

Risk Assessment/Counseling and Deaf Culture

Thanks to Emily King, Master's candidate in Genetic Counseling at the University of Cincinnati, Cincinnati, Ohio, and to Sarah Hatcher, undergraduate student at Centre College, Danville, Kentucky, for their work as contributing authors for this case.

Commentary by Ginger Norris, MGC, CGC, Genetic Counselor

Learning Objectives

By the end of this case, genetic counselors will be able to:

1. Discuss the meaning of disability referring to the pathological and cultural models.
2. Identify the four main types of nonverbal communication and their impact on the overall communication process.
3. Define incidental learning and explain its relevance to genetic counseling.
4. Explain how to use the PRACTICE mnemonic in genetic counseling.

Case Study

Ellen is a genetic counselor at a major university medical center where she provides hereditary cancer genetic counseling services. Her next client, Jean, is a 35 year old Euro-American woman referred due to a family history of breast cancer. In further review of Jean's intake form, Ellen is surprised to note that Jean is deaf and that the session will be conducted with an American Sign Language interpreter. Ellen has no previous experience providing genetic counseling services to people who are deaf.

Personal Reflections

- What concerns and biases might Ellen have going into the session?
- What concerns and biases might Jean have going into the session?
- How might the perspectives of the two individuals involved in this case differ? How might they be similar?
- How might these perspectives impact the genetic counseling session?
- What does it mean to be part of a culture?
- How familiar are you with people who are deaf?

- How do you think your experiences and perspectives would be different if you were deaf?
- Consider your experiences and perspectives related to deafness and hearing loss. Do you consider deafness to be a disability? Why or why not?
- How would you prepare for this genetic counseling case?

Cultural Framework

The deaf and hard of hearing community is heterogeneous group. People with hearing loss are from many different races, ethnicities, religions, sexual orientations, and cultures. There are many causes of hearing loss and different degrees of hearing loss. Each deaf or hard of hearing individual has a unique perspective on his or her hearing loss. These perspectives can vary due to an individual's age of onset, educational background, communication styles, family and community life, as well as their own feelings about hearing loss.

Although great diversity exists among those with hearing loss, many individuals who are deaf share a common language and culture, referred to as Deaf culture. In 1972 James Woodward proposed a convention of using the lowercase *deaf* when referring to the audiological condition of not hearing, and the uppercase *Deaf* when referring to a particular group of people who share a language and identify with a culture (Woodward, 1972). Culture is defined as a set of learned behaviors of a group of people who have their own language, values, rules of behavior, and traditions. Members of Deaf culture pass on their language and traditions through generations and share pride in their culture. Many will actively seek other Deaf individuals to socialize with, and often, individuals will marry other members of Deaf culture. Individuals who are Deaf often attend Deaf churches, schools for the d/Deaf, and participate in distinct social, sports, or recreational institutions and activities. It has been estimated that about 90% of deaf children have hearing parents (Garrett, et al., 2006). Since most deaf individuals are born into hearing families, a great majority of Deaf individuals are not born in to their culture, but instead choose Deaf culture for themselves.

The essential link to Deaf culture among the American deaf community is not the degree of hearing loss but rather the preference for communicating using American Sign Language, or ASL. ASL was developed by American deaf people to communicate with each other. In 1817, Laurent Clerc and Thomas H. Gallaudet established the first school for the deaf in the United States. The signed language that developed was a combination of French signs and signs brought in by the students. This language became what is now known as American Sign Language. Since then, the language has spread to other parts of the United States and Canada, primarily through residential schools for the d/Deaf. See the following website to review the genetics educational resources currently offered by Gallaudet University:

http://genetics.gallaudet.edu/Genetics/Genetics_Education.html

American Sign Language, or ASL, is a complete language with its own grammar and syntax. ASL incorporates signs made with the hands and other movements, including facial expressions, gestures, and body movements. It is the first language of many deaf Americans, and the third most commonly used language in the United States (Osborne, 2003). As with spoken language, there is no one form of sign language used around the world. Furthermore, different sign languages are used in different countries or regions. Although ASL is the primary signed language used in America, it is a completely separate language from English. ASL has unique rules for grammar, punctuation, and sentence order. However, ASL does not have its own written form. Therefore, to communicate with English speakers, ASL users learn written English. Learning English without the ability to hear can be extremely challenging, and because of this, many deaf people are not English proficient.

Case Follow Up

As Ellen asks questions about the family history, Jean bangs her fist on the table. Ellen interprets this action as impatience and decides to skim through the rest of her questions.

Personal Reflections

- What would you do if your patient banged her fist on the table?
- What might be your emotional reaction?
- What might you say?
- List five nonverbal cues expressed by your last genetic counseling client.

Nonverbal Communication

Because Ellen does not know ASL and cannot communicate directly with Jean, both the counselor and the client will rely heavily on interpreting cues provided by nonverbal communication. However, when counseling a patient who is a member of Deaf culture, nonverbal communication may be more difficult to understand because the Deaf culture has social rules which might seem rude for those unfamiliar with its norms. For example, common means of getting one's attention in the Deaf community include touching the person, stomping the foot, banging a fist on a table, or waving the hand in front of the face (Kehl & Gartner, 2009). A genetic counselor who is not familiar with these social norms may misinterpret the meaning of a deaf client's actions as anger or annoyance, even though these actions are considered appropriate and polite ways of getting another's attention in the Deaf community.

Communication occurs through the use of language and various aspects of nonverbal communication. Nonverbal communication is defined as the aspect of the communication process where messages are exchanged through techniques

that are not a part of the spoken language (Hickson, Stacks, & Moore, 2004). While verbal and nonverbal behaviors are different aspects of communication, these components are not mutually exclusive. According to Esposito (2007), nonverbal behaviors often emphasize verbal expressions and reflect intrapersonal, interpersonal, and environmental relationships. Nonverbal behaviors can be divided into four categories: kinesics, proxemics, paralinguistics, and appearances (Hu, 2007).

Before looking at each category in further detail, the cultural stage must first be set. The majority of human communication, both verbal and nonverbal, is culturally molded and trained (Esposito, 2007). Because all behaviors occur in a cultural context, it is important to recognize the cultural differences between those involved in the communication process. The objective aspects of culture, including clothing, food, and artifacts, can be easily seen and recognized by people of other cultures. Although cultural stereotypes may originate at this level, few cross-cultural misunderstandings occur at the objective cultural level. However, the subjective aspects of a culture, referring to values, ideals, attitudes, roles, etc., are less easily understood by people of other cultures and provide the basis for much misunderstanding between people of different cultures. Understanding and appreciating the subjective aspects of another culture can pose a great challenge to healthcare professionals. Despite this, achieving insight at this level is important in establishing appropriate rapport and therapeutic partnerships (Singh, McKay, & Singh, 1998). Specific cultures may have unique characteristics when we consider the four categories of nonverbal communication.

Kinesics

The study of kinesics, more commonly referred to as body language, includes examining body orientation (posture), eye contact, or any type of bodily movement. When we examine how people communicate through use of their kinesics, we can learn about a client's personality or their emotional state of mind (Hickson, et al., 2004). Much information can be determined from attention to body movements and facial cues, as many gestures carry an intended meaning. Several body movements may convey similar meaning. For example, in Euro-American cultures, gestures of smiling, laughter, engaged body position (forward lean or open posture), and frequent eye contact are perceived as conveying intimacy and non-dominance. In contrast, kinesics such as a stoic facial expression, staring or lack of eye contact, and a disengaged body position tend to convey dominance, disinterest, or emotional distance (Burgoon, Birk, & Pfau, 2006; Mehrabian & Williams, 1969) in Euro-American cultures.

Eye contact is a particularly important aspect of interpersonal communication and perception (Webster & Sundaram, 2009). The amount of eye contact considered to be "appropriate" varies widely from culture to culture. For example, a person from the United States might interpret lack of eye contact as a sign of anxiety, lack of interest, or even deception. In Western cultures, people are taught to show attention and interest by looking directly at the person they are addressing.

However, a Chinese American may interpret lack of eye contact as a sign of respect (McCarthy Veach, LeRoy, & Bartels, 2003). In some holistic cultures, people are taught that it is rude to look directly at others when talking to them, especially parents, elders, and other persons of high status (including health care providers) (Resta, 1992).

Proxemics

The study of proxemics refers to the perception and use of personal and interpersonal space between individuals (Sue & Sue, 2003). Clear norms exist concerning the use of physical distance in personal interactions. Four interpersonal distances have been established that are characteristic of Western culture: *intimate*, contact up to 18 in; *personal*, from 1.5 ft to 4 ft; *social*, from 4 ft to 12 ft; and *public* (lecture and speeches), greater than 12 feet (Hall, 1969).

