The DNA Exchange

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Guest Post: We Can Do Better – The Experience of a Minority Genetic Counselor, by Tala Berro

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Bob Resta recently wrote a blog on his experience of <u>being a man, as well as the advantages and disadvantages of being a woman, in our woman-dominated field</u>. He called upon us good readers to share experiences "where you are not quite like everyone else." Being a queer person of color in genetic counseling, I immediately took up his call. In part due to my various identities, there have been countless instances during my genetic counseling training and career when I have felt "not quite like everyone else."

Let's start with intersectionality, a <u>term coined by Black feminist scholar Kimberlé Crenshaw in 1989</u> to highlight the ways in which black women were excluded from the feminist movement. Crenshaw notes that "not only are women of color in fact overlooked, but their exclusion is reinforced when white women speak for and as women." In this blog post, I want to take a deeper dive into how my own intersecting identities as a queer, Arab woman affect my experience as a genetic counselor.

The genetic counseling profession within the Unites States is overwhelmingly white. As reported by the National Society of Genetic Counselors (NSGC), 92% of the 2018 Professional Status Survey respondents identified as white, which is easily visualized when one walks through the exhibit hall at the NSGC Annual Education Conference. Although there are many reasons why we often see a higher percentage of white individuals in jobs that require a graduate degree, genetic counseling is an especially white field. In comparison, 54% of software engineers are white, 80% of public school teachers are white , and 68.2% of physicians/surgeons are white.

The foundation of empathy is what drew me to the genetic counseling profession. I knew that I would come in as an outsider, but I hoped that caring, open-minded genetic counselors would make for caring, open-minded classmates, supervisors, and coworkers. However, we have a long way to go. Genetic counseling training programs incorporate lessons on the importance of culturally appropriate counseling of patients, but this same openness and acceptance is not always extended to fellow genetic counselors.

I started to notice my "otherness" in the field of genetic counseling from the beginning of graduate school. Being an Arab genetic counseling student always had its pros and cons. My favorite instances as a student were when an Arabic speaking patient would come into a genetic counseling session and I could utilize my knowledge of Arabic. This shared language and its ability to add comfort to my patient always felt really special. More often than not, though, sessions with Arab patients would end in a debriefing session with a supervisor who would ignorantly state microaggressions, judging family sizes, and gender dynamics. After one of these sessions, my supervisor and I were discussing the patient and mentioned the specific Arab country they were from. A medical professional in the workroom overheard and noted that, to her, this specific country is associated with danger and violence. There was no response to this comment. I was left shocked, dismayed, and anxious, without an outlet to seek support from other genetic counselors of color or Arab background.

What is currently seared into my mind as a genetic counselor of Arab descent whose community often attends mosque, is the massacre in New Zealand. I came to work devastated and shaken. While not all individuals of Arab descent are Muslim, I (and

many others) consider those who are Muslim to be members of my community. Perhaps a genetic counselor saw a Muslim patient that Friday and provided comforting words. I wondered, though, how many genetic counselors reached out to their peers or students who may have been impacted by this. From my own experience of not receiving messages of support, I would guess not many.

In addition to racial barriers, being a queer genetic counselor comes with its own barriers to navigate. Based on my training experience, genetic counselors are growing in their awareness of pronouns and gender identity, often using the word "partner" when counseling. However, on an interpersonal level, it takes more than just awareness for true inclusion. I recall a conversation from back when I first started as a genetic counseling student in which I proudly identified myself as queer. This statement was met with discomfort and confusion. I know that genetic counselors are educated on the importance of mindfulness and inclusivity of the LGBTQIA+ community and are taught to be verbally-inclusive with patients who identify this way during a session. However, there seems to be a discrepancy in how these lessons of acceptance are actively applied by genetic counselors in and out of clinic. The ability to sustain a relationship with a patient over a 60-minute genetic counseling session does not translate to intentionally cultivating an authentic relationship with someone of a different identity from you.

One universally challenging aspect of genetic counseling training is providing and receiving feedback. To be evaluated on your words, demeanor, and body language while you are learning to interact with patients and cope with emotional situations is difficult. However, feeling like you are also being evaluated for your values, beliefs, and cultural upbringing is much harder. At times, I have been critiqued for my character and values, as opposed to my specific counseling skills. I have been encouraged to "play devil's advocate" to my own beliefs. For example, during my training, I was given feedback that highlighted my potential to advocate for underserved patient populations, and also challenged me to find ways of connecting with patients who are different from me. This feedback came before I even had the opportunity to interact with a single patient. I felt critiqued not on behaviors I exhibited but on behaviors that were assumed of me. It also felt like this feedback was unnecessary reiteration that I am different, as the minority, and that I will be expected to live and fit in a world of the majority. Through these experiences I wondered: were my professors and supervisors feeling defensive because I was different from them and teaching me felt different than teaching others in our field? Who could I turn to within the field to talk about my thoughts and concerns?

Whenever I hear the term devil's advocate, I think back on a blog post by Juliana Britto Schwartz. She writes, "dearest devil's advocates: speak for yourself, not for the 'devil'. Teach yourself. Consider that people have been advocating for your cause for centuries, so take a seat. It's our time to be heard." It is often forgotten that those with underrepresented identities have lived their entire lives being forced to understand the majority. These same privileged experiences to which I was encouraged to have an open mind are mirrored by what I read about in fiction, watch on television, and learn about in the history books. As a queer genetic counselor of color, I understand how to navigate these spaces because I have been forced to my whole life and will continue to do so in my professional life. Instead of ensuring that I understand and empathize with the majority experience, why don't we make sure that the majority understands and empathizes with the minority experience?

As genetic counselors, we consistently discuss and learn about empathy for our patients. My hope is that we can take these lessons and apply them to our colleagues and peers outside of a counseling session. To my fellow genetic counselors, I propose the following version of the golden rule: treat your peers as you treat your patients.

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