Received: 27 November 2019 | Revised: 17 February 2020 | Accepted: 25 February 2020
DOI: 10.1002/jgc4.1268

SPECIAL ISSUE

Creation and utility of 'Boston Minority Genetic Counselors'

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Abstract

The genetic counseling profession began shortly after the Civil Rights Movement, before effective strategies for inclusion of racial minorities had emerged. Given the historical context of the field and the continued lack of diversity in the professional body, inclusion among genetic counselors of social minority backgrounds is important to examine and address. A group of genetic counselors in the Boston area with social minority backgrounds initiated the Boston Minority Genetic Counselors (BMGC) group to bolster interconnection and support for themselves and their local genetic counselors and trainees of social minority backgrounds. In this paper, we describe the formation of the BMGC and its ongoing work. Future directions include using the BMGC model and/or that of similar organizations, such as the Minority Genetic Professionals Network, as a template to create similar genetic counseling groups that provide support around topics of social minority identities and promote sentiments of inclusion across the profession.

KEYWORDS
affinity group, disparities, diversity, genetic counseling, inclusion, peer support

1 | INTRODUCTION

The genetic counseling profession emerged in the United States (US) shortly following a marked time in the nation's history, the Civil Rights era. While the temporal initiation of the Civil Rights movement is debatable, the 1950s and 1960s are undeniably recognized as decades that held various confrontations, considerations, and altercations based on race. Cases like Brown versus. Board of Education and nonviolent protests such as the Montgomery bus boycott challenged the fairness of previously existing laws requiring segregation of Blacks and Whites in various public sectors. The Civil Rights Act of 1964 banned discrimination based on race, creed, color, or nationality by any public facility or institution (Collier-Thomas & Franklin, 1999). Movements to promote equality based on gender, sexual orientation, health, and disability status followed and continue to grow in the modern US narrative.

Soon after these important movements contributing to social restructuring of the nation, advances in US medical services included introduction of genetic technologies and prenatal diagnosis. During its inception, prenatal genetic testing (through amniocentesis, for example) was primarily utilized as a way to increase a prospective parent's or couple's autonomy and decision-making abilities regarding the potential birth of a child with a serious disorder and/or disability. Controversy existed—and continues to exist—around the utilization, purpose, and outcome of these technologies (Frati et al., 2017). Alongside the increase in availability of these medical services, wrongful birth cases surged in the 1960s and 1970s with a number of parents in the United States suing physicians for negligence or omission of information that would have influenced the parent's decision to birth a child with a serious disorder and/or disability (Wilmoth, 1980).

In a logical and necessary response to the social and medical issues in the United States, the first master's degree genetic counseling program was founded by Melissa Richter at Sarah Lawrence College (SLC) in New York in 1969. Genetic counselors were envisioned as healthcare professionals who could compassionately and accurately bridge the gap between genetic research breakthroughs and the lay person (Stern, 2009). SLC was founded as a junior women's college in 1926, started accepting men who were veterans in the mid-1940s, and has been expanding from that time onward ('Sarah, Meet Lawrence:' Men at Sarah Lawrence College, n.d.). In 2018, 56 graduate students (19%) enrolled at SLC identified as men and 241 (81%) identified as women (Sarah Lawrence College Student Population Trends, n.d.). Prior to founding the genetic counseling program at SLC, Richter had been Dean of Graduate Studies at SLC and an advocate for women's representation in educational and career pursuits. Richter believed SLC 'was the ideal home for a genetic counseling program, and would appeal to its core constituency, married women in their 30s with two to four children living at home' (Stern, 2009). Richter described women as distinctly suited for genetic counseling 'because they generally are more concerned with health and the preservation of life' (Richter, 1968).

