



DiversityRx 'Your Voice' Webinar Series: Webinar #9

Another “Double Helix”: Language and Cultural Challenges in Genetic Counseling Encounters

Monday, June 14, 2010

Additional Q&A answered by the speakers post-webinar

General:

Q: I work in a setting in which patients return on a frequent basis due to congenital orthopedic issues, thus the interpreters know the families on a more personal level. The interpreter therefore gets off topic easily and inserts their own comments while interpreting. Do you have any suggestions on how to handle/address this?

A (Cindy) – This may be tricky, but since it sounds as if it is happening with several interpreters, maybe a meeting with all of them to discuss ways to more effectively serve patients could be arranged. You could then bring up this issue as well as other ways to work together better.

A (Katherine) - There shouldn't be a "therefore". This is an indicator that whoever you are working with is not complying with professional standards. I have worked with many patients over the long term to the point where our greetings (when there is no provider present) change to reflect the longevity of the relationship, but it is always a professional relationship. If your interpreters cannot maintain this, then you need to advise their supervisors or employers. If they are free lance with no oversight, then I suggest you find a time to directly discuss your concerns and clearly state your expectations including that it is you or the patient who direct the topics and that all messages are to originate either from you or the patient. You might want to find out where (if) these interpreters received their training. If they haven't been through any training, you might want to remove them from your roster until they can complete a training program. From the way the question is phrased, I'm assuming that these comments are not helpful or relevant. Often a patient will ask a nurse a question to which the answer is "Ask the doctor that one." If the patient doesn't ask the question of the doctor, I will ask the doctor for permission to clarify something the patient has said earlier and then ask the patient if he/she still wants to ask it. This is only if it seems like the patient doesn't know when it is appropriate to bring-up the question.

A (Nancy) - It sounds like the interpreters in this clinic are very invested in helping the patients. However, as you noted, while the interpreters' familiarity can streamline conversations in clinic, it can also move the conversations away from the necessary focus. It is important to share what you have observed and to

discuss it openly with the interpreters. You can use the positive foundation of their patient-centeredness make it safe to brainstorm together on what's working well and what improvements can be made overall in providing accurate, effective and professional communications.

Q: How accurate are genetic tests?

A (Cindy) – The accuracy of genetic tests varies greatly depending on the test. Most genetic tests are highly accurate FOR WHAT THEY ARE DESIGNED TO TEST FOR. Some genetic disorders may be caused by a variety of underlying genetic changes, but not all of the genetic changes can be tested for at the present time. Also it is important to know if the test being done is a diagnostic test, a carrier test, or a screening test. Genetests.org features a section called "GeneReviews." Specific genetic disorders are reviewed in detail by experts and available genetic testing is discussed, including a discussion of the accuracy of the test in question.

Q: Does insurance have to know about the results of the tests?

A (Cindy) – It is my understanding that health insurers do not have the right to know the outcome of genetic tests under the GINA (Genetic Information Non-Discrimination Act) and HIPAA (Health Insurance Portability and Accountability Act) laws. However, other insurers, such as life insurers, may require an individual to release their medical records in order to obtain coverage.

Q: What are the most common genetic diseases interpreters may confront in a GC encounters?

A (Nancy) - This will often depend on the setting in which services are being provided. One of the challenges of interpreting in genetics centers is that many of the conditions are rare, so it may be the first time the interpreter is involved in a case with that specific diagnosis. Another issue, especially in pediatric genetics, is that there may not be a specific diagnosis at all. When this happens, several possible diagnoses and their genetic counseling implications are included in the events of the session. Diagnostic and counseling "uncertainty" is common in genetics, which may greatly increase the complexity and length of the appointments.

A (Cindy)- This will depend upon whether the encounter is for pediatric, prenatal, cancer, adult or other genetic specialty. Pediatric cases tend to encompass a wide variety of rare disorders and the focus of the encounter may be to determine a diagnosis. In prenatal cases, chromosomal disorders such as Down syndrome, trisomy 18 and trisomy 13 are seen frequently. Hereditary breast and ovarian cancer and Lynch syndrome, or HNPCC (hereditary nonpolyposis colorectal cancer) are the most common family cancer syndromes encountered.

