PERSPECTIVES IN GENETIC COUNSELING

NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.

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CONTINUING EDUCATION CRITERIA AND CONTINUING EDUCATION UNITS: POLICY ISSUES

Beverly R. Rollnick

Genetic counselors are interested in increasing their knowledge and skills and in demonstrating continued professional competence. Continuing education (CE) is generally recognized as contributing to those goals. However, the quality and relevance of CE offerings vary. To ensure that the National Society of Genetic Counselors (NSGC) CE offerings meet high and systematic standards, CE criteria were developed and presented to the NSGC membership in *Perspectives* (Volume 3, Nos. 1 and 4) and at the 1981 annual membership meeting. The criteria were approved at the 1981 meetings of the membership and board of directors. Copies are available from Karen Greendale, Secretary.

An ad hoc committee (the committee) has been established by the board of the NSGC to implement those criteria. Committee members are Barbara Bowles, Rosalie Goldberg, Donna Goodwin, Janet K. Williams, and Beverly R. Rollnick, chair. Several issues have been addressed by the committee and are here presented to the membership for consideration and comment.

Issues

Implementation of NSGC CE Criteria—The goals are threefold: 1) to assist planners of NSGC CE offerings to employ CE criteria; 2) to make sponsors and planners of non-NSGC CE offerings more aware of NSGC CE criteria; and 3) to promote knowledge of CE concepts among NSGC members.

Implementation of NSGC CE criteria will adhere to those goals. Copies of the CE criteria have been distributed to those members planning the 1984 national CE meeting, and Donna Goodwin will work with the conference planners. CE criteria have also been distributed to the regional representatives who are responsible for planning regional education meetings. Rosalie Goldberg will work with those individuals. The resulting CE programs will be evaluated by the committee. Implementation of goal two will occur in phases. Relevant health professions will be identified and notified of NSGC CE criteria. In response to requests, members of the committee will assess CE offerings of such organizations. The purpose is to identify and recommend CE offerings that meet NSGC CE criteria and are of particular relevance to NSGC members. Finally, NSGC CE program planners and members of the committee will employ and discuss CE criteria to promote knowledge of CE concepts among NSGC members. We hope those concepts will become integrated into all CE efforts.

Awarding of CE Units by NSGC—CE units are similar to credits awarded by a university or college for completing a course. Units (or similar designations) are awarded by nonacademic institutions or organizations. One contact hour equals 50 minutes; ten contact hours equal one unit.

There are three hypothetical reasons for the NSGC to award CE units. First, the NSGC could mandate that genetic counselors earn a specified number of CE units to qualify for membership in the society. It is improbable that this decision will be made. Second, some states mandate that professionals earn a specified number of CE units for licensure or relicensure. At this time genetic counselors are not licensed by any state. Economic considerations and the small number of genetic counselors in most states make state licensure unlikely in the foreseeable future. Therefore, this is not a valid reason for the NSGC to award CE units. Third, the American Board of Medical Genetics (ABMG) may require CE units for future certification or recertification. At this time, the ABMG has not determined whether recertification will be required. In addition, the board has not adopted a policy regarding CE units. Those decisions may be made in the future.

While CE units are not currently required for genetic counselors for any of the three reasons discussed above, a few members of the NSGC who have training and degrees in nursing are required to obtain CE units for relicensure. According to the CE office of the American Nurses' Association, only 10 states (California, Nevada, New Mexico, Colorado, Minnesota, Iowa, Kansas, Kentucky, Massachusetts, and Florida) require nurses to obtain CE units for relicensure. In most of those states, about one to one and a half CE units are required. Social workers are not required to obtain CE units.

Based on the foregoing considerations, the committee recommends that the NSGC not award CE units at this time. Members of the committee will assist planners of NSGC CE offerings to employ CE criteria. In addition, the committee will review the CE offerings of the NSGC and other organizations upon request. Approved offerings could indicate that the program meets NSGC CE criteria. If genetic counselors are required to obtain CE units in the future, a mechanism will be in place for the society to award them. NSGC members are encouraged to keep personal records of attendance at CE offerings in the event units are awarded retrospectively. The committee believes that the course of action outlined here will result in the successful implementation of NSGC CE criteria and in the development of a mechanism to award CE units, if necessary. Your comments are invited.

