

Emerging Quality Improvement Measures in Genetic Counseling

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The need to establish guidelines for total quality management in genetic counseling is now recognized as new genetic technologies are being introduced into genetics services and primary care. Genetic counselors have an important role in developing methods for assuring quality in the genetic counseling process. Emerging quality improvement measures as well as selected examples from the Quality Assurance Program in the Genetics Services Division at the Foundation for Blood Research are presented as examples of direct genetic counselor involvement. Suggestions for future directions of quality improvement activities for genetic counselors are discussed.

KEY WORDS: quality improvement; quality management; genetic counseling; patient satisfaction; peer review; consumer involvement.

INTRODUCTION

The need for national guidelines for practice and quality improvement (QI) in genetic counseling is becoming apparent as new genetic technologies are introduced into genetics services and primary care (Andrews *et al.*, 1994; Greendale *et al.*, 1994; ASHG Human Genome Committee Report, 1991). The purpose of establishing guidelines and QI programs in genetic counseling is to continually assess whether individuals and families are receiving appropriate, sensitive, accurate, and up-to-date information with which they can make informed health decisions, and to take steps to improve and assure quality if deficiencies are identified. Genetic counselors are actively involved in the formulation of meaningful, outcome-oriented

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guidelines for practice. In the larger arena, genetic counselors and other genetics professionals are developing methods of evaluating the effectiveness of genetic counseling that are relevant to clinical genetics settings and that can be applied to similar settings nationally and internationally (Greendale *et al.*, 1994; Wertz and Gregg, 1995).

This paper discusses emerging quality improvement measures in genetic counseling. Several quality improvement measures developed and implemented as a part of the Quality Assurance Program in the Genetics Services Division of the Foundation for Blood Research are presented as examples of direct involvement of genetic counselors in this process. Suggestions for future directions of quality improvement activities for genetic counselors are also discussed.

DEFINING QUALITY IMPROVEMENT IN GENETIC COUNSELING

Concern with quality improvement in genetic counseling has coincided with advances in human genetics and genetic technologies. These advances have extended the scope and complexity of health issues to which genetic counseling is relevant. Assessment of the quality of the genetic counseling encounter beyond measurements of professional competence, counting of clinic visits, or contribution to a lessening of the burden of genetic disease on society appears to be necessary at this point in the evolution of the field (Sorenson *et al.*, 1981; Chadwick, 1993).

Evaluation of the quality of genetic counseling depends first on recognition of the definition of genetic counseling and its goals. The definition of genetic counseling has been in existence since (1975). The ultimate goal of genetic counseling is to be informative, supportive, and enabling (Sorenson *et al.*, (1981; Chadwick, (1993), with the intent to enhance an individual's understanding of a genetic condition, and the chance for recurrence, as well as to provide support for the family's adaptation to the genetic condition, and to assure informed decision-making with regard to future reproduction, and other genetic health care decisions (Epstein, 1975; Evers-Kiebooms and van Den Berghe, 1979). Genetic counseling activities designed to promote and support individuals in their own decisions include education regarding the diagnosis, prognosis, and treatment of genetic conditions, as well as options available for dealing with condition, "decision facilitation" to help individuals make the best decision for themselves, and support during and after decision-making process (Sorenson *et al.*, 1981).

Several factors have contributed to the growing interest in quality improvement in the general clinical setting. Two may be applied to quality improvement in genetic counseling as well. These are: (1) a broadening of the concept of quality itself, and (2) a growing interest in the quality of services among all concerned parties. The term "quality" refers to a range of desirable outcomes of patient encounters and encompasses effectiveness, efficiency, adequacy, and acceptability (Vuori, 1989). One way to conceptualize the quality of a genetic counseling encounter is to consider the definition outlined in the Institute of Medicine's report on "Defining Primary Care: An Interim Report":

Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge. (Donaldson *et al.*, 1994)

Some aspects of genetic counseling fit this definition without significant modification. For example, most would agree with measuring quality of care by assessing reduction in morbidity and mortality due to renal cell carcinoma in von Hippel-Lindau syndrome or aortic aneurysm in Marfan syndrome. Genetic service providers, by identifying rare genetic disorders in individuals at risk, can use their knowledge of the natural history of such disorders to design or utilize surveillance protocols which may maximize the likelihood of desired health outcomes. The application of this definition is more questionable in reproductive or presymptomatic genetic counseling encounters, however, since the "desired health outcomes" are more difficult to define, and more influenced by individual differences in ethical and sociocultural viewpoints.