Genetic counseling emerged as a service that could promote autonomy, understanding, compassion, and specific attention to families undergoing difficult circumstances related to their health. The societal circumstances at the time of the birth of the profession have had lasting effects on the demographic identities of the workforce. The 2019 Professional Status Survey distributed by the National Society of Genetic Counselors (NSGC) reported 95% of the 2,438 respondents self-identifying as female and 5% of respondents self-identifying as male. Four of the 2,438 respondents elected not to select their gender, and one respondent identified as gender non-binary. Regarding race and/or ethnicity, 90% of respondents self-identified as non-Hispanic White. Two percent of respondents identified as being part of a disability community (National Society of Genetic Counselors Professional Status Survey, 2019). With the lack of diversity in its professional body—meaning lack of representation of different fixed and fluid traits of individuals—sentiments of inclusion among genetic counselors are worthy of evaluation. Inclusion can be understood as the cultural and environmental sense of belonging. The members of an inclusive group or organization feel valued, respected, accepted, and encouraged to participate authentically. Shore et al. (2011) define inclusion as 'the degree to which an employee perceives that he or she is an esteemed member of the work group through experiencing treatment that satisfies his or her needs for belongingness and uniqueness'. Social justice facilitator Meg Bolger (2017) has differentiated questions to improve the diversity of an organization or group as well as its inclusion:

> *Efforts to increase diversity involve questions like: (1) How can we get more 'diverse' people in our pipeline? (2) How can we incentivize recruiting 'diverse candidates'? (3) Why aren't people of differing identities applying for our jobs?*
>
> *A focus on inclusion asks different questions: (1) What is the experience for individuals who are the minority within the organization? (2) What barriers stand in the way of people with marginalized identities feeling a sense of welcome and belonging? (3) What don't we realize we are doing that is negatively impacting our new, more diverse, teams?*

While the NSGC Professional Status Survey had not been assessing inclusion at the time this manuscript was written, conversation about methods for such assessment had been initiated. To gain an understanding of minority genetic counselors' experiences within their training programs and professional roles, Schoonveld, Veach, and LeRoy (2007) interviewed eight genetic counseling students and seven practicing genetic counselors who identified with a cultural or ethnic group that was underrepresented in the genetic counseling profession. Some participants related feelings of inclusion, while others cited experiences of exclusion. For example, one respondent mentioned 'our class size is so small, it makes us an automatic group; I don't think anyone would be excluded because of race'. On the other hand, one male student stated, 'it's like I'm an outsider. There's this small group of us, and I'm always the one to be singled out or excluded'. Another respondent described, 'I feel like I might perceive things differently but … don't really want to be different or stick out, so I don't usually voice these differences' (Schoonveld et al., 2007).

Genetic counselors of minority identities have shared their experiences within a forum called *The DNA Exchange*, which is founded and maintained by genetic counselors. One author recalled barriers she faced as a deaf person entering the profession during her training, 'I was told by rotation supervisors that deaf people should not be genetic counselors'. She acknowledged support and advocacy received by her graduate school despite these experiences. The author also acknowledged efforts our profession has made to increase diversity, while falling short on including 'disability' as one of its efforts: 'I have seen this profession make attempts to make this field more diverse. Usually diversity is thought to include people from different socioeconomic, ethnic, and religious background. Why can't diversity include people of "disabilities?"' (Rogel, 2009). Another author, who identifies as queer and Arab, reflected on her graduate school experience:

> *I knew that I would come in [to genetic counseling] 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*
>
> *(Berro, 2019)*

The author goes on to describe a difficult aspect of genetic counseling training that was compounded by her minority identities:

> *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*
>
> *(Berro, 2019).*

During the 2018 Annual Education Conference of the NSGC, one of the plenary speakers of a session titled 'Adapt, Evolve, Thrive' discussed her experiences as a genetic counselor of color and how particular experiences of 'other-ness' led to self-consciousness and fatigue within the profession (Channaoui, 2018).

The firsthand accounts of various minority genetic counselors reflect that sentiments of exclusion exist within the profession. Genetic counseling is not the only medical profession that is impacted by lack of minority representation. Healthcare professions, as a whole, fall short of matching the racial and/or ethnic percentages of their professional body with that of the patients they hope to serve. While other demographic features are likely underrepresented as well, race and/or ethnicity are the features most regularly referenced, catalogued, and surveyed. There are a variety of methods to improve inclusion within a group, organization, or company. These include but are not limited to data collection on diversity and inclusion, data analysis, equitable opportunities for leadership, mentor opportunities, and spaces to express oneself freely.