Different cultures maintain different standards of personal space. Comfortable personal distances depend on social situations, gender, and individual preferences. These preferences must be interpreted against a given cultural framework (Esposito, 2007). Individuals from most Western cultures tend to prefer greater interpersonal distance than members of many other cultural groups. Latino/Latinas, Hispanics, and Middle Easterners may be more comfortable with less distance and may prefer seating arrangements that reflect that preference. For example, a person may not feel comfortable in a health care setting where a desk is placed between them and the person they are speaking to, while Euro-Americans may prefer to keep a desk between themselves and others (Sue & Sue, 2003). It is always best to let the client(s) choose where they would feel most comfortable in the genetic counseling setting.

Paralinguistics

The term paralanguage, also referred to as vocalics, is used to refer to other vocal cues that individuals use to communicate, other than words. For example, loudness of voice, pauses, silences, hesitations, rate, and voice inflections are all included under the term paralinguistics (Hickson, et al., 2004). Paralanguage coincides with conversation conventions such as how we greet and address others or take turns in speaking. It can communicate a variety of different features about a person, such as age, gender, and emotional responses, as well as the race and gender of the speaker (Banks & Banks, 1993).

There may be complex yet unspoken rules regarding when to speak or yield to another person. For example, in the U.S. people generally tend to feel uncomfortable with a pause or silent stretch in the conversation, and may feel obligated to fill it with more talk (Sue & Sue, 2003). From a genetic counseling perspective, silence should not be considered to be a sure sign for the counselor to take up the conversation. Many crucial indications as to how the other person is feeling or what they are thinking can be missed with persistent talking. People of British and Arab descent may use silence for privacy, while individuals of

Russian, French, or Spanish background tend to interpret silence as agreement among participants (Hall, 1969).

Another important aspect of paralinguistics is the amount of verbal expressiveness. The amount of verbal expressiveness in the U.S., relative to other cultures, is quite high. Most Euro-Americans are encouraged from a young age to enter into conversations, ask questions, and state their thoughts, feelings, and opinions. Individuals from other cultures may consider Euro-Americans to be arrogant, immodest, rude, and disrespectful based on differences in “acceptable” levels of verbal expressiveness (Sue & Sue, 2003). The volume at which people articulate their ideas, thoughts, and opinions can vary widely. In Asian countries, people tend to speak more softly and they may interpret the loud volume of an American visitor to aggressiveness, loss of self-control, or anger. When compared to Arabs, however, people in the U.S. may be considered to be soft-spoken (Sue & Sue, 2003).

Appearance

Physical appearance is another nonverbal element that plays an important role in the communication process. This area of nonverbal communication may be slightly uncomfortable to individuals who were taught “not to judge a book by its cover.” Because physical appearance may be the first nonverbal cue to be noticed, it can have a profound impact on relationships. Physical appearance communicates meaning and intent, which can lead to insight, or stereotypes (Hickson, et al., 2004). What is most important to remember is that there are two components to physical appearance: what you are trying to convey, and what is actually being received (Sue & Sue, 2003).

The type of attire considered appropriate for members of a culture varies. For example, for some women of the Islamic faith, it is viewed as inappropriate and sexually impure to reveal any skin. Therefore, the typical dress is a burka. However, in the U.S., dress is viewed as a form of self-expression and personal choice. The attire worn or the amount of skin shown often depends on the social situation.

Healthcare professionals need to consider the verbal and non-verbal cultural context of communication because they provide the basis for understanding and appreciating client behavior (Singh, et al., 1998). Nonverbal behavior is a valuable source of information for counselors, especially when concerning the client’s emotional state. However, it can easily become a source of misunderstanding when the counselor reacts inappropriately to nonverbal signals (Vogelaar & Silverman, 1984). Dynamics and intent of nonverbal communications can vary across generations. Communication methods change in emphasis and meaning as generations interact with other generations, more dominant cultures, and even with people of the same generation. Differences in communication methods are influenced by the degree to which people are immersed in traditional cultural practices (Singh, et al., 1998). Therefore, it is our

responsibility when striving to interact with patients in a culturally sensitive manner (Vogelaar & Silverman, 1984) to adapt our style of communication to the client’s style. Never expect clients to adapt to your style (McCarthy Veach, et al., 2003).

Deaf Culture and Communication

Consider the array of communication styles that people use on a daily basis. Our communication behaviors may be so routine that we forget that they are culturally-based specifically in the dominant hearing community. For example, nodding by the client, which often indicates understanding, cannot be used as a proxy to indicate comprehension when the client is deaf (Israel, et al., 1992). How open are you to considering the range of communication patterns that you might encounter? Consider how you might react to variations in communication that might be typical for individuals in the culturally Deaf community. The following table compares general communication styles and behaviors among members of the hearing community and the culturally Deaf community. While every individual is unique, consider your attitudes toward differences in communication styles.

	Hearing Community	Culturally Deaf Community
Mode of Communication	Words are produced by actions in the vocal tract that result in sounds.	Words are produced by actions of the hands, arms, face, and head that produce visual signals.
Nonverbal Communication	Facial expressions and body language convey emotional messages.	While nonverbal communication is also used to convey emotion, facial expression, eye gaze, and head movements take on grammatical meaning in ASL.
Introductions	When meeting someone for the first time, a limited amount of information is generally shared—such as names and location of current residence.	When two Deaf people meet, they will often share more detail/information than is common in the hearing culture. For example, they may share the city in which they grew up and/or the residential school attended.*
Getting Another Person’s Attention	To get another person’s attention, someone will say their name aloud. Touching a person to get his/her attention may be considered	Tapping individuals gently on the shoulder, waving hands, banging on things, flicking lights, and making vocal noises that are not

	impolite.	words are appropriate ways to get another person's attention.
Eye Contact	Eye contact is made for several seconds at a time. Staring is considered rude.	When communicating using sign language, eye contact is extremely important. Looking away is considered rude.
Privacy	Members of the hearing community usually expect their conversations to be kept private. Listening to other people's conversations is not socially acceptable.	Deaf people consider it impolite to be excluded from any conversation taking place in their presence. They prefer being included in any conversations, even those not directly relevant to them.
Environmental Sounds	Depending on the meaning, location and frequency, environmental sounds may be completely ignored, acknowledged by turning one's head toward the sound, or they may result in an expected behavior.	Deaf people cannot hear most or all environmental sounds. Sounds should be communicated to the person by pointing to the locus of the sound and speaking the accompanying word(s). **
Departures	In the hearing community, saying the word "goodbye" followed by physically departing is usually a quick process.	Departures and saying goodbye in Deaf culture can be a lengthy process. Before leaving, Deaf people will say goodbye to everyone in the room, which may lead to further conversation.

*Start American Sign Language. (2008). *Deaf Culture*, Retrieved from <http://www.start-american-sign-language.com/deaf-culture.html> on June 24, 2010

**from Meador, H. E., & Zazove, P. (2005). Health care interactions with deaf culture. *Journal of the American Board of Family Practice*, 18(3), 218-222.

High Context vs. Low Context Communication

Vivian Ota Wang (2009) and other authors distinguish between low and high context languages. Low context languages such as Danish, German and English convey information primarily through direct verbal and written communication, and background information must be made explicit. Other languages, such as Japanese, Chinese, Vietnamese, French, Spanish, and Greek are high context,

where the surroundings and the context are far more important than the literal meaning of the words, and the full message must be interpreted by the listener through nonverbal cues and indirect messages. Review these mini-exercises by Dr. Sangeeta Gupta to assess your preferred communication styles:

<http://www.guptaconsulting.com/docs/CrossCulturalSamplePage.pdf>

Do you tend to let your words speak for themselves or do you use a range of verbal and nonverbal cues? Don't assume that your preferences will match what your client needs to gain a clear understanding. As we explain later, ASL is a high-context language. Deaf people who use ASL are high context communicators who acquire knowledge from situations and by building relations between situations. This relationship building process depends on trust and takes time to build up.