In the past, some researchers and policymakers have implicitly or explicitly considered reduction in number of babies born with genetic conditions such as Tay-Sachs disease as evidence of the quality of their programs. Others (Sorenson *et al.*, 1981; Chadwick 1993) have expressed concern that these paradigms, while appropriate for public health campaigns such as those against smoking, shift the purpose of the genetic counseling encounter into an unacceptable eugenic realm.

For this reason, quality in genetic counseling has been re-defined in a number of studies to be those counseling activities which lead to a measurable difference in the patient's or family's understanding pre- and post-genetic counseling encounter (Antley, 1976; Evers-Kiebooms and Van den Berghe, 1979). These studies often focused on retention of genetic information, emotional reactions to the genetic counseling, or judgments regarding the influence of genetic counseling on decision-making. Additionally, the studies attempted to assess the impact of genetic counseling on reproductive decision-making and behavior (Evers-Kiebooms, 1979; Van den Bergh, 1979).

A third approach to defining the quality of the genetic counseling encounter has been to equate quality with patient satisfaction, reasoning that the recipient of genetic counseling is the best judge of the value of the imparted information. This view is reflected in studies such as that of Shiloh (1990) who developed a tool to identify determinants of satisfaction with content and to assess whether the patient's expectations were met. Others have evaluated the success of genetic counseling in terms of its acceptability and appreciation by patients (Reid, 1988). Black and Weiss (1989) surveyed members of support groups to collect qualitative data on experiences in obtaining genetic and related services. In this study, support group members called for genetic professionals to improve their interpersonal skills, and widen their referral networks (Black and Weiss, 1989).

More recent efforts addressing the importance of this aspect of quality improvement include two projects supported by regional genetics networks. The New England Regional Genetics Group (NERGG) has supported a 1994–1995 project by Wertz and Gregg, "Optimizing Genetics Encounters: Suggestions from Consumers and Providers in the New England Regional Genetics Group." A document is being developed based on the comments of consumers and providers who participated in a series of focus groups and individual interviews (Wertz and Gregg, 1995).

Middleton *et al.* have also received funding from the Mid-Atlantic Regional Human Genetics Network (MARGHN) for a 1995–1996 research project to evaluate "Consumer Expectations and Satisfaction with Genetic Services." The intent of their endeavor is to consider patient satisfaction in terms of original expectations and the providers' success at meeting these. They plan further exploration of Shiloh's finding that fulfillment of expectations about medical services affects client satisfaction (Shiloh, 1990). They also plan to evaluate the effectiveness of a genetics educational intervention in a prenatal population (Middleton *et al.*, 1995).

Currently, quality management in genetic counseling is being considered in terms of process and outcome-oriented measures that will allow for continuous assessment of the quality of care (Andrews *et al.*, 1994; Greendale *et al.*, 1994). One example of this approach is provided by the Clinical Genetics division at the Carolinas Medical Center, Charlotte, North Carolina. The quality improvement program established for genetic counselors by Cam Knutson incorporates a Ten-Step Monitoring and Evaluation Process utilized by the Joint Commission on the Accreditation of Health Care Organizations. This method is being used to evaluate and improve content and completeness of medical records. Involvement of the entire staff in articulating goals and choosing QI items of concern in genetic counseling has helped to promote the ongoing process of evaluation and improvement of patient care in terms of fulfillment of patient needs and desires, and closeness of fit to "state-of-the-art" genetic counseling (Greendale *et al.*, 1994).

A process and outcome-oriented approach to quality improvement in genetic counseling may be useful in assessment of effectiveness, appropriateness, and satisfaction with information received. Such measures may also help to assure that individuals and families receiving genetic counseling services are consistently receiving information that is accurate, sensitive, that is "consistent with current professional knowledge," and is likely to lead to "desired health outcomes" according to individual beliefs and values.