A (Katherine) - From my experience, in a perinatal context the most common conditions are Down syndrome, trisomy 13 and trisomy 18, spina bifida and hydrocephaly. Breast and ovarian cancers seem to be the most prominent in oncology settings. Pediatric sub-specialty issues seem to be more diffused. There have been a wide variety of issues including cleft palate, Klippel-Trenaunay syndrome, dwarfism, sickle cell disease, and glucose-6-phosphate dehydrogenase deficiency. Again, this is my experience.

We have to remember that certain populations have propensities for different genetic issues. For example alpha thalassemia is the most common genetic disorder among people of Asian descent, sickle cell disease among people of African descent and Tay-Sachs among people of Ashkinazi Jewish descent. Even some generally rare disorders may cluster in certain populations as is the case for Cohen syndrome and Crigler-Najjar syndrome among the Amish in Ohio and Pennsylvania (respectively). It is advisable to ask a genetic counselor for information on which genetic disorders are more prevalent in which populations.

Q: For Nancy: Would you please send me the questions that you mention are not answered by the PSS (Professional Status Survey)? I can see about modifying the 2012 PSS to ask these questions.

A – There are several potential questions that could be included in a future PSS. They could be research questions. Less than 1% of the PSS respondents self-identified as having some type of disability, but we don't know how many counselors are bilingual, or how many are familiar with languages other than English. We also don't know how often or how comfortable counselors are in working with an interpreter.

Q: In some cultures, the Elder in the family has a key role in family decisions. What challenges could come up that may complicate the flow of information?

A (Cindy) – It seems appropriate to include this person in the discussion if the patient desires. It may be beneficial, however, to speak with the patient privately as well, so s/he is free to express her/his own feelings.

A (Katherine) - Genetic counseling is a group event anyway. Family members are welcome and their understanding and input is considered very important. The most serious complication would be assuring that the person most directly affected gets all of his/her questions asked and answered. This would extend to testing and treatment options which may be culturally inappropriate, but individually desirable. For example, if a pregnant woman wants an amniocentesis, but the cultural view is never to risk the unborn child, then the elder could have one view and the woman another. The issues here go beyond communication. The genetic counselor must figure out how to interview the woman alone in a way that will not result in her being ostracized from her support group. A good interpreter will help the genetic counselor formulate appropriate strategies that honor the cultural norms and yet give the client a chance to speak alone or with a more selective subset of his/her family.

A (Nancy) –The counselor should try to gain an understanding of what key roles people play and why. Decision making may be more of an iterative, and not necessarily a simple, process when several people are involved. Explicitly asking the client to explain to you how decisions are generally made in his/her family, or to share how another decision was made, may be very helpful. Extra time or additional sessions may be required.

Ethics:

Q: What are the ethical obligations for genetic counselor and interpreter?

A (Nancy) – Please refer to the Code of Ethics documents for each profession noted below. These documents are also posted as handouts on the webinar site:

- National Council for Interpreting in Health Care: www.ncihc.org
<http://data.memberclicks.com/site/ncihc/NCIHC%20National%20Code%20of%20Ethics.pdf>
- National Society of Genetic Counselors: www.nsgc.org
<http://www.nsgc.org/about/codeEthics.cfm>

A (Katherine) - I think we covered these at length during the Webinar. The PowerPoint slides are available as are the source documents. Unless there is a specific issue, I think the best course is to review this information.

Q: I would like information regarding genetic research. If we have to enroll patients into research, what ethical issues and moral responsibilities need to be considered? As we know genetic information is confidential. Before we use this for research purposes, we need to take consent from participants. Please comment on it.