Incidental Learning

Many d/Deaf individuals lack background health information, which can make it difficult for them to report medical events, understand medical terms, or self-advocate in the healthcare setting. People who are deaf have fewer opportunities for incidental learning, which is information that hearing people absorb by listening to conversations, the media, or other sources (Harmer, 1999). Growing up, children generally learn about family history and medical conditions by “overhearing” and talking with parents as topics come up. Deaf children may not experience incidental learning, especially if parents or providers find it difficult to communicate family and person health information. Since 90% of deaf individuals come from hearing families, there may have been fewer opportunities for individuals who are deaf to discuss their health care or personal family history. In addition, there may be fewer opportunities for incidental learning about health care through the TV or radio. Misunderstanding medical words is another reason that individuals who are deaf lack background health information, which can negatively influence all aspects of their health care. The average deaf high school graduate reads at a 4th grade level (Scheier, 2009), which means that deaf individuals are at greater risk for misunderstanding medical terms.

Perspectives on Deafness

We present two prevailing perspectives on deafness, the Pathological Model and the Cultural Model. Health care providers often view deafness through a pathological model, while the person who is deaf may view his/her lack of hearing through a cultural model.

Deafness as Pathology

The pathological model of deafness (also referred to as the medical model) posits that deafness is the pathological absence of hearing and that a hearing-impaired individual is disabled because of faulty hearing (Senghas & Monaghan, 2002). This model views deafness as a defect which needs treatment or correction. For example, a cochlear implant or hearing aid aims to restore hearing as much as possible, with the view that to be hearing is the preferred option (A Middleton, 2007). This view focuses on how deaf people are different from non-deaf people

and generally, these differences are viewed as limitations. In their training, physicians typically learn about hearing loss through courses that focus on etiology, detection, and treatment of hearing loss itself. Because of this, the physician is likely to view deafness through a pathological model, while the person who is deaf may consider the broader positive cultural and communication issues associated with deafness.

Deafness as Culture

People who perceive deafness through the cultural model do not view deafness as a disability, but simply as a linguistic minority. The “cultural” model views deafness as creating a different, not inferior, experience. In fact, many individuals who are deaf do not believe that their deafness should be corrected. Many deaf adults do not consider their lack of hearing as a problem. They lead rich and full lives and are proud to be deaf.

Communication problems can occur when individuals fail to appreciate these different worldviews. Individuals who are deaf may be wary of hearing people in general and health care providers in particular. This perspective may have developed from a lifetime of exposure to hearing people who perceive individuals who are deaf as disabled, impaired, and otherwise undesirable, and health care providers who typically focus on the pathology of hearing loss (Harmer, 1999). To learn more about discrimination of the deaf and the history of the development of American Sign Language, see the following website:

<http://www.aslinfo.com/trivia.cfm>.

Genetics of Hearing Loss

Approximately 1 in 1000 children in the United States are born with profound hearing loss, and approximately half of these cases are thought to be genetic in origin ("American College of Medical Genetics Statement: Genetics Evaluation Guidelines for the Etiologic Diagnosis of Congenital Hearing Loss," 2002). Of the cases that are considered to be genetic in origin, some children have hearing loss due to a genetic syndrome or a family history that includes several generations of deaf individuals (autosomal dominant hearing loss). However, most cases of genetic hearing loss will be autosomal recessive and non-syndromic. Genetic alterations in a family of genes called the connexins are largely responsible for non-syndromic, sensorineural hearing loss. The most common genetic alterations occur in the *GJB2* gene on chromosome 13, which codes for a protein called connexin 26. Genetic changes that alter the connexin 26 protein are called connexin 26 mutations. One in 33 Caucasians is a carrier of a cx26 mutation. The clinical presentation of cx26 hearing loss is variable, ranging from mild to profound even among members of the same family who inherited the same genetic alteration (Garrett, et al., 2006).

Newborn Screening and Early Intervention

Early diagnosis and intervention services have many benefits for children who are deaf, and facilitate acquisition of language skills. Multiple professional societies,

advocacy groups, and government agencies participating in the Joint Committee on Infant Hearing (JCIH) endorsed universal newborn hearing screening as an essential component of early detection and intervention for infants with hearing loss ("American College of Medical Genetics Statement: Genetics Evaluation Guidelines for the Etiologic Diagnosis of Congenital Hearing Loss," 2002). As of March 2010, newborn hearing screen is required by law in 36 states, and is available in all 50 states. Newborn hearing screening is performed with ABR (auditory brainstem response) or OAE (otoacoustic emissions) audiological tests. As with metabolic newborn screening, NBHS can miss some infants with mild hearing loss and will miss infants who will develop hearing loss later in childhood. It is also important to realize that false positives occur with NBHS, and follow up testing is important for any infant identified with a hearing loss by NBHS. For more information on newborn screening for deafness, visit the National Newborn Screening and Genetics Resource Center at <http://genes-r-us.uthscsa.edu/>.

Health Disparities

The National Health Interview Survey of 2006 found that adults who were deaf or hard of hearing were about three times as likely as adults with good hearing to be in fair or poor health and to have difficulty with physical functioning, and more than four times as likely as adults with good hearing to have experienced serious psychological distress (Schoenborn & Heyman, 2008). Diabetes and high blood pressure were more prevalent among adults who were deaf or had a lot of trouble hearing. Individuals who are deaf or hard of hearing also have higher rates of mental illness. The incidence of STDs, alcohol, and substance abuse are higher among deaf than among hearing individuals (Scheier, 2009).

Many of these health disparities may be exacerbated due to physician-patient miscommunication. Reasons miscommunication can occur include a lack of background health information, differences between patients' and providers' perceptions of deafness, limited English proficiency, and struggles with interpretation services. Patients who are deaf usually have no options for obtaining care from health professionals who are fluent in American Sign Language. Differences in language and culture between health professionals and Deaf patients, as well as a lack of knowledge of many health issues in the deaf community, can impede providers ability to make appropriate diagnoses as well as limit patients' understanding of information on prevention, treatment, and the potential consequences of failing to comply with recommended care ("Agency for Healthcare Research and Quality Health Care Innovations Exchange," 2009).

LEP and Interpreter Services

A person with "limited English proficiency" (LEP) does not speak English as his/her primary language and has a limited ability to read, speak, write, or understand English. Many d/Deaf people consider English to be their second language and are therefore considered to have LEP. In 2000, the President signed Executive Order 13166, "Improving Access to Services for Persons with Limited

English Proficiency.” http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=2000_register&docid=fr16au00-137.pdf

This Executive Order requires Federal agencies to examine the services they provide, identify any need for services to those with LEP, and develop and implement a system to provide those services so LEP persons can have access to them ("Federal Agency LEP Guidance and Language Access Plans,").

http://www.justice.gov/crt/lep/guidance/guidance_index.html

To provide quality healthcare to individuals who are deaf, it is essential to achieve effective client/provider communications. The Americans with Disabilities Act (ADA) of 1990 (<http://www.ada.gov/>) requires language accommodations for people who are deaf or hard of hearing in health care settings. However, it has been shown that many providers have limited understanding of the communication needs and preferences of deaf individuals and they tend to make erroneous assumptions about speechreading, the efficacy of written notes, and the health literacy skills needed in the health care setting (Harmer, 1999). Below is a list of various methods of communicating with people who are deaf and the benefits and limitations of each. Every deaf person is unique, and the method of communication that one deaf person prefers may not work for another. When planning language accommodation, it is important to ask the person with whom you will be communicating which method they prefer.

1) TDD (telecommunications device for the deaf) and TTY (teletypewriter): These terms describe an electronic device that converts digital electronic data produced by a computer to text communication, which can assist the distance communication with deaf clients. Users of these devices type messages back and forth to each other, and these messages are transmitted through a telephone line. The term TDD is often used for digital devices in which the text is shown on a computer screen, and the term TTY is often used for manual devices in which the text is printed out on a piece of paper, like a typewriter. These methods allow people who are deaf or hard of hearing to make and receive telephone calls. However, because sign language has no written form, English must be used for these methods of communication. A hearing counselor without access to a TDD or TTY can contact the deaf client using Relay where communication is assisted by a third party who listens to the hearing individual, types the message using a TTY for the deaf individual and then reads the deaf individuals response to the hearing person.

2) The video phone is another device used in place of the telephone for communication. The video phones allow two people to communicate using ASL. Similar to the TTY Relay, there is also video relay (VRS) to facilitate communication between hearing and deaf individuals. In general, deaf people who have access to video phone prefer using the video phone to using a TTY.

3) Written notes: The efficacy of written notes depends on the English language proficiency in the individual. A disadvantage of using written notes to

communicate is that information that would otherwise be spoken may not be written. Important information may be left out in the interest of time.