SELECTED QUALITY IMPROVEMENT MEASURES FOR GENETIC COUNSELING IN THE QUALITY ASSURANCE PROGRAM AT THE FOUNDATION FOR BLOOD RESEARCH

Development of a quality improvement program for genetic services is beneficial since it provides a framework for quality management measures in genetic counseling, and it allows for continuous improvement of genetic counseling to patients and families. Genetics organizations and many individual genetics service centers are developing quality improvement programs and specific measures to achieve quality improvement in genetic counseling encounters. The Quality Assurance Program in the Clinical Genetics Division at the Foundation for Blood Research, initiated in 1990 by the Director, is an example of emerging efforts by genetic counselors to become accountable for the quality of genetic health care they provide to individuals and families. This Quality Assurance Program is based on an educational feedback model that is dynamic and adaptable, and that provides opportunities for ongoing continuing education to staff, consumers, and health care providers. The key components of this program include: (1) regular assessment of consumer satisfaction; (2) guidelines for counseling in specific situations; (3) standardized letters and glossary paragraphs to enable continued improvement; (4) formalized peer review of genetic counseling skills; and (5) consumer involvement in the development of genetic counseling materials.

REGULAR ASSESSMENT OF PATIENT SATISFACTION

Consumer satisfaction with information and services received at the time of genetic counseling is one means of measuring the quality of a genetic encounter. For this reason, and because of the potential special needs of rural populations in Maine, the Clinical Genetics Program at the Foundation for Blood Research designed and implemented a patient satisfaction survey to elicit specific information about the acceptability and accessibility of genetic counseling. The main purpose of the survey is to determine

whether genetic counseling and evaluation services are meeting the expectations and needs of patients. Satisfaction with genetic counseling, in this setting, is being assessed in terms of successful communication of information, as evidenced by the patient's understanding of the purpose and worth of genetic counseling, and assessment of whether the counseling was helpful in making decisions that were best for the patient in light of personal values and goals.

A survey tool consisting of 22 questions (Fig. 1) was developed in 1993. The questions cover three health care aspects considered relevant to satisfaction (Ben Sira, 1976). Two of the questions evaluate patients' impressions of the competence of the genetic counselor and the clinical geneticist; seven cover evaluation of genetic counselors' and physicians' genetic counseling; and 13 address procedural or administrative aspects. An open-ended question is used at the end of the survey to elicit comments about how services could be improved. This survey is sent to prenatal and clinical genetics patients in conjunction with a letter summarizing their genetic counseling session. Survey questionnaires are sent out to all patients being counseled over a 3-month period twice per year. Information obtained from the survey is analyzed, summarized, and distributed to all members of the genetics team for review.

A summary of patient satisfaction questionnaires sent between 1993–1995 is presented in Table I. The number of questionnaires sent reflects the number of patients seen for genetic counseling by a genetic counselor in prenatal and regional genetics clinics. Response to the questionnaire has been between 50–60%. More than 85% of respondents have expressed satisfaction with the genetic counseling process. Because 40–50% of patients surveyed did not respond, the possibility of bias in response cannot be overlooked. However, written comments by respondents (51% as of 1995) have helped to identify areas of concern such as appointment waiting time, inadequate preparation for the appointment, and unsatisfactory counseling experiences. For example, two patients' comments about pre-appointment experiences reflect problems with inadequate information and unexpected waiting:

You should verbally tell patients they need to take time off from work after an amnio. I was mentally ready for the amnio, but couldn't take the 2 days off in a row (because of lack of prior knowledge). Very disappointing.

The wait was so very long! We were in the waiting room for forty minutes before we saw anyone. After we met with the counselor, we waited another 20 minutes. After the ultrasound we waited another 40 minutes! It was very nerve wracking!

Positive experiences with genetic counseling are reflected in written feedback from patients as well:

The entire staff knew I was concerned and made both myself and my husband very comfortable. This was one of the first appointments I have had where we were not rushed and all our questions were answered. I felt relieved after I left this appointment. My questionnaire does not need to be kept confidential. I appreciate everything the office has done for us.

Keep sending summary follow-ups. You're very upset and concerned at your appointment and being able to read the summary makes everything very clear. The staff and doctors were very helpful and understanding.

Patient comments and concerns are discussed at regular clinical and staff meetings, and specific measures to improve the genetic counseling process are determined. Comments pertinent to specific genetic counseling sessions are discussed individually with the genetic counselor, medical geneticist, and supervising genetic counselor (State of Maine Genetics Grant, 1995).

Two activities have been undertaken by the staff at the Southern Maine Regional Prenatal Diagnostic Program as a result of feedback received from patient satisfaction surveys. First, an ongoing educational outreach program for prenatal providers has been initiated to address concerns expressed regarding inadequate preparation of the prenatal diagnostic appointment and the value of the genetic counseling experience. Second, a brief summary of the goals of genetic counseling has been developed for prenatal patients being seen at the Southern Maine Prenatal Diagnosis Program to address patient expectations of the purpose of genetic counseling. This summary is given to patients prior to or at the time of their visit to prepare them for what they can expect from the genetic counseling encounter. The effectiveness of both of these efforts will be measured through ongoing use of the patient satisfaction surveys as a part of the quality improvement process.