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BEREAVEMENT AND THE GRIEVING PROCESS: A REPORT ON THE REGION II ANNUAL CONFERENCE

Anita L. Lustenberger and Deborah L. Eunpu

The 1982 Region II continuing education conference focused on bereavement and the grieving process. Judith Dichter, Deborah Eunpu, and Peggy Blattner chaired this conference at the Children's Hospital of Philadelphia.

The morning program consisted of talks on the adjustment of parents after a pregnancy or neonatal loss and after the loss of an older child. An overview of the bereavement experience was presented, including a discussion of the development of a young child's understanding of death and the stages of grieving experienced by an older child or adult.

After luncheon, Barbara Fairfield outlined the results of her research on family coping. Niecee Singer, Donna Goodwin, Lynn Godmillow, and Rosalie Goldberg presented case reports that illustrated problems or aspects of the grieving process.

Genetic counselors deal almost daily with the losses their clients experience. It is therefore imperative to understand grieving both as a universal dynamic process and as a personal experience of specific individuals. This conference permitted exploration of both aspects.

Bernadette Foley, Director of Social Work at Jeanes Hospital, is involved in the hospital-based program UNITE (Understanding Newborns in Traumatic Experience), which offers meetings and support for parents who have experienced pregnancy losses or neonatal deaths. According to Mrs. Foley, those losses are especially difficult because a miscarriage or the death of a child is often the first loss experienced by the couple, and they do not have coping mechanisms established through prior experiences. Since the family and the community are not equipped to provide the support such couples need, the couple is deprived of valuable assistance from individuals they have felt close to in the past.

Other problems confronting those couples include the effect of a reproductive loss on the couple's sexual relationship, the difficulties experienced when deciding whether to attempt another pregnancy, and the difficulties of explaining the problems to friends and families.

Ms. Foley offered several suggestions for professionals planning follow-up for couples. Counselors, says Ms. Foley, should be sensitive to times of heightened difficulty. Those periods may include two weeks after death or miscarriage, six to eight weeks after the loss (often coincident with the post-partum check-up), a year after the loss, and at the birth of a subsequent child. Many couples expect to recover quickly from a child's death—an expectation that is reinforced by well-meaning but misinformed friends or relatives. If they do not recover quickly, the couple may begin to feel that they are abnormal. Ms. Foley suggests that professionals can help couples by acknowledging the loss genuinely and thereby validating the couple's grieving, by offering appropriate referrals (for example, to a parent group or counselor specializing in this area), and by giving as much attention to the father as he will allow.

George Steinberg, group leader and a parent member of The Compassionate Friends, Inc., described his work with this support organization. Mr. Steinberg's comments closely echoed those of Ms. Foley, especially with regard to the often unvoiced needs of fathers, the strains imposed on a couple's relationship after the death of a child, and the need most couples have for support long after the death has occurred.

Jeanette Ferszt, a psychiatric nurse specialist who is Associate Director of the Pediatric Nurse Practitioner Program in Oncology at Children's Hospital of Philadelphia and the Hospice Program at Pennsylvania Hospital, discussed the broader dimensions of the grieving process. Ms. Ferszt described the universal response to a loss of a child as that of feeling alone or isolated, and commented that for each couple the experience is unique, despite any generalization about stages of grief as outlined by various researchers and specialists. Finally, the healthy resolution of grief does not mean forgetting the loss, but rather integrating the experience into one's life. She suggested that it is helpful to review the couple's loss history when considering their ability to deal with the present death.

Ms. Ferszt outlined and described the typical manifestations of the stages of grief (shock and disbelief, active grieving, disorganization, and restitution/integration), and provided a useful summary of those manifestations that indicate unusually intense grieving that might require further counseling of other intervention. The signals professionals should watch for include severe physical manifestations, the total absence of recognition of the loss, over activity, prolonged regression, furious hostility, self destructive acts, and manifestation of the symptoms of the deceased individual.

Ms. Ferszt also presented a number of practical suggestions to help families experiencing the loss of a child. Being available at the critical times surrounding the death and in follow-up can be most helpful. Informing parents about how or when they will receive the death certificate can avert unexpected problems. Helping the couple to consider how they will feel about children or pregnant women may help them deal with potentially painful experiences.