4) Speechreading: Some people with hearing loss rely on speechreading for communication. Using speechreading to communicate may result in miscommunication, as patients with no hearing usually read lips with only 40% accuracy (Davenport, 1977). The ability to speechread improves when an individual already has some hearing capability in place, thus, generally speaking, speechreading is not acquired by congenitally deaf persons. Speechreading may be particularly difficult in a medical setting when a patient is anxious or complex medical terms are being used. Read more about speechreading at

<http://www.agbell.org/docs/speechreading.pdf>

5) English sign system: In this method, messages are conveyed to the deaf person word for word in English by spelling out the word using hand signals. Again, this method assumes English language proficiency.

6) ASL (American Sign Language): The ASL interpreter relays information meaning for meaning, not word for word as with the English sign system. A challenge in using this method is that health-related vocabulary that might be familiar to an English speaker may not have a corresponding sign in ASL. It is helpful to meet with the ASL interpreter before a session to make sure that he/she is familiar with the medical terms and concepts that will be used with the patient.

Client Views on Genetics, Genetic Counseling, and Genetic Testing for Deafness

Culturally Deaf individuals may come into a genetic counseling session with preconceived views toward the genetic counseling process, which may be positive or negative. In one study, culturally Deaf participants were seven times more likely to use negative words rather than positive words to describe how they felt about new discoveries in genetics (A. Middleton, Hewison, & Mueller, 1998). In the same study, 55% of deaf/Deaf individuals answered that genetic testing would do more harm than good, 46% thought that its potential use devalued deaf people, and 49% were concerned about new discoveries in genetics. It is important for the genetic counselor to be aware of these biases. An individual's perceptions about genetic counseling may be influenced by the cultural definition of deafness, how the person views their own deafness, and their preferences for deaf or hearing children (Israel, Cunningham, Thumann, & Arnos, 1992).

In the past, schools for deaf children were referred to as schools for "the deaf and dumb." Deaf people were encouraged not to marry each other to avoid passing on the deafness to their children. Under the Nazi regime, deaf children and adults were ordered to be sterilized. Given the historical context to the misuse of genetic knowledge, it is no surprise that d/Deaf people are often suspicious of modern day genetics services. There is often a sense that genetics services in the past "devalued" the role of Deaf people in society (A Middleton, 2007).

There has been considerable discourse about reproductive decision making and the Deaf. Some d/Deaf individuals are reluctant to participate in genetic counseling at all for fear that they will be told not to have children. Some couples would welcome the birth of a deaf child ("American College of Medical Genetics Statement: Genetics Evaluation Guidelines for the Etiologic Diagnosis of Congenital Hearing Loss," 2002). One study suggested that Deaf individuals often do not have a preference for deaf or hearing children or an interest in prenatal diagnosis for hearing status (Enns, Boudreault, & Palmer, 2009). In another study, nearly two-thirds of hearing individuals expressed interest in attending a genetic counseling session before proceeding with genetic testing for deafness, but only 42% of the deaf/hard of hearing group expressed interest (Martinez, Linden, Schimmenti, & Palmer, 2003). The results of this study suggest a degree of hesitation in seeking genetic counseling services within the broader deaf and hard of hearing community. A culturally sensitive genetic counselor will provide information and services in a way that is open to different reproductive decisions and cultural perspectives.

No matter what the reason for referral for health care, providers need to be cognizant of past inequities in treatment of people with deafness, as these may influence the client's perspectives. Members of Deaf culture consider it important that geneticists and genetic counselors be familiar with their culture. In a national survey, when asked if the professional discussing genetic testing should be familiar with deaf culture, 95.4% of young deaf adults responded "yes" (Withrow, et al., 2009).

Cultural Empathy

Cultural empathy is the learned ability of counselors to understand accurately the self-experiences of clients from other cultures (Ridley & Lingle, 1996). Cultural empathy is based on three principles: 1) every client should be understood from their unique frame of reference, 2) normative information can be useful as background information but does not always fit a particular client, and 3) people are a mixture of multiple roles and identities (McCarthy Veach, et al., 2003).

Cultural empathy consists of two major processes: cultural empathetic understanding and cultural empathetic response.

Cultural empathetic understanding begins with striving for the goal of understanding each client as a unique individual. This means considering the meaning of each client's self-experience, including his or her feelings, attitudes, thoughts, values, motivations, coping style, and behaviors (Ridley & Udipi, 2002). This self-experience occurs in a cultural context, as people are the products of the culture in which they were raised, and the cultures they choose. Cultural empathetic understanding is the process through which counselors understand the self-experience of their culturally different clients.

Cultural empathetic responsiveness means utilizing that understanding in a way that lets the client know they are understood. If a client cannot detect the counselor's understanding, then the understanding holds no value for the therapeutic process. This means that the counselor must express himself or herself so that the meaning of their understanding is not lost in the communication process.

Genetic counselors can develop cultural empathy by becoming more familiar with individuals who are Deaf by participating in cultural immersion activities. Having experience with members of Deaf culture may make the genetic counselor more comfortable in the session and enhances cultural empathetic understanding. In a study of genetic counselors assessing attitudes toward deaf people and scenario-specific comfort levels discussing and offering genetic testing for deafness, respondents with deaf/Deaf friends had more positive attitudes toward deaf people than those without deaf/Deaf friends (Enns et al., 2009). More positive attitudes toward deaf people correlated with higher comfort level talking about genetic testing and correlated with a higher comfort level offering genetic testing to culturally Deaf clients wishing to have a deaf child. This study suggests that genetic counselors' attitudes toward deaf people may influence their level of comfort when interacting with culturally Deaf clients. This important finding is supported by evidence that attitudes and biases can influence both content and presentation of information relevant to decision-making and the options offered by health care providers.

Cultural Immersion Activities

To increase your comfort level interacting with deaf/Deaf individuals, the genetic counselor may wish to immerse himself/herself in the Deaf community. Find out more about what resources and activities are present in your community. To get to know the deaf/Deaf community in your area, consider attending a specific event, church services, or paying a visit to a school for the Deaf. Perhaps a local college offers ASL classes. Use these community institutions to find more information about events for members of the deaf community. Consider enhancing your understanding of Deaf culture and ASL by talking to ASL interpreters or taking a sign language class.

For a list of activities for the deaf, visit <http://www.ohsoez.com/>. The goal of this website is to make it easy for deaf, hard of hearing, interpreters, and friends of the deaf community to find out about deaf community and interpreter related events.

For further information or suggestions on how to meet members of the deaf community, see <http://www.deafnix.com/DeafCommunity/meet.html>.

There is currently only one known support group for Deaf breast cancer survivors in the country. The *Pink Deafies* group meets monthly at various community locations in the Minneapolis/St. Paul area. For more information, visit <http://www.tcdeaf.com/events/20100227pinkdeafies>

Preparing for the Cancer Genetic Counseling Session

In our case, Jean is a deaf woman who is seeking cancer genetic counseling. How should the genetic counselor approach the following case preparation activities for a cancer genetic counseling session with Jean?

- Send an information packet before the session
- Access medical records
- Request information about family members
- Prepare visual aids
- Gather information about genetic testing
- Identify educational materials

Here are some suggestions:

Send an information packet before the session

Describe genetic counseling

It is possible that Jean may be unfamiliar with the genetic counseling process or that she holds personal opinions about genetic counseling. One study showed that 49.5% of deaf and hard of hearing people did not know what genetic counseling was, and 28% thought that genetic counseling aims to reduce deafness in society (A Middleton, Emery, & Turner, 2010). Describing genetic counseling may make Jean more familiar with the process and better able to benefit from genetic counseling.

Plan extra time

When working with a deaf client who speechreads or communicates through an ASL interpreter, be sure to schedule plenty of extra time to cover the necessary information. Explicitly describe how much time the session may take in the information packet. It also may be necessary to meet in two face to face sessions. These options should be discussed with the client.

Access medical records

Request medical records before the session

As discussed, Jean may be unfamiliar with medical terms or have limited background health information. It may be especially important to get Jean's medical information before the session. A request for medical records should be sent to Jean's doctor. It is also critical to send a form eliciting Jean's health history before the session to give Jean plenty of time to access information about her health history. This limits the number of health and family history questions Ellen will have to ask Jean through the interpreter. Instead, Ellen will be able to focus on reviewing and clarifying the information provided on the form and discussing the important points with Jean.

Request information about family members

Collect family history prior to the session

In a cancer genetic counseling session, collecting a family history is crucial to conducting an appropriate risk assessment. As we discussed, when the patient is deaf, her knowledge of family history information may be limited. To help the client obtain this information, sending forms written at an appropriate reading level with questions about the client's family history enables the client to obtain input from family members as needed. Information about the client's family members may also need to be documented through requests for medical records. It makes sense to take care of most of this aspect of the session beforehand, to leave more time the parts of the session that must be facilitated by the ASL interpreter.