GUIDELINES AND STANDARDIZED WRITTEN MATERIALS FOR COUNSELING IN SPECIFIC ENCOUNTERS

Quality and consistency of information provided to individuals and families is recognized as another important aspect of QI. A Quality Assurance Manual, developed by genetic counselors with input from the medical geneticists in the Clinical Genetics Program, beginning in 1992, contains Genetics Division Goals and Policies which serve as the framework for the provision of genetic counseling services. The goals and policies include: Program Philosophy and Values, Program Mission Statement, Minimum Guidelines for the Delivery of Genetics Services, and a Confidentiality Policy. The manual also contains genetic counseling outlines for specific situations such as repeated miscarriage and teratogen exposures.

Please answer each question that applies. Some questions ask you to use a scale from 1 to 5 (1 is least and 5 is most). Please answer those questions by circling one number. We appreciate any comments that you may wish to add.

A. Scheduling the appointment

1. How many days did you have to wait to get an appointment?
 2. Was this too long?..... Yes _____ No _____
 3. Did you schedule your own appointment for the counseling session?
..... Yes _____ No _____
- If "Yes", please answer question #4.
- | | Definitely
Not | | | Definitely
Yes | |
|--|-------------------|---|---|-------------------|---|
| 4. Was scheduling your appointment for the counseling session stressful? | 1 | 2 | 3 | 4 | 5 |
| handled courteously? | 1 | 2 | 3 | 4 | 5 |
| handled clearly and efficiently? | 1 | 2 | 3 | 4 | 5 |
5. How many minutes did you have to wait to be seen at the time of your appointment?

B. Preparing for the appointment

1. Did you receive written information about the appointment before coming to your appointment?
- | | Definitely
Not | | | Definitely
Yes | |
|----------------------------------|-------------------|---|---|-------------------|---|
| 2. If "Yes", was it clear? | 1 | 2 | 3 | 4 | 5 |
| helpful? | 1 | 2 | 3 | 4 | 5 |
| confusing? | 1 | 2 | 3 | 4 | 5 |
| too little? | 1 | 2 | 3 | 4 | 5 |
| too much? | 1 | 2 | 3 | 4 | 5 |
3. Did this written information help prepare you for your appointment?
 4. Were the directions for going to the location clear?
 5. Where was your appointment? (check one)
- MMC Division of Maternal-Fetal Medicine
- Foundation for Blood Research (Dr. or Genetic Counselor only)
- Foundation for Blood Research
- Foundation for Blood Research
- Adult Cleft Lip and Palate Clinic at Foundation for Blood Research
- Infant Cleft Lip and Palate Clinic at Plastic & Hand Surgical Associates.....

Fig. 1. Southern Maine Genetic Services PD Patient Survey.

C. The appointment itself

| | Definitely Not | | | Definitely Yes | |
|--|-------------------|---|---|-------------------|---|
| 1. Were you made to feel comfortable while waiting to be seen? | 1 | 2 | 3 | 4 | 5 |
| 2. Do you feel that you had to wait too long in the waiting area before being seen for counseling? | 1 | 2 | 3 | 4 | 5 |
| 3. Were you treated courteously by everyone? | 1 | 2 | 3 | 4 | 5 |
| 4. Were you able to understand what was being discussed? | 1 | 2 | 3 | 4 | 5 |
| 5. Were all of your questions answered? | 1 | 2 | 3 | 4 | 5 |
| 6. Did you have enough time to discuss all of your concerns? | 1 | 2 | 3 | 4 | 5 |

D. After the appointment

| | Definitely Not | | | Definitely Yes | |
|--|-------------------|---|----------|-------------------|---|
| 1. Were you encouraged to call if you had further questions? | 1 | 2 | 3 | 4 | 5 |
| 2. Did you read your letter summarizing the counseling session?..... | Yes _____ | | No _____ | | |
| 3. If "Yes", was it | Definitely Not | | | Definitely Yes | |
| clear? | 1 | 2 | 3 | 4 | 5 |
| accurate about what was discussed? | 1 | 2 | 3 | 4 | 5 |
| helpful? | 1 | 2 | 3 | 4 | 5 |