Ms. Ferszt's comments about surviving siblings were also useful. Children under six years of age typically have a very simplistic view of death as a separation. They do not understand the permanence of death and may be frightened by it. Children between six and twelve years of age have a developing understanding of the true meaning of death. However, they often harbor residues of magical thoughts where they link themselves to the death in some causal relationship. Children at this stage need to be reassured that they in no way caused their sibling's death. By twelve years of age, most children have a clear perception of death and its finality—a perception similar to that of an adult. In any family, decisions about how and what to tell siblings about the death or about what kind of involvement siblings will have in funeral or memorial activities must be reviewed on an individual basis using the foregoing merely as a guide.

Although the speakers at this conference did not confine their discussions to losses due to a genetic cause, the basic principles are applicable to families who are being seen for genetics services. Certainly, genetic services can only be improved by understanding and applying to our work the experience of others.

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Bereavement (continued)

REFERENCES

Anthony EJ, Koupernik C: *The Child in His Family, Volume II; The Impact of Disease and Death*, New York, John Wiley and Sons, 1973.

Grollman EA: *Talking About Death: A Dialogue between Parent and Child*, Boston, Beacon Press, 1970.

Kirkley-Best E, LaRoche C, *et al:* The Forgotten grief: A review of the psychology of stillbirth. *Am J Orthopsychiatry* 52(3);420, 1982.

Kubler-Ross E: *On Death and Dying*, New York, MacMillan Co., 1970.

Schiff H: *The Bereaved Parent*, New York, Penguin Books, 1977.

Schneiderman G: *Coping with Death in the Family*, Toronto, Chimo Publishing, 1979.

Schoenberg B, *et al.: Loss and Grief: Psychological Management in Medical Practice*, New York, Columbia University Press, 1970.

Zeligs R: *Children's Experience with Death*, Springfield, Charles Thomas Publisher, 1974.

AMERICAN BOARD OF MEDICAL GENETICS, INC. CERTIFICATION EXAMINATION

Certification examinations for Clinical Geneticists, PhD Medical Geneticists, Genetic Counselors, and Clinical Laboratory Cytogeneticists and Biochemical Geneticists will be given on June 27 and 28, 1984. The deadline for applications is September 15, 1983, following which a late fee will be assessed. No applications will be accepted after December 31, 1983.

Individuals who will plan to complete their fellowships by June, 1984 and have otherwise fulfilled the requirements of the board will be eligible to apply for this set of examinations.

Accreditation of clinical genetics training programs will be undertaken by the board this year.

Information and application forms for both certification and accreditation can be obtained by writing:

David L. Rimoin, MD, PhD, President
American Board of Medical Genetics, Inc.
Harbor-UCLA Medical Center
1000 W. Carson St., E-4
Torrance, CA 90509

BOOK REVIEW
Tillie Young

Intensive Care by Mary-Lou Weisman New York: Random House, 1982. 306 pages, Hardcover, $13.95.

In recent years there has been a spate of books, plays, and movies concerning birth defects and genetic disease. A few are memorable—the movie "Best Boy," the play "Joe Egg," the various versions of the "Elephant Man," and the Massie family's book *Journey*.

A new book, *Intensive Care*, deserves to be added to this list, and it may be the most affecting of all. Mary-Lou Weisman's story of herself, her husband, and their sons, Adam and Peter, is a vivid account of their lives as Peter's muscular dystrophy progresses.

Much of the family's response is familiar to professionals in genetics. The disbelief, denial, anger, and final acceptance of the diagnosis and its meaning is a familiar pattern. But the dialogues, the sheer physical work, the emotional roller-coaster, are astonishingly real. (A wheelchair will never be just that to me after reading this book.) Mrs. Weisman pulls out all the stops, yet somehow avoids being maudlin. Her wit, sense of self, and appreciation of the absurd save her and the book.

Intensive Care is important reading for genetic counselors, students, and health care personnel in general. It is more than a special book about living and dying. Above all, it is as the author subtitles it, a family love story.

Tillie Young is a genetic counselor at the Hackensack Medical Center, Hospital Place, Hackensack, New Jersey 07601.

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.

Note: To eliminate some of the problems we have experienced with mailing NSGC materials by third class, we have now returned to first class postage. This will enable forwarding of mail when there is a valid forwarding address and should also eliminate the unreasonable delay between distribution and date of receipt.