Prepare visual aids

Use a variety of counseling visual aids

Be sure to use counseling visual aids to complement the genetic counseling discussion. Pay attention to the words written on the aids to be sure they are not excessively complex. You may need to create new low literacy counseling aids. We typically assume that a genetic counseling client is proficient in English, although the average deaf high school graduate reads at a 4th grade level (Scheier, 2009). Visual aids may enhance communications within a genetic counseling session for a patient who is deaf, especially if they do not include excessive text. As this is a cancer genetic counseling session, it is also particularly important to use visual aids that help the client and counselor process the meaning of personal, predictive and family risks, as well as the risks/benefits of genetic testing options. Israel et al. (1992) suggests modifying "how and when" visual charts are used when working with deaf clients so the client will not miss valuable information when transitioning from one visual medium to another. For example, the counselor should first explain the content of the illustration orally through the interpreter, maintaining eye contact, and then proceed to use the visual aid.

Gather information about genetic testing

Plan to explore culturally-grounded views on genetic testing

The cancer genetic counseling session typically involves a discussion of genetic testing. Given the sensitivity of individuals who are deaf regarding genetic testing for deafness itself, the genetic counselor should allow the client to express her views on genetic testing in general.

Identify educational materials

Use literacy and culturally appropriate educational materials

Consider the ability of your patient to understand any written information you use in the session and additional educational materials you plan to give her to take home. It may be helpful to ask Jean general questions to get a general sense of her health literacy. However, determining literacy and health literacy levels in individuals who are deaf does not correlate with health literacy levels of comparable non-English speakers. People who are deaf cannot sound out words, a technique that hearing people use to figure out the meaning of unfamiliar words (<http://www.healthliteracy.com/article.asp?pageID=3772>). The genetic counselor

should not assume that standardized tests of health literacy in adults, such as the TOFHLA (Test of Functional Health Literacy in Adults) apply to deaf clients. Indeed, there is little research on assessing health literacy in deaf adults. The counselor should turn to the ASL interpreter for assistance in determining the appropriateness of any educational materials for clients who are deaf. Take advantage of educational materials that have been developed in signed language if this is the client's preferred method of communicating. The <http://www.deafmd.org/> website provides health information in American Sign Language for the Deaf and hard of hearing population. This website describes tests such as mammography and colonoscopy that are relevant to cancer genetic counseling sessions.

Other considerations

Meet with the interpreter

If there has been an interpreter assigned to the case, it is appropriate for the genetic counselor to meet with the interpreter before the session. Medical interpreters may be knowledgeable about some of the procedures involved in a genetic counseling appointment, but they may have limited exposure to the specific genetic terminology needed in this case. Meeting the interpreter before the appointment to review the counseling process and any anticipated genetic terms will facilitate communication during the session. Some interpreters may find it useful to have a list of words and their meanings prior to the counseling session.

In 1983, Gallaudet College published a booklet "Signs for Genetic Counseling" (Boughman & Shaver, 1983) to attempt to standardize some signs that are commonly used in genetic counseling (gene, genetics, chromosome, dominant, recessive, X-linked, pedigree, Usher syndrome, Rubella syndrome, Down syndrome, Waardenburg syndrome, amniocentesis). This short booklet is no longer in print, although it is available from the Gallaudet University Archives, 800 Florida Ave., N.E., Washington, DC 20002 for a nominal printing fee. Visit <http://archives.gallaudet.edu/>.

Currently, there are many online resources available to help counselors communicate in ASL with clients who are deaf. Suggested sites that may enhance your learning are listed below. Try to learn some simple signs, such as how to introduce yourself. Your efforts will mean a lot to the client.

http://www.youtube.com/watch?v=sWZFMG3df_A&feature=channel
(introducing yourself)

<http://aslstem.cs.washington.edu/topics/view/409>
(genetics topics)

<http://www.lifeprint.com/>

(American Sign Language University; numerous topics)

<http://commtechlab.msu.edu/sites/aslweb/browser.htm>

(American Sign Language browser; numerous topics)

Collaborate with the interpreter

If you know that a deaf patient prefers to communicate in ASL, a trained ASL interpreter should be seamlessly integrated into the dynamics of the genetic counseling session. It is important to use a trained interpreter rather than family members or friends. The interpreter will want to sit a little behind and to the side of the genetic counselor to allow the patient to clearly see both the interpreter and the counselor, and to speechread if desired. As we discussed earlier, the interpretation of nonverbal cues is particularly important when working with clients who are deaf. Ask the interpreter to point out potential misunderstandings.

Send a patient letter

It may also be helpful to send a detailed summary letter to clients with whom you have communicated primarily through an interpreter. The letter may include a written summary of the session, as well as a copy of the visual aids that were used. The letter provides another opportunity to clearly and logically present factual information using simple words and to summarize your understanding of what happened during the session. Be sure to encourage the client to forward any questions or concerns.

Risk Assessment/Counseling

Risk communication is the two way exchange of information and opinion about risk, leading to better understanding and decisions (Edwards, Elwyn, & Mulley, 2002; Sivell et al., 2008). This complex set of tasks is integral to the general genetic counseling process. However, the relative importance of risk communication in a particular genetic counseling session may be major or minor (Michie, Lester, Pinto, & Marteau, 2005). Current genetic counseling job tasks were determined by the American Board of Genetic Counseling as the outcome of a Genetic Counseling Practice Analysis (Hampel et al., 2009). The following lists the **Risk Assessment** and **Risk Counseling** tasks:

A. RISK ASSESSMENT

1. Analyze Pedigree
 - a. Assess etiology (e.g., hereditary, familial, sporadic)
 - b. Determine mode of inheritance
 - c. Identify ethnicity and consanguinity based risks
2. Integrate medical, laboratory, and genetic information
3. Modify differential diagnosis
4. Perform Quantitative Risk Assessment
5. Select risk assessment model based on client data (e.g., empiric data, Bayesian analysis, Gail model)
6. Calculate risk (e.g., personal health, reproductive, susceptibility)

B. DIAGNOSIS AND NATURAL HISTORY DISCUSSION

1. Formulate counseling agenda
2. Integrate natural history, characteristics, and symptoms of working diagnosis
3. Incorporate client specific findings and needs
4. Develop management plan
5. Convey information about the following:
 - a. diagnosis/indication
 - b. etiology
 - c. natural history
 - d. variable expressivity
 - e. penetrance
 - f. prognosis
 - g. prevention
 - h. treatment
 - i. management
6. Assess client understanding and response
7. Tailor management plan according to client circumstances
8. Modify counseling based on client's understanding and response

C. INHERITANCE/RISK COUNSELING

1. Educate clients about
 - a. basic genetic concepts
 - b. modes of inheritance
2. Counsel clients about the following
 - a. genetic risks (e.g., carrier, reproductive, predictive)
 - b. risk modifiers
 - c. disease risks
3. Evaluate client risk perception and response
4. Address client misconceptions about their risks
5. Modify counseling based on client's understanding and response

Cancer Risk Assessment/Counseling and Cultural Competence

In 2004, the National Society of Genetic Counselors presented a set of practice recommendations for genetic counselors conveying cancer genetic risk assessment and counseling (Trepanier et al., 2004). A variety of information is collected to assess the client's perceived estimate of personal cancer risk and the methods by which decisions are made. Such information may include but is not limited to the following:

- 1) Motivations for seeking a cancer risk consultation
- 2) Beliefs about cancer etiology and perception of risk
- 3) Ethnocultural information
- 4) Socioeconomic and demographic information

- 5) Psychosocial factors
- 6) Cancer screening
- 7) Health behaviors
- 8) Coping strategies

To assess Jean's risk perception, what questions would you ask?

Example:

1) Phrase a question to ask Jean to assess her motivations for seeking a cancer risk consultation.

Q: _____

Example: What is your understanding of why you were referred for genetic counseling today? How do you feel about being here?

2) Phrase a question to assess Jean's beliefs about her perceived risk of cancer.

Q: _____

Example: What do you think your chance is of developing breast cancer?

3) Phrase a question you would ask Jean to get a better understanding of her cultural framework.

Q: _____

Example: Do you identify with a particular culture? Please tell me about your culture.

4) Phrase a question to assess Jean's socioeconomic and demographic information.

Q: _____

Example: Who lives at home? Tell me about your home life.

5) Phrase a question to assess Jean's psychosocial support.

Q: _____

Example: Who have you talked to about this appointment?

6) Phrase a question to assess Jean's cancer screening practices.

