Development of Spanish Genetic Counseling Lexicon

Principal Investigator: Priscila D. Hodges, MS, CGC
6410 Fannin Street, Suite 1217
T: 713.486.2289
E: Rayza.Delgado@uth.tmc.edu

Co-Investigators: NSGC: Nevena Krstic, MS, CGC
                      CAGC: Rachel Vanneste, MSc, CGC, CCGC
                                    Mireille Cloutier, MSc, CGC, CCGC
                                    Guillaume Sillon, MSc, CCGC
                                    Julie Hathaway, MSc, CGC, CCGC

Project Purpose

The purpose of this project is to improve the provision of genetic counseling services by developing an updated web-based comprehensive English-Spanish lexicon of approximately 3000 - 4000 terms that covers vocabulary used in [all areas of genetic counseling, including] prenatal, pediatric, adult, and cancer genetic counseling sessions by expanding Lexigene® (www.lexigene.com), a current English-French lexicon, to include Spanish. This online tool is intended to be used as an appropriate resource for medical interpreters that work with genetic counselors in order to supplement and enhance their linguistic competency. Also, it will be a useful resource for bilingual genetic counselors and students in training to supplement and enhance their linguistic competency, as well as enrich their knowledge of dialectal variations across the Spanish language. This will be a collaboration between members of NSGC as well as members of CAGC in order to improve quality of genetic counseling services in North America.

Statement of need and relevance

"Limited English Proficiency" (LEP) refers to individuals whose native language is different from English and are unable to communicate in and understand the English language effectively (Hunt & de Voogd, 2007). Recent statistics reported by the Migration Policy Institute state that there were approximately 25.1 million individuals in the United States with LEP in 2013. Furthermore, 16.2 million (64%) of LEP individuals spoke Spanish, making it the most common spoken language (Whatley & Batalova, 2013). Based on these statistics, the number of individuals with LEP is likely going to increase

and this will significantly impact providers in general because communication is a key element in health care, every interaction is dependent on effective communication between all parties involved (Maher et al., 2012) even more so during genetic counseling sessions where genetic counselors are trying to assess the patient's understanding, goals, expectations, concerns and facilitate decision making.

Numerous studies have demonstrated that it is more probable for LEP individuals to "suffer adverse health outcomes" compared to those whose native language is English or who are proficient in English (Thompson et al., 2013). When providers and patients speak different languages, medical interpreters are used in order to bridge "patient-provider linguistic and cultural differences" (Dysart-Gale, 2007). Employing properly trained medical interpreters is crucial to guaranteeing successful communication and quality of care for individuals with LEP (Seers et al., 2013), and numerous studies have demonstrated that the utilization of a trained medical interpreter is correlated to improved patient care (Hudelson et al., 2013). In addition, providers who feel confident with their language skills and are bilingual may overestimate their ability to communicate in that language and could still make interpreting mistakes (US Department of Health and Human Services, 2001).

In the United States, several agencies are available to provide training for individuals interested in becoming medical interpreters. According to the NCIHC, basic minimum training consists of 40 hours of instruction, and "should cover the interpreter role, ethics, modes, basic conversation skills, handling the flow of the session, intervening, and medical terminology" ("FAQ - Healthcare Professionals," n.d.). All individuals with a certificate of completion for 40 hours of training are eligible to sit for the Certified Medical Interpreter Credentialing exam which covers 7 different topics (The National Board of Certification for Medical Interpreters, 2014, p. 9). The 2 largest topics, "Medical Terminology in Working Languages" and "Medical Specialties in Working Languages," encompass 38% and 23% of the certification exam, respectively. The latter consists of 21 subtopics, including obstetrics and gynecology, which is combined with genetic counseling. Therefore, it is plausible to approximate that only 0.5% of the exam relates specifically to genetic counseling, assuming that the exam gives equal weight to each subtopic. In addition, it is possible that the terminology covered under the obstetrics and gynecology

subtopic may be more related to prenatal genetic counseling, with less emphasis on pediatric or adult genetics.