POSITIONS AVAILABLE

Project Coordinator/Genetic Counselor: Established maternal serum alphafetoprotein screening program based in the Division of Maternal and Fetal Medicine, Department of Obstetrics and Gynecology, and the Division of Genetics, Department of Pediatrics of the University of North Carolina School of Medicine. Faculty appointment and salary commensurate with training and experience; master's degree in genetic counseling and experience required. Available March 1, 1983. Please contact Robert C. Cefalo, MD, PhD, or A. Myron Johnson, MD, 214 MacNider 202H, University of North Carolina School of Medicine, Chapel Hill, NC 27514, telephone (919) 966-2229.

Assistants in Pediatrics (2): Two positions are available within the Division of Pediatric Genetics. MS degree in genetics with experience in genetic counseling required. Duties will include genetic counseling; teaching of medical students, housestaff, and other health professionals; public education; and clinical research. Recruiting deadline: April 1, 1983. Anticipated Starting Date: July 1, 1983. All interested applicants should contact: Jaime Frias, MD, Box J-296, JHMHC, Department of Pediatrics, University of Florida, Gainesville, FL 32610. An equal employment opportunity/affirmative action employer.

Genetic Associates (2): University of British Columbia, Department of Medical Genetics, Clinical Unit Grace Hospital requires two genetic associates. The positions are within a rapidly expanding clinical genetics program, involve collection of data precounseling, counseling of prenatal and specialty clinic cases, screening of referrals, and follow-up of families. Public education involvement and participation in research projects required. Formal genetic associate training expected, practical experience desired. Position to commence immediately. Please reply with C.V. and three (3) referees to: Dr. J.G. Hall, Director of Clinical Services, Medical Genetics Clinical Unit, Grace Hospital, 4490 Oak Street, Vancouver, B.C. V6H 3V5.

Genetic Counselor-Prenatal Program: Master's degree in human genetics or genetic counseling or comparable training and clinical experience required. Responsibilities will include outreach to develop referral base. Starting salary approximately $2000-2400 per month. Send resume to: John D. Stephens, MD, Inc., Blossom Ridge Medical Building, 15066 Los Gatos-Almaden Road, Los Gatos, CA 95030.

Genetic Counselor/Research Associate: University of Rochester Medical Center, Rochester, New York, has a position available July 1, 1983. Responsibilities include screening of persons affected with Huntington's disease and their families for participation in the research study "Baclofen As Protective Therapy in Huntington's Disease," counseling of participants in the study, and coordination of social needs and resources for patients and their families. The genetic counselor is also actively involved with patients and families in the Movement Disorder Clinic at the Medical Center and acts as a support group leader for the Rochester Chapter of the Committee to Combat Huntington's Disease. An interest in biostatistics and computer analysis is also desirable. Masters level training is preferred. Please respond to: Ira Shoulson, MD, Department of Neurology, University of Rochester Medical Center, 601 Elmwood Avenue, Rochester, NY 14642.

Genetic Associate: Boston University School of Medicine, Center for Human Genetics; full-time position coordinating prenatal diagnosis and serum alphafetoprotein programs. Available immediately. Contact: Aubrey Milunsky, MD, at (617) 247-5720.

CORRESPONDENCE

To the Editor:

The feature article, "New Roles for Genetic Counselors," in the June, 1982 issue of *Perspectives in Genetic Counseling*, prompts a response about expanding an existing role of genetic counselors. This is the role of the genetics educator in schools. As public interest in human genetics increases, so does the demand for accurate, current public education. One existing forum for public education is schools. A genetic counselor with special training in curriculum and instruction and an area of school knowledge such as science or health could provide help and guidance to schools. By working with professionals in both disciplines, the genetics educator helps ensure that the information presented to students is both genetically accurate and free of myths and presented in a manner that conforms to good educational theory. The activities of such a genetic counselor would include collecting, evaluating, producing, and distributing educational resources; providing pre-service and in-service teacher training at the university, high school, and elementary school level; being available to speak with students at each level; and maintaining contact with teachers and students through an information hot-line and/or a newsletter. Such a program in genetics education is currently developing at the Statewide Genetics Services Network in Wisconsin.

Angelo Collins
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