E. In summary...

| | | | | | |
|--|---|---|---|---|---|
| 1. Overall, how useful did you find the genetic counseling? | 1 | 2 | 3 | 4 | 5 |
| 2. Would you recommend genetic counseling to a friend or relative in a similar situation?..... | 1 | 2 | 3 | 4 | 5 |

F. What suggestions would you have to improve our genetic counseling service?

Please return this survey in the attached postage-paid envelope. If you have questions to which you would like a response, please be sure to include your name and address below. **ALL SURVEY RESPONSES WILL BE KEPT CONFIDENTIAL.** Thank you for your help.

Name _____
 Address _____
 City _____ State _____ Zip _____

Return To:
 ATN: Richard A. Doherty, M.D.
 Southern Maine Genetics Services
 Foundation for Blood Research
 Scarborough, ME 04070-0190

Fig. 1. (Continued)

Table I. Patient Satisfaction Questionnaire Rates of Return (1993–1995)

| | Total sent | Total received | Response (%) |
|------------------|------------|----------------|-----------------|
| 1993 (July–Nov.) | 230 | 122 | 53 |
| 1994 (Jan.–Mar.) | 165 | 99 | 60 |
| 1995 (Apr.–Jun.) | 21 | 122 | 58 ^a |

^aTotal number of write in comments 62 (51%).

Table II. Genetic Counseling Protocol for Neural Tube Defects

1. Defect detected on ultrasound examination
2. Discuss case with perinatologist
 - a. Prognosis
 - b. Whether or not the patient will be followed by perinatologist for the remainder of the pregnancy
 - c. Make sure that the referring physician is notified of defect (DMFM physician usually calls)
 - d. Make sure that the counselor's notes are in DMFM chart
3. Patient referred for genetic counseling
 - a. Address patient's immediate questions and concerns
 - b. Explain defect
 - c. Hand out patient information (NSGC "Now That You've Been Told" pamphlet)
 - d. Discuss options
 - To continue pregnancy
 - To terminate pregnancy
 - Explain reasons for and procedure for amniocentesis
 - e. Take detailed family and pregnancy histories as appropriate
 - f. Evaluate patient's needs and refer to appropriate resources
 - Social Services
 - Neurology
 - Neonatal Nursing
 - Spina Bifida Clinic
4. If patient continues pregnancy as a DMFM patient, confirm that
 - a. An office visit is arranged
 - b. A visit with Social Services is arranged
5. If patient continues pregnancy with referring OB
 - a. Discuss case with perinatologist
 - b. Have perinatologist speak with referring OB to give referrals for treatment and support as necessary
6. If patient decides to terminate
 - a. Refer to Termination Protocol
7. Schedule follow-up appointment as necessary
 - a. Discuss recurrence risk for future pregnancies
 - b. Discuss screening for future pregnancies
 - c. Explain folic acid recommendations
 - d. Offer support
8. Write follow-up letters
 - a. Patient (include folic acid recommendations)
 - b. Physician (include folic acid recommendations)

Genetic counseling protocols (see example provided in Table II) documenting information that needs to be covered in the genetic counseling sessions for indications such as prenatal diagnosis of an open neural tube defect have been developed. The genetic counseling protocols help to assure that all genetic counselors in the program are providing the same up-to-date information to individuals and families. Standard patient and health provider letters suitable for documentation of the typical genetic counseling encounter accompany each counseling outline and protocol assuring consistency and continuity of care. The letters are adaptable and can be modified to fit specific patient and genetic counseling encounters. All letters, protocols, and outlines are updated on an annual basis.

A computerized document containing paragraphs which are routinely used in patient/health care provider letters was also developed in 1992 by the genetic counselors and medical geneticists. Standard paragraphs are ordered alphabetically by topic and are located in a common access computer file used by Genetics Division secretarial support personnel, genetic counselors, and medical geneticists. A cross-referenced index of these standard paragraphs is updated as necessary, and new medical genetic information is added as appropriate.

Use of these paragraphs results in greater efficiency in the production of accurate and clearly articulated patient and health care provider letters, promotes a controlled and organized means of improving the communication of medical genetics information, and provides further assurance of the consistency and accuracy of genetic counseling content (State of Maine Genetics Grant, 1995).

