

Student Forum

Expanding Our Borders: A Summer Rotation In Jordan And Many Lessons In Cultural Competency

By Jasmine Wong, MS, Sarah Lawrence College Class of 2009



Jasmine Wong (L) and a Bedouin woman (R)

Two students from Jordan, **Nadeen Jaradat** and **Rifaat Rawadesh**, were accepted into the Sarah Lawrence College (SLC) Genetic Counseling Program in 2007. In the first term they made a presentation on their country with the hope that two fellow students would assist in assessing the possibility of introducing a genetic service in Jordan. My classmate, **Monique Simard**, and I quickly jumped aboard since we were avid travelers and interested in participating in this research and clinical opportunity.

Such a great opportunity came with a great deal of work; from late winter to early summer, we found ourselves very busy planning and coordinating the project. First we formed a task group that met every month – we called ourselves Team Jordan. It was composed of **Caroline Lieber** (SLC Genetic Counseling Program Director), **Dr. Siobhan Dolan** (a public health specialist and instructor at SLC), Nadeen, Rifaat, Monique and me. Next, we began formulating our graduate theses which, after many revisions, we decided to combine. Monique focused on surveying the population of Jordan looking at attitudes, knowledge and resources regarding three common genetic diseases: beta-thalassemia, cystic fibrosis and Down syndrome. Complementing Monique's thesis, I surveyed Jordanian physicians along similar measures. We hoped that combining our projects would allow for a well-rounded needs assessment and a guideline for future genetic counselors in Jordan.

To begin, we researched the Jordanian medical system, culture, and law. Jordan is a developing country, strong in Muslim religion and Arabic family tradition, and borders the politically restless countries of Syria, Israel and Iraq. It is well known for its seventh new wonder of the world, Petra, an ancient city carved into sheer dusty pink rock, which has been featured in movies such as *Indiana Jones* and *Transformers*.

Jordan currently does not have medical geneticists or genetic counselors. Genetic counseling is provided by non-genetic physicians. **Dr. Saied Jaradat**, Director of Molecular Genetics at the King Abdullah Hospital in Irbid and our supervisor in Jordan, noted that Jordan may benefit from genetic services. High

consanguinity rates, traditional large families and anti-abortion laws naturally result in a higher prevalence of genetic disorders to the country. Also, the country is quickly developing its health care system. In 2004, Jordan started pre-marital screening for beta-thalassemia, and this year Northern Jordan will launch newborn screening. We aimed to study these considerations as well during our time in Jordan.

On July 27, 2008, I took a plane from New York City to Amman, while Monique arrived ten days later. The culture shock was immediate: stray camels roamed the streets and Bedouins and Gypsies sold their wares. By the end of the third week, I had begun to adjust to some of the cultural differences, such as sexual segregation and the practice of polygamy. I learned that I could shake a man's hand only if he put his out first and found that introducing myself as a Canadian studying at an American school was best received.

Once we felt more comfortable with Jordanian customs, social etiquette, and medical practices, we took part in genetic counseling sessions. Along the way we learned that most Jordanians believe that a greater power gives them trying situations, which they can endure. For some, genetic explanations for these trials were thought of as being discrepant with their beliefs. For others, it did not present a challenge to their faith. Because of this, we learned to ask each family if they were interested in hearing about the inheritance of their family's disease and respected their choices. We found that this approach was well received and appreciated.

Another adjustment to counseling style was necessary since abortion is illegal in Jordan and, therefore, not available and not discussed medically. Instead we focused on exploring the options that were available such as resources for a child with a disability and planning future pregnancies. We found it challenging, yet interesting, to alter our counseling styles to accommodate this and other different cultural, political and legal norms.

I found that modifying our counseling techniques was made easier by understanding Jordanian culture. To illustrate, traditionally it is the parents who choose their children's spouses. Therefore, if it were a public goal to lower the number of consanguineous marriages, parents would be the proper individuals to target for public education. In the clinic, most of our affected patients had autosomal recessive disorders and were from consanguineous marriages. When counseling the parents, I attempted to present information in a balanced manner by respecting and discussing the pros of consanguinity – financial stability, decreased risk of assault on women, and maintaining tradition – while reviewing how consanguinity can increase the risk of inherited disorders. The parents may choose to integrate the information about inherited disorders in their decision-making regarding a spouse for their child.

To finish, I would like to share the inspiring story of a Bedouin woman I met while in Jordan. Dr. Saied found a way for us to speak with a Bedouin community in the county of Mafraq. The little I knew about Bedouin people was gained from a few "National Geographic" images of weathered, bronzed women in colorful wool costumes. They are a nomadic group who live symbiotically with their camels and other animals. With simple expectations, we went to Mafraq.

The county was poor, with a lone intersection of stores and tents scattered every twenty miles. In a narrow corridor outside one of these intersections was a small women's community center. We met the founder of the center and marveled at her story. She married at the age of 14 (a typical age for Bedouin girls) and had seven children. In her twenties, she had a pivotal moment and went on to complete her Ph.D., while having four more children. But she still was not satisfied; after a man donated 100 Jordanian Dinars (about 140 U.S. dollars) to her, she started a women's center, which is now filled with exercise

machines, a beauty parlor, an arts and crafts center, computers and a kitchen. Workshops run weekly on topics such as blanket making, basket weaving, interviewing, internet surfing, nutrition, typing and hairstyling. It is available to many families in the surrounding area, some which she told us had a variety of rare genetic diseases because of a high consanguinity rate. She explained that the consanguinity rate was perpetuated by the family stigma of genetic disease, which inhibited members from marrying outside their family. Likewise, children with these diseases were hidden.

She shared that she is currently working with a social worker to aid these families. Together, we brainstormed ideas for other ways to help the families in this community and decided that we would provide workshops on consanguinity.

Overall, we never could have prepared for this experience through research or readings. Much was learned from firsthand experience in a culture so different from our own. I have always been an individual who seeks a good understanding of my own attitude, values and biases regarding society and culture. This experience shook my understanding of myself, and I am forever changed because of it; I imagine that this change has trickled into how I practice genetic counseling.

Generally, I have learned to be more patient, non-judgmental and empathic toward others, of my own culture and of other cultures. For example, before this experience, I generally felt uneasy when a man dominated a prenatal session because I imagined that this may be a relationship filled with control and not love. Of course, this scenario can certainly exist, but I no longer feel uncomfortable during a prenatal session when a husband/wife asks me to speak specifically to the husband. The Qur'an teaches that the woman has to do the most difficult and important task of all, to give birth, and a man must do all else for it to be more equal. Some men of Muslim faith or another faith/culture may believe that love and compassion is taking it upon himself to make a difficult decision for the family. It is not my own culture, but I see beauty in it and am happy to respect a couple's relationship, as long as it is legally appropriate. Lastly, I have learned that there is a want and a need for medical genetic services in countries around the world that are just awaiting a 'first step.'

I encourage other genetic counselors and genetic counseling students to seek out ways to become more internationally involved. Many developing countries lack genetic resources and Monique Simard, Caroline Lieber and I are currently asking for donations of old-edition textbooks and reference books. If you are interested in donating books, please contact me at Jasmine.Wong@albertahealthservices.ca. Thank you.