Q: _____

Example: Tell me about when and why you visit the doctor.

7) Phrase a question to assess Jean's health behaviors.

Q: _____

Example: Jean, how would you describe your health? What do you do to stay healthy?

8) Phrase a question to identify Jean's coping strategies.

Q: _____

Example: How do you usually deal with stressful events in your life?

Cultural competency is a set of skills, knowledge, and attitudes that enhances a clinician's understanding of and respect for a patient's values, beliefs, and experiences; awareness of one's own assumptions and value system; and ability to adapt care to the patient's expectations and preferences. The PRACTICE mnemonic was developed to help health care providers integrate cultural competency skills in genetics into primary care (Reynolds et al., 2005). Let's consider how a typical cancer counseling session aligns with the format of PRACTICE. We've inserted typical topics of discussion in the cancer counseling session under each section of the PRACTICE mnemonic framework. We encourage you to consider ways to incorporate PRACTICE into your genetic counseling caseload.

Prevalence Prevalence of a disease in the population, and known statistics and racial disparities in disease prevalence and mortality

Breast cancer is a common disease, and 1 in 8 women will develop breast cancer in her lifetime.

Risk Risk that a disease has a genetic basis

About 5-10% of breast cancer is associated with hereditary cancer syndromes. Certain ethnic groups, such as individuals who are Ashkenazi Jewish, are more likely to have breast cancer due to a hereditary syndrome than others. Questions about the patient's health and family history provide critical information for ruling out specific genetic causes of breast cancer and for determining risks.

Attitude Attitudes of physicians and patients and how these influence the delivery of genetic services

The attitudes of physicians can determine which patients are referred for breast cancer genetic counseling. The attitudes of patients can determine whether they will utilize genetic counseling services. Previous experiences in health care settings can lead patients to trust or distrust health care providers. These experiences will be influenced by factors such as language, discrimination, communication, and other cultural factors of the patient and providers.

Communication Communication bridges and barriers with attention to the use of schematic illustrations and interpreters for difficult to understand concepts

Be sure to utilize interpreter services for individuals with limited English proficiency. Cancer genetic counseling sessions incorporate a variety of risk estimates such as percentages, odds, and ranges. Describe risks in multiple ways and with visual aids to help the client understand. Check client understanding and perceptions using different counseling strategies, including asking open ended questions, and asking the patient to describe her understanding of the content and/or her options (teach back).

Testing Testing with references to sensitivity and specificity and positive predictive value of genetic testing for a specific disorder

Genetic testing for hereditary breast and ovarian cancer genes will identify about 90% of mutations.

Investigation Investigation of the family history focusing on clues for inherited disorders; discussion on how culture influences available family history information

An accurate family history is crucial to the genetic counseling cancer risk assessment. A patient's culture and family dynamics may influence what information is reported to the provider.

Consent Consent for testing and whether there are cultural preferences for oral versus written consent; and exploration of who makes decisions and who keeps medical information within families

The genetic counselor must consider cultural preferences for obtaining consent, including the appropriateness and ability of the ASL interpreter to translate the consent form. The provider should determine the patient's preferences for involving others in the consent process.

Empowerment Empowerment of the patient to take ownership of the decision whether or not to undergo genetic testing

The decision to undergo genetic testing is an individual choice that depends on many personal factors, such as cultural values, beliefs and experiences. The genetic counselor supports each client's personal worldviews and how they impact genetic testing decisions.

Presenting Risk Information

Smerecnik et al. (2009) suggest that genetic counselors provide context to help clients understand risk information, using both verbal and numerical risk estimates to communicate personal risk information, and visual aids to enhance communication of numerical risk information. Information and services should be

provided in a fashion that is sensitive to different reproductive choices or cultural differences. For example, in genetic counseling, word choice can convey bias. The word “risk” can have negative connotations. It is preferable to use the word “chance” instead. Smerecnik et al. also suggest that counselors first present accurate, objective numerical risk estimates verbally and with visual aids first, then ask the client what the risk estimate means to him/her, continuing on to a discussion of the meaning and impact to the client of the risk information.

While proportions are commonly used in genetic counseling to express risk, they are more difficult to understand than rates regardless of the clients’ age, language, and education (Grimes & Snively, 1999). Because “innumeracy, the mathematical equivalent of illiteracy” also presents a challenge, alternative ways of conveying risk should be used. Most risk information is provided as numbers alone or as numbers with narrative translations. Lipkus and Hollands (1999) summarized various ways to visually communicate risk, including risk ladders, stick and facial features, graphs, dot formats, pie charts, and histograms. Research on the effectiveness and influence of various formats is lacking, although it is known that risk ladders are effective at conveying magnitude and range of risk, based on the positioning on the ladder; stick figures, faces, asterisks and histograms may induce risk aversion when added to numbers; and people have difficulty understanding low probability events, even with the aid of visuals. Lipkus suggests that research is needed to examine which graphics and visuals are best matched to particular risk communication tasks.

As we noted, the word “risk” implies that the outcome is a disadvantageous or an adverse event. Palmer and Sainfort describe a historical shift in the genetic counseling profession from measuring the magnitude of risk on a objective level (numeric recurrence risk numbers) to a subjective level (interpretation of risk is uniquely defined by the person) (Palmer & Sainfort, 1993). Furthermore, the psychological process of *risk perception* transforms risk information into an individual’s unique perspectives influenced by the counselee’s life experiences and other sources of information (Uhlmann, Schuette, & Yashar, 2009). Risk is a complex entity that is “lived and experienced” (Sivel et al., 2008). It has been suggested that the best way of risk communication depends on the individual client and the aims of the genetic counseling session (Fransen, Meertens, & Schrandt-Stumpel, 2006). The literature is sparse in terms of research with a focus on different cultures or ethnic minorities and risk communication, presentation and perception (Sivell et al., 2008). Botorff et al. (1998) cite the following factors that may influence the interpretation of risk information: temporal factors, intelligence, gender, cultural or ethnic identity, religiosity, as well as readiness to receive information, mood, personal experiences and understanding of general population risks.

Assessing Perception of Risk

Risk perception is a complex concept that captures the varied meanings that an individual attaches to being at increased risk. Genetic risks are often

underestimated and overestimated (Fransen, Meertens, & Schrandt-Stumpel, 2006). Understanding the factors influencing risk perception and how these factors relate to behavior change is a goal of the genetic counseling risk assessment and counseling process (Pilarski, 2009). Perceived risk may influence choices to access testing; inaccurate risk perceptions may lead to inappropriate choices. Watson et al. (1998) found a poor correlation between objective risk level of developing breast cancer recalled by women who had cancer genetic counseling and their perceived risk. The authors surmised that precise risk figures may be less important to women than having a general perception of their risk and a sense that this risk is manageable. While many individuals may find it difficult to quantify their cancer risks, accurate risk recall does not necessarily provide insight into the clients' understanding of his/her risk nor the meaning attributed to it (Sivell, et al., 2008). Sensitivity and interpersonal skills of the counselor are important components of effective cancer risk communication (Bottorff et al., 1998), which creates even more of a challenge when working with clients who are deaf.

Positive and negative message framing and dichotomous interpretation by the client that an event or outcome will/will not happen, at either a high/low level, create a disconnect between the counselor's task of explaining uncertainty with words and visual aids, and the client's inclination to assign personally meaningful certainty to risk (Lippmann-Hand & Fraser, 1979; Bottorff et al., 1998; Hunt, Castaneda, & de Voogd, 2006). Failure to highlight the varied and contrasting meanings of risk articulated by client/provider dyads can undermine clinical communication, informed consent, and true patient-centered counseling and decision making (Hunt, Castaneda, & de Voogd, 2006). Patients in Hunt's 2006 study of private and public genetic specialty clinics did not weigh relative probabilities related in prenatal counseling sessions but reacted to risk with a sense that their baby was endangered. For these patients, it seems that "the at-risk concept was not understood to mean that something *could* be wrong, but that something actually *was* wrong." The authors conclude that differences in clinical and personal meanings are not just a failure of effective transfer of information, but due instead to much deeper conceptual issues.

Austin (2010) eloquently describes the genetic counselor's task as far more complicated than "assessing recall of objective numerical probability as the sole measure of whether or not our risk communication is effective." The counselor is challenged to actively explore the many factors that may contribute to client risk perception, including the information shared in a genetic counseling session, but certainly not limited to that snippet of information. This approach to understanding client perspectives about risk, and other topics in a genetic counseling session, is consistent with culturally responsive counseling. Culturally responsive genetic counseling takes place when the counselor learns from the client, to help the client gain personally meaningful information and make the best decision for her unique situation.