GENETIC COUNSELING: PEER REVIEW

Annual review of genetic counselors by the medical geneticist and supervising genetic counselor is a further means of quality assurance. In the Genetics Division at the Foundation for Blood Research, this concept has been expanded to include peer review of genetic counseling sessions. The basis for peer review is the educational feedback model developed as the core of the QI program. The peer review model involves genetic counselors observing one another's counseling sessions with special attention to content, technique, and style. An assessment form to evaluate genetic counseling skills has been developed. It incorporates the components of the genetic counseling process including: assessment skills, information gathering, informative counseling, supportive counseling, organizational skills, and follow-up after the session.

Following review, the counselor being reviewed discusses his/her peer's evaluation in a one-to-one meeting. With the reviewing counselor, the evaluation is discussed with the supervising genetic counselor and medical geneticist, who address key issues with each individual counselor at the time of her/his annual review. The evaluation becomes a part of the counselor's personnel files.

Peer review for assurance of quality and consistency in genetic counseling takes into account variation in technique of presenting genetic information to patients of different ages, educational levels, ethnocultural backgrounds, and degrees of risk. The peer review process has encouraged discussion of how best to present complex genetic information in highly emotional situations. Most importantly, it has fostered professional growth and development of genetic counselors.

The peer review process has been in place for one year. Response by staff being reviewed in this manner has been positive. Medical geneticists have shown interest in becoming participants in the process as well. A stronger team approach to genetic counseling services is emerging, and the potential for continued quality assurance and improved patient satisfaction through peer review is evident (State of Maine Genetics Grant, 1995).

INCLUSION OF CONSUMER REPRESENTATIVES AS CONSULTANTS TO GENETIC COUNSELING SERVICES

Direct consumer involvement in the development and assessment of genetic counseling services is another important means of assuring that the genetic counseling encounter is relevant to and meets patient and family needs (Black and Weiss, 1989). The QA Program at the Foundation for Blood Research has a consumer advisor to genetic services as well as consumers who provide input to genetic counseling for a variety of genetic conditions. A consumer is invited to attend regular staff meetings where genetic counseling policies and procedures are reviewed, as well as educational sessions developed and implemented for families and health professionals. Also, consumer representatives have been chosen as consultants for the development of consumer support and educational information including fragile X, Down syndrome, and cleft lip and palate. Here consumers have provided direct feedback to the genetic counselors regarding programmatic and educational aspects. Consumer representatives are also involved in the development of genetic counseling materials for families. Involvement of consumers in all of these areas of genetic counseling has helped to expand genetic counselors' educational and support resources to families.

CONSIDERATIONS FOR ADDITIONAL DEVELOPMENT OF QUALITY IMPROVEMENT IN GENETIC COUNSELING

Developing meaningful ways of assessing the quality of genetic counseling encounters is an important aspect of providing genetics services. Efforts to assure and enhance quality improvement are taking place in individual genetics service centers, as well as in national organizations and settings such as the American College of Medical Genetics, the Council of Regional Networks (CORN), the American Society of Human Genetics, and the International Society of Nurses in Genetics. The National Society of Genetic Counselors Genetics Services Committee is involved in developing guidelines for specific genetic counseling encounters that will help to establish consistency and accuracy of genetic information in a format that permits sensitivity to individual genetic counseling clients (Anderson, 1994).

Further development and support of quality improvement measures in genetic counseling is critical as genetic services become integrated into primary care settings. Elements that warrant further development include: (1) continued assessment of mechanisms to maintain professionalism, and expertise in genetic counseling; (2) evaluation methods of genetic counseling skills such as peer review; and (3) consumer evaluation and review of genetic counseling by surveys or interviews. These efforts should be considered in collaboration with professional genetics societies and organizations.

Guidelines for genetic counseling encounters also need to be developed with input from genetic counselors, consumers, and other members of the genetics team. Once developed, additional research is needed to determine the usefulness and acceptability of such guidelines for genetic counselors and the individuals and families they serve. The National Society of Genetic Counselors is taking a lead in developing and supporting such efforts. This will enhance efforts to develop, field test, and implement quality improvement guidelines for genetic counseling.

As genetics services become integrated into primary care practice, further development of appropriate methods for assuring quality in provision of genetic counseling in such situations will be needed. For example, genetic counselors may be called upon to expand their roles as educators and consultants to primary care practitioners in areas such as carrier screening. Genetic counselors will need to be involved in efforts to develop new models for practice that will incorporate a team approach to provision of genetic counseling in a changing medical environment.

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