A (Nancy) –Genetic research requires the counselor to establish trust with the client. We must also ensure voluntary participation and informed consent including proper translation of documents. It may be necessary to review consent forms with the client several times to be sure comprehension is achieved. The following references may be useful:

- *Use of a Modified Informed Consent Process among Vulnerable Patients: A Descriptive Study* by Rebecca L. Sudore et al. *J Gen Intern Med* 2006; 21:867-873.
- *Are Good Intentions Good Enough? Informed Consent Without Trained Interpreters* by Linda M. Hunt and Katherine B. de Voogd. *Society of General Internal Medicine* 2007; 22:598-605.

A (Cindy) – The ethical issues, moral responsibilities and privacy issues would be the same for English speaking and LEP participants. If the study includes people of LEP, I would hope that any written documents, such as consent forms, would be available in a variety of languages, however it would be important to find out if the participant has the reading skills to understand the documents, even in their own language. As with any research study, it is important to make sure the participant understands that their health care will not suffer if they choose not to participate. It is good to have patients restate the information provided in their own words to ensure understanding.

Q: Was the last question possibly inquiring about genetic privacy in general from the non-genetic providers? There are laws that protect against genetic discrimination.

A (Cindy) – Yes, the Health Insurance Portability and Accountability Act (HIPAA) and the Genetic Information Non-Discrimination Act (GINA). More information can be found at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/genetic/index.html>.

Q: Katherine, I was curious regarding a situation we have come across lately. We have an interpreter from an agency about whom we, colleagues and patients, have made multiple complaints. In working with an agency what are our rights/course of action? We have already requested not to have that person assigned to our cases, but this is not always possible. When do we have the rights to say we need proof of this person seeking competency training before they interpret again or something like that? When can we refuse that individual interpreting for us and seek an alternative (we luckily do have strong interpreters/bilingual speakers on staff that are occasionally able to help us out)? Just curious as this has been detrimental to the care of several patients.

A (Cindy) – *I would think that you could refuse to have an incompetent interpreter at any time you felt it was in the patient's best interest.*

A (Katherine) - *I assume you are documenting the complaints. If not, then you should start immediately in written form with dates, issues and if the complaint originated from the patient, provider or both. If there is a confidentiality issue, then I suggest you say that if this is the only interpreter available you will reschedule the patient, use a phone service or other resource. I would contact the owner/director of the agency and request a face-to-face meeting where you can directly present your concerns and set your limits. If the agency is not willing to hold their interpreter accountable or honor you demand that this interpreter not come to your site maybe you should look for alternative sources. While that would be inconvenient, it is much less problematic than facing a lawsuit from a patient or patient's family that has been injured while under your care. Unfortunately, competency training is not a guarantee that someone will consistently put those competencies into practice. So, I would not ask for a proof of training only, but would write out the issues (from both providers and patients) so that the interpreter knows exactly what will constitute instant dismissal from an appointment if you agree to let him/her back into your facility.*

Resources:

Q: Are there any glossary resources for genetic terminology specifically in other languages, such as Spanish, Hmong, Somali, etc?

A (Nancy) - <http://www.genetics.com.au/multilingual.asp>
<http://www.geneticalliance.org.uk/translations-library1.htm>

Later this year, additional resources will be available online from the National Society of Genetic Counselors and the Genetic Counseling Cultural Competence Toolkit, as mentioned in the webinar.

A (Cindy) – *Here is a glossary of genetic terminology in English. I don't know of resources for other languages, but understanding the meanings may help in interpreting into other languages for which there may not be word-equivalents. <http://genetics.com.au/glossary/index.asp>.*

A (Katherine) - *Genetic terminology is certainly available for languages like Spanish with standardized written forms and well developed tertiary education in the biological sciences. Other languages may have borrowed or calqued terms from either world languages or colonial languages or the languages that provide textbooks for the university science curricula. For specific languages, I would start with Medlineplus and see what is available there. Then I would do country of origin newspaper searches*

(assuming there are newspapers in that language) in both health sections and education sections for children. After that, I would try to find health organizations or linguists who work with different linguistic groups to see if they know of available resources. Of course, not every language in the world has a standardized written form and if it does, there is no guarantee that the terminology for any given specialty is widely recognized. It may be necessary to establish a set of terms to be used with a specific client. It would be helpful for the interpreter to leave that set of terms in written form with the genetic counselor to see if they will be useful when seeing someone else from that same linguistic group; but be prepared to have to negotiate the terms again.