Research focused in the interactions between genetic counselors and medical interpreters is limited. A platform presentation at the 2015 NSGC AEC discussed some of the challenges that interpreters face during genetic counseling sessions as well as potential solutions. In summary, the study suggests that interpreters find genetic counseling terminology extremely challenging in the following instances:

- *Genetic counseling terminology is complex and they do not have a clear understanding of the vocabulary words used during genetic counseling sessions.*

- *There is a lack of genetic counseling terminology. Interpreters do independent research and use other resources to expand their vocabulary; however, the references they use sometimes increase their level of confusion rather than clarify their doubts.*

- *Interpreting courses vary and the genetic counseling terminology covered during the training courses is limited. Some interpreters did not even recall learning any kind of genetic counseling terminology at all (Delgado-Hodges, 2015).*

This project is of great importance to the genetic counseling profession because it directly relates to the practice based competencies, specifically the communication domain as well as enhances cultural competency through correct use of language. An entry-level genetic counselor must be able to "convey genetic, medical, and technical information [...] including but not limited to diagnosis, etiology, natural history, prognosis, and treatment/management of genetic conditions and/or birth defects to clients with a variety of educational, socioeconomic, and ethno- cultural backgrounds" ("Practice-Based Competencies", n.d.). Given that Spanish is the most common language spoken among individuals with LEP in the United States, and is probably the most common language encountered in counseling, genetic counselors who do not speak Spanish highly depend on medical interpreters to appropriately interpret the information they need to convey. This lexicon could be used as a supplement for interpreters in order to enhance their linguistic competence related to genetic counseling terminology and address some of the

challenges mentioned above. Additionally, the lexicon would serve as a reliable resource for bilingual genetic counselors to refresh and update their vocabulary and increase their awareness of dialectal variations among Spanish speaking patients and ultimately provide better care to Spanish speaking patients. This lexicon may also be used as a tool for genetic counseling students in training, particularly those who desire to increase their Spanish proficiency.

Goals

- To translate into Spanish approximately 3650 genetic counseling terms that cover vocabulary used in [all areas of genetics, including] prenatal, pediatric, adult, and cancer genetic counseling sessions already found in www.lexigene.com

- To provide a comprehensive resource for medical interpreters that work with genetic counselors and their patients in order to supplement or enhance their linguistic competency

- To improve the availability of easy to access resources for genetic counselors who currently provide or wish to provide services in Spanish

- To enhance the training of genetic counselors by giving more students and new graduates the opportunity to counsel in Spanish

- To enhance and promote cultural competency among bilingual genetic counselors through an increase of awareness of dialectal variations among Spanish speaking patients

Methods

Phase 1.- Translation and curation of terms

Translation of terms found in Lexigene® will be performed by 11 volunteers who are fluent Spanish speaking genetic counselors and medical geneticists; they are from various Spanish speaking countries like El Salvador, Mexico, Chile, Ecuador, and Spain. Volunteers were recruited through the NSGC and CACG's listserv. Each volunteer will be expected to translate ~323 words that fit their area of expertise/practice (i.e. prenatal genetic counselors are mainly translating prenatal genetic counseling terms).

The translation process will require certain standards in order to guarantee accurate and proper

translation; therefore, for this project the following verification process has been established:

- All common terms (i.e. family terms, numbers) require one reference, if possible.

- More complex words and less known terms require two to three references.

- After all words are translated, teams of 3 - 4 people will review each word with their respective reference (second curation process). If there is a discrepancy in the translation of the word, each team will try to reach consensus in order to provide the best most accurate interpretation. If no consensus is reached, the word will be revised by all volunteers in order to reach a group consensus.

- For the final curation, all volunteers will review all words and their respective translations (third curation process).

- As part of the translation process, each volunteer will add dialectal differences that they may have heard in the past and associate it with a country of reference, if possible.

Phase 2: Incorporate terms into Lexigene®

The established Lexigene® website has built-in capabilities to add other languages for which all of functions would be available and would only require a transfer from a Google app engine onto a different server. This will increase the speed of the tool and efficacy of the website administration.

Phase 3: Pilot

The lexicon will be piloted with a group of 10 bilingual counselors (mix of current students, new graduates and experienced counselors). Their responses will be used to refine the tool.

Phase 4: Dissemination

Availability of the new Spanish lexicon through Lexigene® will be disseminated via the NSGC, CAGC, TSGC (Texas Society of Genetic Counselors), TAGC (Transnational Alliance for Genetic Counseling) and genetic counseling programs that offer a Spanish immersion program or conversational Spanish classes (i.e. The University of Texas Graduate of School of Biomedical Sciences, Stanford University and The University of Alabama at Birmingham) as well as The National Board of Certification for Medical Interpreters. Also, we would be in contact with program directors of all genetic counseling programs

across the United States and Canada in order to promote the use of this tool among genetic counseling students.

As part of a continuous dissemination process we would take Lexigene®'s business cards and poster to different educational conferences to increase its awareness among the genetic counseling community. We would also approach dissemination through social media (i.e. Twitter and Facebook).

Finally, we would submit for an article in Perspectives and we would hope for the support of NSGC in the addition of Lexigene® as part of tool kit in NSGC's website.

