book for professionals, but, unfortunately, it is inappropriate for parents and siblings because of its emphasis on counseling workshops and techniques for professionals. This book reminds us that the presence of a handicap in a family affects not only the affected individual and his or her parents, but also the unaffected siblings. By recognizing the needs of the entire family, professionals can assist the family in developing cohesiveness and an open atmosphere of communication. This book will help pave the way for more work and research with siblings of exceptional families.

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1. Brussell, EE (ed): *Dictionary of Quotable Definitions,* Englewood Cliffs, New Jersey, Prentice-Hall, Inc., 1970.

2. Cerreto, MC: *Sibs of children with chronic conditions: Counseling considerations.* In *Strategies in Genetic Counseling: Clinical Investigation Studies,* Fine, BA, and Paul, NW (eds), White Plains, New York, March of Dimes Birth Defects Foundation, 1984.

Donna D. Walgenbach
Helene Fuld Medical Center
Trenton, NJ 08638 and
University of Medicine and Dentistry of New Jersey
School of Osteopathic Medicine
Camden, NJ 08103

ANNOUNCEMENTS

Information on Careers in Genetic Counseling

NSGC is attempting to coordinate its responses to requests for information on graduate programs and careers in genetic counseling. Please send all requests to: Robin Belsky, 275 E. Hancock, C.S. Mott Center, Detroit, MI 48012.

Resources Editor

The *Perspectives* editorial staff is seeking an editor for the "Resources" column. The resources editor coordinates publication of information that is useful in genetic counseling practice. The editor reviews or solicits reviews of educational materials written for patients and families, as well as instructional aids for use in genetic counseling settings. This section also includes descriptions of new family support groups or genetic disease foundations. (Books written for professionals are reviewed in the "Book Review" section.) The editor must contact publishers to receive copies of publications. "Resource" announcements are also accepted. Those interested in this position should send a curriculum vitae and writing samples by 31 January 1986 to: Joseph D. McInerney, BSCS, The Colorado College, Colorado Springs, CO 80903.

Longitudinal Study of Infants Exposed to Accutane

Maternal use of isotretinoin (Accutane) during the first trimester has been associated with a high risk for major malformations and probably an increased risk for miscarriage. The Massachusetts General Hospital is conducting a study to assess the risks for other adverse outcomes among infants exposed to Accutane during pregnancy, including minor malformation, hearing and visual deficits, and immune deficiency. Participating families would not incur expenses from the study and would not be asked to travel; all evaluations would be performed locally. We are also interested in referrals of Accutane-exposed fetuses. It would be optimal if exposed fetuses were reported as early in gestation as possible (i.e., before any diagnostic ultrasound procedures). In addition, we are interested in receiving pathologic results, or arranging for pathologic evaluations, of electively or spontaneously aborted Accutane-exposed fetuses. Anyone with information concerning Accutane-exposed fetuses or infants is requested to contact: Edward Lammer, MD, Embryology-Teratology Unit, Massachusetts General Hospital, Boston, MA 02114, phone: (617) 726-1742.

CORRESPONDENCE

To the Editor:

I write this letter out of a real and growing concern over the rapid expansion and vehemence of the antiabortion movement, which threatens to end women's reproductive options. Why has the Supreme Court agreed to hear several cases on reproductive choice when *Roe v. Wade* was reaffirmed at the Court's most recent review of the issue only last year?

We in the NSGC have an obvious interest in this country's continuing commitment to *Roe v. Wade.* I urge all members of the society to support the right to choice vociferously, and to expose the growing violence of antichoice activists. More important, however, I would like the NSGC itself to take a firm stand on the side of prochoice while it can still do so. It would be unthinkable to have this right taken away while NSGC did nothing.

Please add your voice. Let the social issues committee know how you feel about this threat and what actions, if any, the NSGC should take.

There are several possible choices to consider, including these: 1) the NSGC could contribute funds in support of one of the existing prochoice organizations such as Planned Parenthood; 2) the NSGC could publicly add its name to the list of groups supporting freedom of choice; 3) the NSGC can continue to be silent on this issue while individual members speak out to their legislators in Congress.

I urge you to make your views on this issue known to Edward M. Kloza, chair of the NSGC social issues committee, c/o Division of Clinical Genetics, Foundation for Blood Research, P.O. Box 190, Scarborough, ME 04074, or to *Perspectives.*

Judith D. Widmann
The New York Hospital
Cornell Medical Center
New York, NY 10021

POSITIONS AVAILABLE

Genetic Counselor: A full-time, permanent position is available 1 February 1986 for a board-certified/eligible genetic counselor in the Medical Genetics Unit at Children's Hospital, Oakland, CA. The counselor will see patients referred for prenatal diagnosis, MSAFP screening, and medical genetics, although a greater proportion of responsibilities will relate to the prenatal diagnosis/MSAFP programs. Submit curriculum vitae to: Personnel Department, Children's Hospital, 747 52nd Street, Oakland, CA 94609. For more details please call: (415) 428-3550.

Genetic Counselor: The Michigan Department of Public Health is conducting a search for an experienced genetic counselor to join our Michigan Genetic Services Program. The program staff consists of William Young, PhD, project director, and four genetic counselors, each assigned to one of four clinical genetics centers in the state. We presently have an opening at Wayne State University in Detroit. We hope to recruit someone with three to five years of experience, who will enjoy an independent and responsible work setting. The salary for an experienced counselor will be approximately $33,000. Interested applicants may contact: Diane L. Baker, Genetic Counselor, University of Michigan Medical Center, Division of Pediatric Genetics, D1225 Medical Professional Building, Ann Arbor, MI 48109, phone: (313) 764-0579, or Dr. William Young, Michigan Department of Public Health, Genetic Services Program, 3500 N. Logan, P.O. Box 30035, Lansing, MI 48909, phone: (517) 373-0657.