Q: I am looking for specific education & resources on the field of genetics and genomics.

A (Nancy) – *Learn.Genetics: Genetic Science Learning Center, University of Utah*
<http://learn.genetics.utah.edu/>

Genetics Home Reference: National Library of Medicine
<http://ghr.nlm.nih.gov/>

CDC Public Health Genomics Quick Facts
<http://www.cdc.gov/genomics/public/eFactSheet/menu.html>

A (Cindy) – *In addition to the resources already listed, the Genetics Education Center at*
<http://kumc.edu/gec/> *has some good links to a variety of subjects. The March of Dimes also has some nice information about pregnancy-related issues:* <http://www.marchofdimes.com/> *and a nice Spanish language site:* <http://www.nacersano.org/>.

Qualifications:

Q: for Katherine: What qualifications do people need to do what you do, other than speaking another language?

A (Katherine) - *I'm going to take this opportunity to mention a couple of facts about bilingualism. Most people are not balanced bilinguals—this means that they speak one language better than the other. While not exactly qualifications, there are necessary personal characteristics like maturity, responsibility, objectivity and impartiality. In the medical field it is helpful not to be squeamish at the mention of or sight of bodily fluids, needles, etc. One needs knowledge of health literacy and the US medical culture. Interpreting is a field in the process of professionalization; so qualifications are pretty fluid. (This is less so in the legal field.) Organizations like the NCIHC (National Council on Interpreting in Health Care) continue to publish guidelines, but there are no overarching industry standards yet. Several states have their own requirements. Individual institutions also set their own qualifications. Then there are certain situations outside of anyone's control, for example, if an educational qualification were to be rigorously applied, it could take years for potential interpreters to meet those qualifications, particularly if their language group has not had access to such educational opportunities in the country of origin. Having said that, the guidelines suggest that interpreters should have training in interpretation and health literacy. Medical interpreting is the first field, after legal interpreting, to develop a certification process.*

Q: What level of technical proficiency is required in a research environment and how are interviews handled differently from a clinical environment?

A (Cindy) – The level of technical proficiency would depend upon the specific research project. My involvement in research studies has been limited to the recruitment of participants from patients who are undergoing genetic counseling for a related issue anyway, so the interviews are very similar in my experience.

A (Katherine) - I'm not sure I know what this question is asking, but I'll make a couple of observations. Every field has its technical terminology. Any good interpreter will learn this vocabulary before going into a situation where it is required, and so will know not only the terms for the focus of the study but research terminology (population, control group, blind/double blind study, etc.). Most of the research interviews I've participated in require an explanation of the intent of the research and for informed consent to be obtained. If consent is obtained, then whatever follows has been pretty much the same as clinical interviews. The only difference is that the information is sent to the researcher to be pooled with other information. These have not been clinical trials or any type of experimental treatment or therapy. It is often in the sharing of research results that the interpreter may find more challenges, especially if those results are just beginning to be disseminated. Of course, this means a familiarity with statistical as well as biological terminology.

A (Nancy) – The level of technical proficiency about genetic testing technologies, interviews or protocols required by an interpreter working in a research genetics environment would be determined by the nature of specific projects. However, in general, genetic counselors try to simplify terms to accommodate all levels of health literacy, regardless of the topic, project, or setting. The counselor should be thinking of creative and simple ways to use words and visual aids to explain various topics to the client. The responsibility is on the counselor to keep the discussion as “untechnical” as possible, whenever possible!