Summary: Risk Assessment and Counseling

Risk assessment and counseling are core tasks in the genetic counseling process. These tasks require the genetic counselor to use versatile approaches and skills, while maintaining awareness of personal perceptions that could lead to bias in the counselor's choice of how/what information is shared with specific clients. Simultaneously, the counselor must listen *and* watch carefully for the client's reactions. Interpretation of risk is "in the eye of the beholder," based on the client's unique past experiences, learning opportunities, etc. This case points out that most individuals who are deaf have grown up in a unique learning environment in special schools and without the benefit of incidental learning cues from the hearing community. The counselor will want to keep the discussion simple and straightforward without using complex terminology or Western culturally-grounded clichés that do not translate into ASL. Ellen will need to modify her typical counseling procedures, and even her mannerisms. Ellen should maintain eye contact with Jean as much as possible, modify the way she typically uses a counseling aids book, and not rely on Jean's head nods as confirmation of her understanding.

The counselor's attention to, and interpretation of, client non-verbal communication cues should be filtered through the context of *the client's* cultural framework. This case illustrates the importance of knowing about acceptability in the Deaf community of certain non-verbal cues. In our case, Ellen might have felt surprised, or even scared, when Jean banged on the table. If Ellen had known more about the culturally Deaf community, she might have considered other interpretations for this behavior. Perhaps Jean was simply trying to get Ellen's attention. Rather than rush through the remaining intake questions, it would have been more appropriate for Ellen to check her own body language (to be sure she is maintaining eye contact and conveying interest in the client), and to use cultural empathy. Ellen should focus on building trust with Jean, and reinforcing the importance of the counselor/client partnership. Perhaps Ellen could have said: "Jean, I appreciate your being patient with me. I am not accustomed to communicating through an ASL interpreter. How can I do a better job of understanding and responding to your needs? Thank you for teaching me!"

Cultural Competence

- Self assess on knowledge, feelings, and attitudes towards people who deaf.
- Consider how your attitudes and beliefs can affect risk communication in genetic counseling.
- Consider your focus on verbal vs. non verbal communication in genetic counseling sessions.

- Be sensitive and listen to your clients. Ask clients to express preference for terms (hearing loss, deaf, hard of hearing). The term hearing “impaired” should not be used.
- Send an information packet and forms before the session.
- Plan for extra time for taking medical and family histories and counseling.
- Ask clients how they prefer to communicate. If a certified ASL interpreter will facilitate the session, meet with the interpreter before the session to review terminology, etc.
- Be sure your office is well lit, limit visual distractions, keep objects away from your mouth, and speak directly to the client.
- Deaf people are high context communicators. Allow them to share information or ask questions that may not seem directly relevant, but that may help them integrate the information into their world.
- Use neutral language. Use chance vs. risk. Use condition vs. disease.
- Use cultural mnemonics such as PRACTICE to explore the patient’s understanding, concerns, and interest in genetic tests.
- Prepare and use visual aids. First, explain the content of the illustration orally through the interpreter, maintaining eye contact, allow the client time to study the visual aid, and then proceed to explain the concept using the visual aid.
- Send a written summary of the session using principles of low health literacy.
- Find ways to step deeper into the world of Deaf culture.

References

- Agency for Healthcare Research and Quality Health Care Innovations Exchange. (2009). *Deaf Community Health Workers Provide Education and Support to Deaf Patients, Facilitating Access to Linguistically and Culturally Appropriate Care, Improving Patient Health Knowledge and Adherence to Recommended Care*. Retrieved from <http://www.innovations.ahrq.gov/popup.aspx?id=2757&type=1&name=print> on June 24, 2010
- American College of Medical Genetics Statement: Genetics Evaluation Guidelines for the Etiologic Diagnosis of Congenital Hearing Loss. (2002). *Genetics in Medicine*, 4(3), 162-171.
- Austin, JC. (2010). Re-conceptualizing Risk in Genetic Counseling: Implications for Clinical Practice. *Journal of Genetic Counseling* 19: 228-234.
- Banks, J., & Banks, C. (1993). *Multicultural Education*. Boston: Allyn & Bacon.
- Bottorff, J., Ratner, P., Johnson, J., Lovato, C., & Joab, S. (1998). Communicating Cancer Risk Information: The Challenges of Uncertainty. *Patient Education and Counseling*, 33, 67-81.
- Burgoon, J., Birk, T., & Pfau, M. (2006). Nonverbal behaviors, persuasion, and credibility. *Human Communication Research*, 17(1), 140-169.
- Carteret, M. (2008). Non-Verbal Behavior in Cross-Cultural Interactions. Accessed on 7/20/10 from <http://dimensions of culture.com>
- Davenport, S. (1977). Improving Communication with the Deaf Patient. *The Journal of Family Practice*, 4(6), 1065.
- Edwards, A., Elwyn, G., & Mulley, S. (2002). Explaining Risks: Turning Numerical Data into Meaningful Pictures. *British Medical Journal*, 324, 827-830.
- Enns, E. E., Boudreault, P., & Palmer, C. G. (2009). Examining the Relationship Between Genetic Counselors' Attitudes Toward Deaf People and the Genetic Counseling Session. *Journal of Genetic Counseling*, 19(2), 161-173.
- Esposito, A. (2007). Nonverbal Communication as a Factor in Linguistic and Cultural Miscommunication. *Fundamentals of Verbal and Nonverbal Communication and the Biometric Issue*.

- Federal Agency LEP Guidance and Language Access Plans. (May 11, 2010). *Limited English Proficiency: A Federal Interagency Website* Retrieved from http://www.justice.gov/crt/lep/guidance/guidance_index.html on June 2, 2010
- Fransen, M., Meertens, R., & Schrandt-Stumpel, C. (2006). Communication and Risk Presentation in Genetic Counseling: Development of a Checklist. *Patient Education and Counseling*, 61(1), 126-133.
- Garrett, J., Harvey, E., McInemey, J., McNeilly, L., Neils-Strunjas, J., Stanton, S., et al. (2006). Genetics in the Practice of Speech Language Pathology and Audiology. *Connexin 26 Genes and Hearing Loss*, Retrieved from <http://shla.nchpeg.org/site.asp>
- Grimes, D., & Snively, G. (1999). Patients' Understanding Medical Risks: Implications for Genetic Counseling. *Obstetrics and Gynecology*, 93(6), 910-914.
- Hall, D. (1969). *The hidden dimension*. New York: Doubleday.
- Hampel, H., Grubs, R., Walton, C., Nguyen, E., Breidenbach, D., & Nettles, S. (2009). Genetic Counseling Practice Analysis. *Journal of Genetic Counseling*, 18(3), 205-216.
- Harmer, L. (1999). Health Care Delivery and Deaf People: Practice, Problems, and Recommendations for Change. *Journal of Deaf Studies and Deaf Education*, 4(2), 73-110.
- Hickson, M., Stacks, D., & Moore, N. (2004). *Nonverbal Communication: Studies and Applications*. Los Angeles: Roxbury Publishing Company.
- Hu, Y. (2007). Nonverbal Communication and Its Translation. *Canadian Social Science*, 3(4), 77.
- Israel, J., Cunningham, M., Thumann, H., & Arnos, K. (1992). Genetic Counseling for Deaf Adults: Communication/Language and Cultural Considerations. *Journal of Genetic Counseling*, 1(2), 135-153.
- Kehl, K. A., & Gartner, C. M. (2009). Can You Hear Me Now? The Experience of a Deaf Family Member Surrounding the Death of Loved Ones. *Palliative Medicine*.
- Lipkus, I., & Hollands, J. (1999). The Visual Communication of Risk. *Journal of the National Center Institute Monographs*, 25, 149-163.
- Martinez, A., Linden, J., Schimmenti, L., & Palmer, C. (2003). Attitudes of the Broader Hearing, Deaf, and Hard-of-Hearing Community Toward Genetic Testing for Deafness. *Genetics in Medicine*, 5(2), 106.

