plenary session II: saturday, march 11

Extending the Reach of Genetic Services: Experience with Distance Technology

Overview of telegenetics. B.B.Butler. Univ. of Arkansas for Medical Sciences, Little Rock, AR

Patients and health care providers have always sought better ways of communicating with each other. We have progressed from drums and smoke signals to the Internet and interactive video. Telemedicine (TM) today is as close as 911 through our telephone or as remote as Everest, Antarctica, and the moon. In 1959, psychiatry first used interactive video and 39 years later in 1998, there were 58,000 teleconsults through 157 programs at 1,345 sites in the United States. One hundred TM programs exist in academic medical centers and health care/hospital networks. Only 7 of these programs are more than 6 years old, while 18 programs are less than 1 year old. A wide range of communication technologies is available for genetic professionals. These include telephone, facsimile, Internet, electronic mail, videophone, interactive video, desktop conferencing, interactive web/cable TV. TM is a moving target with a proliferation of technology and programs that can be overwhelming to the genetics professional. Telegenetics or e-genetics includes 1) clinical: diagnosis and management, counseling, support groups, consultation, and supervision; 2) education: degree courses and continuing education; 3) research: multi-site studies, outreach to participants, and evaluation of telegenetics; and 4) administration: interviewing applicants, board/committee meetings, and communication with society members. The greatest benefit of telegenetics is access, more so in genetics where patients with rare disorders may be scattered across the state or the country. Liabilities include logistics of more than one site and technical difficulties. Legal issues involve licensure across state lines and regulations of TM systems. Inconvenience and expense are barriers. However, the Health Care Financing Administration (Medicare and Medicaid) and most insurance companies reimburse for TM. Funding is also available through grants from several federal agencies and private foundations. Other professional groups are using TM and have developed TM policies and standards. Genetics patients are initiating their own contacts through Internet sites, chat rooms, and e-mail. The future of telegenetics includes desktop video conferencing and video phone contact as the technology improves. It is recommended that ACMG encourage participation in TM and develop guidelines and policies for telegenetics.

Genetic counseling and video phones. B.A. Karczeski. Univ. of Arkansas for Medical Sciences, Little Rock.

Video phones allow portable access to distance technology-based genetic services. Available since the early 90s, these phones are not as yet widely used for clinical or educational purposes in any discipline. Given their low cost and portability, they could become a valuable adjunct to telemedicine-based provision of patient care, especially in the arena of genetic counseling. The advent of technologies such as video phones and interactive video has the power to change the face of genetics clinics and genetic counseling. However, these modes of providing genetic services will impact the administration of a clinical genetics program as well as the basic counseling interaction. Patients seem to be intrigued by the technology and happy to obtain specialized services close to home. Counselors and physicians cite the benefits of increased patient and referring physician satisfaction, and increased access to genetic services. Drawbacks for professionals involved in telemedicine clinics include dealing with "on-demand" counseling and lack of a real, person-to-person connection. Telemedicine-specific issues that need to be addressed include scheduling problems, privacy, access to additional tests and ancillary services, clinic staffing and program marketing. Interactive video and video phone clinics can be successfully incorporated into a traditional genetics clinic as long as their unique administrative and clinical requirements are addressed.

Experience with Telemedicine Genetic Services at the Medical College of Georgia. David B. Flannery, M.D., FACMG, Medical College of Georgia

The Genetics Section of the Department of Pediatrics at the Medical College of Georgia has utilized the Georgia Statewide Telemedicine System to provide outreach Clinical Genetics services since 1995. This constitutes the longest telemedicine experience of any genetic program of which we are aware. Services provided include acute consultations for diagnosis and management provided on a PRN basis, and a monthly Genetic Clinic conducted via Telemedicine between the Medical College of Georgia and the Ware County Health Department, in Waycross, Georgia. Review of our experience with telemedicine genetics provides valuable insights into the uses and limitations of telemedicine. This presentation will demonstrate the telemedicine system we use, and give specific case examples highlighting the principles learned:

1. Telemedicine is supplemental to outreach clinics, not a substitute for outreach clinics.
2. Telemedicine is a high-tech tool, but only part of your armamentarium.
3. Some patients/families are not suitable candidates for telemedicine encounters.
4. Measured satisfaction is high, but may not tell the whole story.
5. How you conduct the telemedicine session must be planned in advance, but one also needs to be flexible during the session.
6. There are methods to conduct telemedicine sessions which can preserve patient/family privacy.

THE ROLE OF FETAL TELEMEDICINE IN OBSTETRIC ULTRASONOGRAPHY.
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The optimal method of providing high quality obstetric ultrasonography for general patient screening is unclear. Options include having all patients attend specialist referral ultrasound units, delayed review of videotape recordings of ultrasound examinations by an expert, or the use of fetal telemedicine to electronically link the expert and the patient without regard to geographic distance. Real-time telemedicine transmission of obstetric ultrasonography requires digitization of data with a videocodec, and adequate transmission can be achieved using an Integrated Services Digital Network (ISDN). A fetal telemedicine network, potentially linking many satellite offices in the community to a single tertiary-level interpretation center, using ISDN, is clinically feasible. The minimum bandwidth for such a system should be 384 kilobits per second. Such a fetal telemedicine application is sufficiently reliable to provide community-wide real-time obstetric ultrasonography interpretation. The use of fetal telemedicine for the interpretation of first trimester sonography has been validated. The use of fetal telemedicine for interpretation of detailed fetal anatomy surveys in the second trimester has also been validated. Real-time telemedicine review is possible at a quality-level sufficient for providing screening sonography for the general obstetric population. Savings in non-fixed costs can offset the high start-up costs associated with implementing a fetal telemedicine network. These savings accrue because of increased efficiency of fetal telemedicine and the impact of computerization on the ultrasonography service. Many practical problems still must be resolved before widespread implementation of telemedicine services can be advocated.