Genetic Associate: The Prenatal Counseling and Diagnosis Center of the Crippled Children's Division, Oregon Health Sciences University has an opening for a full-time genetic associate. This program is part of a large, university-based, multidisciplinary genetics program in Portland, Oregon. Responsibilities will be varied. Salary is dependent on experience. A board certified/eligible genetic counselor is preferred. Contact: Karen Kovac, MS, Crippled Children's Division, Oregon Health Sciences University, P. O. Box 574, Portland, OR 97207, phone: (503) 225-8344. The Oregon Health Sciences University is an Affirmative Action/Equal Opportunity Employer.

Genetic Counselor: A full-time position is available immediately at the North Los Angeles County Regional Center, a private, nonprofit corporation serving developmentally disabled persons and parents at risk. Primary responsibilities include amniocentesis counseling, general genetic counseling, outreach education, participation in genetics clinic, as well as program initiation and development. Applicants must be board eligible by the American Board of Medical Genetics. Full use of an auto is required. To apply, send letter of interest and resume to: NLACRC, 14550 Lanark Street, Panorama City, CA 91042, attention: Gary Frohlich, Prevention Unit. The North Los Angeles County Regional Center is an Equal Opportunity Employer, M/F.

Genetic Associate: A dynamic, fast growing, medical services company based in San Diego, California, has an opening for a genetic associate, beginning in January 1986. The individual selected must be a team player and a self-starter, and will be expected to "wear several hats." This is definitely not a routine position. This position offers ideal professional working conditions in one of the premier biomedical areas in the United States. The climate is ideal, too. Send resume to James D. Eisen, PhD, Scientific Director, DATAGENE Scientific Laboratories, Inc., 11199 Sorrento Valley Road, Suite A, San Diego, CA 92121.

Genetic Associate/Counselor: The University of Illinois at Chicago, Department of Pediatrics, has a full-time position for an individual with a master's degree in genetic counseling. This position is part of the Illinois Genetic Diseases and Counseling Project. Under the direction of the medical geneticist, the associate will be responsible for the Peoria, Illinois, region. Primary responsibilities will include providing genetic counseling and associated follow-up services, working with local health-care providers and agencies to determine genetic-related needs of both the community and individual families, and designing and conducting educational programs. Salary is dependent on experience. Send curriculum vitae with references to: Reuben Matalon, MD, PhD, University of Illinois at Chicago-HSC, Department of Pediatrics m/c 856, Box 6998-Room 1220 CSB, Chicago, IL 60680. The University of Illinois is an Equal Opportunity/Affirmative Action Employer.

Genetic Associate: A new genetic associate position is available in Medical Genetics, University of British Columbia, to commence immediately. Formal genetic associate training preferred (MS degree), practical experience desired. Send curriculum vitae and names of three references to: J.G. Hall, MD, Medical Genetics, Grace Hospital, 4490 Oak Street, Vancouver, B.C., V6H 3V5. U.B.C. is an equal opportunity employer. Preference will be given to Canadian citizens or landed immigrants.

Genetic Associate: The Central Valley Regional Center in Fresno, California, has an opening for a genetic associate. Responsibilities include providing counseling, follow-up, coordination of genetic services, community education, and assisting in the development of genetic services. The position requires a master's degree and successful completion of the qualifying examination of the American Board of Medical Genetics. Submit curriculum vitae to: Susan Snyder, Central Valley Regional Center, 4747 North 1st Street, Suite #195, Fresno, CA 93736, phone: (209) 228-3061. Central Valley Regional Center is an Equal Opportunity/Affirmative Action Employer.

JOBS HOT-LINE
Linda Nicholson
P. O. Box 269
Wilmington, DE 19899
(302) 651-4234

INSTRUCTIONS FOR CONTRIBUTORS

Types of Manuscripts Accepted

Authors may submit articles dealing with the various professional roles of the genetic counselor, counseling case reports original research reports, articles addressing topics relevant to the profession of genetic counseling, or letters to the editor that deal with professional issues of the society.

Instructions

All manuscripts must be typed and *double-spaced.* Please submit three copies of each manuscript. The author's name, preferred title, address, and business telephone number must accompany all submissions.

Send all manuscripts, except case reports, to:

Joseph D. McInerney
Perspectives in Genetic Counseling
BSCS
The Colorado College
Colorado Springs, CO 80903

Send all case reports to:

Carla B. Golden
The Permanente Medical Group, Inc.
281 West MacArthur Blvd.
Oakland, CA 94611

Deadline for 1986 Issues

March Issue:	1 January 1986
June Issue:	1 April 1986
September Issue:	1 July 1986
December Issue:	1 October 1986

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PERSPECTIVES IN GENETIC COUNSELING

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Specific Instructions for Counseling Case Reports

The purpose of counseling case reports is to present organized discussions of the counseling and case management problems confronted in the clinical genetics setting. The format for counseling case reports is as follows:

1. Present a brief statement of the diagnostic information and the reasons for seeking genetic services.
2. Describe the counseling problems or case management difficulties encountered.
3. Discuss how the problems were addressed, including the rationale for your course of action.
4. Present a broader discussion outlining other methods one might use to deal with similar problems.

Sections (3) and (4) should include citations of the counseling or genetics literature to substantiate your discussion and methods.

CHANGE OF ADDRESS FORM

If you have recently changed your address, or anticipate an address change in the near future, please complete the form below and return to:

Marcy B. Eskanos
Perspectives
BSCS
The Colorado College
Colorado Springs, CO 80903

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