- McCarthy Veach, P., LeRoy, B., & Bartels, D. (2003). *Facilitating the Genetic Counseling Process: A Practice Manual*. New York: Springer.
- Mehrabian, A., & Williams, M. (1969). Nonverbal Concomitants of Perceived and Persuasiveness. *Journal of Personality and Social Psychology*, *13*(1), 37-58.
- Michie, S., Lester, K., Pinto, J., & Marteau, T. (2005). Communicating Risk Information in Genetic Counseling: An Observational Study. *Health Education and Behavior*, *32*(5), 589-598.
- Middleton, A. (2007). Attitudes of Deaf People and Their Families Towards Issues Surrounding Genetics. *Genes, Hearing and Deafness: From Molecular Biology to Clinical Practice*, 163.
- Middleton, A., Emery, S., & Turner, G. (2010). Views, Knowledge, and Beliefs about Genetics and Genetic Counseling among Deaf People. *Sign Language Studies*, *10*(2), 170-196.
- Middleton, A., Hewison, J., & Mueller, R. F. (1998). Attitudes of Deaf Adults Toward Genetic Testing for Hereditary Deafness. *American Journal of Human Genetics*, *63*(4), 1175-1180.
- Osborne, H. (2003). In Other Words... Communicating About Health with ASL. Retrieved from <http://www.healthliteracy.com/article.asp?PageID=3772> on June 24, 2010
- Palmer, C., & Sainfort, F. (1993). Toward a New Conceptualization and Operationalization of Risk Perception within the Genetic Counseling Domain. *Journal of Genetic Counseling*, *2*(4), 275-294.
- Pilarski, R. (2009). Risk Perception Among Women at Risk for Hereditary Breast and Ovarian Cancer. *Journal of Genetic Counseling*, *18*(4), 303-312.
- Resta, R. (1992). The Twisted Helix: An Essay on Genetic Counselors, Eugenics, and Social Responsibility. *Journal of Genetic Counseling*, *1*(3), 227-243.
- Reynolds, P., Kamei, R., Sundquist, J., Khanna, N., Palmer, E., & Palmer, T. (2005). Using the PRACTICE Mnemonic to Apply Cultural Competency to Genetics in Medical Education and Patient Care. *Academic Medicine*, *80*(12), 1107.
- Ridley, C., & Lingle, D. (1996). Cultural Empathy in Multicultural Counseling: A Multidimensional Process Model. In P. Pedersen, J. Draguns, W. Lonner & J. Trimble (Eds.), *Counseling Across Cultures* (4 ed., pp. 21-46): Thousand Oaks: Sage.

- Ridley, C., & Udipi, S. (2002). Putting Cultural Empathy into Practice. In P. Pedersen, J. Draguns, W. Lonner & J. Trimble (Eds.), *Counseling Across Cultures* (5 ed., pp. 317–333): Thousand Oaks: Sage.
- Scheier, D. B. (2009). Barriers to Health Care for People with Hearing Loss: A Review of the Literature. *Journal of New York State Nurses Association*, 40(1), 4-10.
- Schoenborn, C., & Heyman, K. (2008). *Health Disparities Among Adults with Hearing Loss: United States, 2000-2006*: Centers for Disease Control and Prevention.
- Senghas, R., & Monaghan, L. (2002). Signs of their Times: Deaf Communities and the Culture of Language. *Annual Review of Anthropology*, 31(1), 69-97.
- Singh, N., McKay, J., & Singh, A. (1998). Culture and Mental Health: Nonverbal Communication. *Journal of Child and Family Studies*, 7(4), 403-409.
- Sivell, S., Elwyn, G., Gaff, C., Clarke, A., Iredale, R., Shaw, C., et al. (2008). How Risk is Perceived, Constructed, and Interpreted by Clients in Clinical Genetics, and the Effects on Decision Making: Systematic Review. *Journal of Genetic Counseling*, 17, 30-63.
- Smerecnik, C., Mesters, I., Verweij, E., de Vries, N., & de Vries, H. (2009). A Systematic Review of the Impact of Genetic Counseling on Risk Perception Accuracy. *Journal of Genetic Counseling*, 18(3), 217-228.
- Sue, D., & Sue, D. (2003). *Counseling the Culturally Diverse: Theory and Practice*: Wiley New York.
- Trepanier, A., Ahrens, M., McKinnon, W., Peters, J., Stopfer, J., Grumet, S., et al. (2004). Genetic Cancer Risk Assessment and Counseling: Recommendations of the National Society of Genetic Counselors. *Journal of Genetic Counseling*, 13(2), 83-114.
- Uhlmann, W., Schuette, J., & Yashar, B. (2009). *A Guide to Genetic Counseling*: Wiley-Blackwell.
- Vogelaar, L., & Silverman, M. (1984). Nonverbal Communication in Crosscultural Counseling: A Literature Review. *International Journal for the Advancement of Counselling*, 7, 41-57.
- Wang, V. (2009). Patient Education and Communication. *Innovations in Service Delivery in the Age of Genomics: Workshop Summary*. National Academy of Sciences, Retrieved from <http://www.nap.edu/catalog/12601.html>

- Watson, M., Duvivier, V., Wade Walsh, M., Ashley, S., Davidson, J., Papaikonomou, M., et al. (1998). Family History of Breast Cancer: What do Women Understand and Recall about their Genetic Risk? *Journal of Medical Genetics*, 35(9), 731.
- Webster, C., & Sundaram, D. (2009). Effect of Service Provider's Communication Style on Customer Satisfaction in Professional Services Setting: The Moderating Role of Criticality and Service Nature. *Journal of Services Marketing*, 23(2), 103-113.
- Withrow, K., Tracy, K., Burton, S., Norris, V., Maes, H., Arnos, K., et al. (2009). Provision of Genetic Services for Hearing Loss: Results from a National Survey and Comparison to Insights Obtained from Previous Focus Group Discussions. *Journal of Genetic Counseling*, 18(6), 618-621.
- Woodward, J. (1972). Implications for Sociolinguistic Research among the Deaf. *Sign Language Studies*.

Assessment and Evaluation Questions
Risk Assessment/Counseling and Deaf Culture

1. True/False

Incidental learning refers to learning about trivial events in the community.

2. True/False

Cultural empathy is a counseling strategy that can be used in any genetic counseling session.

3. True/False

PRACTICE is a new assessment tool for determining a patient's risk for breast cancer.

4. True/False

The TOFHSA screening tool provides an accurate assessment of health literacy in deaf adults.

5. True/False

American Sign Language interprets English word for word from spoken and written communications.

6. True/False

Studies have shown that individuals who are Deaf are more likely to hold biases against genetic testing and genetic services in general.

For questions 7-12, please read Israel, J., Cunningham, M., Thumann, H., & Arnos, K. (1992). Genetic Counseling for Deaf Adults: Communication/Language and Cultural Considerations. *Journal of Genetic Counseling*, 1(2), 135-153.

7. True/False

Genetic counseling does not benefit individuals with known environmental causes of hearing loss.

8. True/False

Knowledge of and/or proficiency in one type of manual communication indicates that a person can communicate effectively using another type of sign language.

9. True/False

The type of school the person attends, the communication mode used, and the interactions with other deaf peers and adults in school and at home all contribute to a deaf person's acquisition of spoken, written, and/or manual language.

10. True/False

Deaf persons' cumulative experiences through family and school environments and their social interaction with deaf and hearing peers and adults shape their cultural perspectives.

11. True/False

An "all important" value of Deaf culture is respect for its language—ASL.

12. True/False

The fact that a deaf person does not use speech indicates the person's inability to use speech.

The following questions are for CEU learners only:

1. I feel I have achieved the following objective as a result of this learning activity:

Discuss the meaning of disability referring to the pathological and cultural models.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

2. I feel I have achieved the following objective as a result of this learning activity:

Identify the four main types of nonverbal communication and their impact on the overall communication process.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

3. I feel I have achieved the following objective as a result of this learning activity:

Explain incidental learning and its relevance to genetic counseling.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

4. I feel I have achieved the following objective as a result of this learning activity:

Explain how to use the PRACTICE mnemonic in genetic counseling.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

5. Please rate the overall effectiveness of this case in promoting learning.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

6. Please rate the overall quality of this case.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

7. The content of this case was presented without bias of any commercial drug or product.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

8. The technology used was appropriate and effective.

4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all

Disclaimer

The purpose of the Genetic Counseling Cultural Competence Toolkit (GCCCT) is to improve the delivery of culturally responsive, client-centered genetic counseling to diverse populations and to reduce health disparities. The GCCCT is an educational resource; any suggestions do not define the standards of clinical or educational practice. All cases and scenarios are hypothetical. The

JEMF, NSGC and Nancy Steinberg Warren, MS, CGC will not be liable for any medical or psychosocial applications connected with the use of or reliance upon any information obtained from this website or associated links and resources.

This work has been supported by the Jane Engelberg Memorial Fellowship, the 2009 grant from the Engelberg Foundation to the National Society of Genetic Counselors, Inc.

© 2010 Nancy Steinberg Warren, MS, CGC, all rights reserved.