Evaluation of Results/ Final Product

The final product will be the online lexicon hosted through Lexigene® that will be ready to use. The site features a feedback button which creates an email form to allow individuals to ask questions, point out errors or suggest a missing term. This allows for updates and corrections to be made on an ongoing basis. As part of a long-term plans, out of the scope of the timeline provided by this grant, our goal is to work with genetic counseling students to do further research on how interpreters are using this tool in hopes to follow up to the research presented at the 2015 AEC (Delgado-Hodges, P. et al. (2015) Interpreting for Genetic Counselors: Identifying common pitfalls and solutions). Other projects could include surveying genetic counselors on their awareness and utilization of this trilingual tool or conducting focus groups with genetic counseling students in Spanish immersion programs or conversational Spanish classes. Two out of the 5 co-investigators are associated with Genetic Counseling training programs and have the experience or the capability of chairing or acting as members on thesis committees. Lexigene has the capability of running analytics on the website's traffic; therefore, we could use that information too to assess utilization.

Projected Timeline

Phase	Duration	Calendar timeline
Phase 1 – Translation	8 months	Jun 2016 – Dec 2016
*1st Translation	4 months	
*2nd curation	3 months	
*Final curation	1 month	

Phase 2 – Add to Lexigene®   2 months   Jan 2016 - Mar 2017
Phase 3 – Pilot   2 months   Apr 2017 - May 2017
Phase 4 – Dissemination   Immediate May 2017
*Tentative timeline

Itemized budget

Web developper cost of incorporation of 3rd language to Lexigene®	$1650 (+tax)
Moving Lexigene® to a different server	$350 (+tax)
Tax total	$200
Marketing:	
Lexigene® business cards	$100
Lexigene® cloth poster to use at conferences	$200
Shipping costs	$100
Volunteer's honorarium - ($200 x 11 volunteers) *including myself as volunteer	$2200
Amount awarded by the Prenatal SIG	-$150
Amount awarded by the TSGC	-$500
Amount awarded by the International SIG	-$112
Total amount of funding requested	**$4038**

References

Delgado-Hodges, P. et al. (2015). Interpreting for Genetic Counselors: Identifying common pitfalls and solutions. Paper presented at the meeting of the National Society of Genetic Counselors, Pittsburgh, PA.

Dysart-Gale, D. (2007). Clinicians and medical interpreters: Negotiating culturally appropriate care for patients with limited English ability. Family & Community Health, 30(3), 237–246. doi:10.1097/01.FCH.0000277766.62408.96

FAQ – Healthcare Professionals. (n.d.). Retrieved December 5, 2014 from http://www.ncihc.org/faqs-for-healthcare-professionals

Hudelson, P., Dao, M. D., Perron, N. J., & Bischoff, A. (2013). Interpreter-mediated diabetes consultations: A qualitative analysis of physician communication practices. BMC Family Practice, 14(1), 163. doi:10.1186/1471-2296-14-163

Hunt, L. M., & de Voogd, K. B. (2007). Are good intentions good enough? Informed consent without trained interpreters. Journal of General Internal Medicine, 22(5), 598–605. doi:10.1007/s11606-007-0136-1

Maher, S., Crawford-Carr, A., & Neidigh, K. (2012). The role of the interpreter/doula in the maternity setting. Nursing for Women's Health, 16(6), 472–481. doi:10.1111/j.1751-486X.2012.01775.x

Seers, K., Cook, L., Abel, G., Schluter, P., & Bridgford, P. (2013). Is it time to talk? Interpreter services use in general practice within Canterbury. Journal of Primary Health Care, 5(2), 129–137.

The National Board of Certification for Medical Interpreters. (2014). Certified Medical Interpreter Candidate Handbook 2014. Retrieved from http://www.certifiedmedicalinterpreters.org//sites/default/files/national-board-candidatehandbook.pdf

Thompson, D. A., Hernandez, R. G., Cowden, J. D., Sisson, S. D., & Moon, M. (2013). Caring for patients with limited English proficiency: Are residents prepared to use medical interpreters? Academic Medicine: Journal of the Association of American Medical Colleges, 88(10), 1485–1492. doi:10.1097/ACM.0b013e3182a3479d

US Department of Health and Human Services. (2001). National standards for culturally and linguistically appropriate services in health care.

Whatley, M., & Batalova, J. (2013). Limited English proficient population in the United States. The Online Journal of the Migration Policy Institute.

Practiced-Based Competencies. (n.d). Retrieved May 2, 2016 from http://www.abgc.net/docs/Practice%20Based%20Competencies_Aug%202006%2010-29-09.pdf