Copious data indicate that affinity groups are a worthy mechanism to promote inclusion. According to the organization Diversity Best Practices, 'affinity groups contribute to business success through several means: recruitment and retention, product development, creating a positive and supportive work environment and helping to deliver the commitment to diversity and inclusion' (2009). Social Impact Strategist, Mekaelia Davis, expresses the origins and benefits of affinity groups:

> *… affinity groups were created in the 60s as a tool to address racial tensions in the workplace. Employees join these groups to feel present and comfortable being themselves in work environments that often strip individuality from what is deemed as 'professional'. Research shows that they [provide] 'safe spaces for innovation', and best practices in adult learning consistently identify the need for safe environments that allow employees to raise and navigate issues they may not feel comfortable exploring in general spaces*
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> *(Davis, 2018).*

Some of the affinity groups that exist within healthcare professional bodies include the Association of American Indian Physicians, Association of Black Cardiologists, National Council of Asian Pacific Islander Physicians, Association of Black Women Physicians, Artemis Medical Society, National Association of Black Physical Therapists, National Black Association for Speech-Language and Hearing, Sisters in Speech Therapy and Audiology, National Hispanic Dental Association, and the Greater San Antonio Hispanic Dental Association.

Within the genetic counseling profession, the Minority Genetic Professionals Network (MGPN) was formed in November 2018 to provide a forum for genetic counselors from diverse backgrounds to connect with one another (Western States Regional Genetics Network, 2018). The MGPN was created by the Western States Regional Genetics Network 'to address the limited diversity among medical genetic professionals'. Given the large geographical area of the United States, individuals often face difficulties in holding in-person meetings, networking, and programmatic planning. In order to facilitate increased involvement and regular in-person meeting opportunities, minority genetic counselors in the Northeast region of the United States formed an affinity group called Boston Minority Genetic Counselors in 2019. This group is comprised of genetic counselors with social minority identities, and its goal is to promote individual wellbeing of members and create a community of interconnection and support. In this paper, we describe the process of our group's formation and its ongoing work, which could potentially serve as a template for the creation of similar groups.

2 | METHODS

Following the creation of the MGPN, an inaugural MGPN meetup was held at the 2018 Annual Educational Conference in Atlanta, GA. A number of genetic counselors of racial minority backgrounds from New England were able to participate. However, the limited number of potential in-person meetups at national conferences was felt likely to provide insufficient support desired by New England genetic counselors of minority backgrounds.

One genetic counselor of minority race and ethnicity in the Boston area sent an email proposing the creation of a resource for prospective genetic counseling students to four genetic counseling colleagues and students of minority race and/or ethnicity who she had previously met via genetic counseling training program involvement, workplace meetings, and informal networking. The email prompted conversation about not only moderating potential resources, but also coming together as a group on a periodic basis. The desire and need for organized support and conversation among local genetic counselors of minoritized identities became quickly and strongly apparent. Additional colleagues from racial minority backgrounds in Boston were added to the group email thread. Given the small size of the genetic counseling community and even smaller number of genetic counselors of minority backgrounds, multiple members had already met each other through various work-related projects and events. This method of word-of-mouth recruitment was important in building trust and to focus on a community-oriented and relationship-guided group.

To formulate structure for the proceedings of the affinity group, recurrent meetings were proposed to discuss the mission and purpose of our group and how to recruit other individuals. Teleconference calls including audio and video were deemed the most accessible way to review structural components of our group. Teleconference meetings were conducted during work hours monthly. Attendance on each call ranged from 29% (2/7) to 85% (6/7) of our group's membership with median attendance of five members each call (71%).

2.1 | Participants

Our current membership is made up of seven genetic counselors based in the Boston. The majority of our group members identify as women of color and the racial/ethnic backgrounds represented are as follows: Arab (Lebanese and Palestinian) (2/7), South Asian (Pakistani) (1/7), Black (Haitian) (1/7), Latinx (Puerto Rican, Guatemalan, and Cuban) (2/7), and Asian (Chinese) (1/7). All members (7/7) are first generation American or Canadian. Despite our group's initial focus on racial minority connections, there has been an explicit desire to represent and discuss the ways in which we are diverse outside of race. Two of our seven members identify as LGBTQ. A diverse set of religious identities is also represented including Muslim, Catholic, Christian, Jewish, and Agnostic. We can also collectively speak six languages including English, Arabic, Urdu, Haitian-Creole, Spanish, and Chinese with six members who are bilingual.

2.2 | Formulation of our group's name and mission

Initially, our teleconference meetings focused on acclimating to one another and building trust. In little time (i.e., during the first teleconference meeting), we shared our perspectives on exclusion and inclusion during genetic counseling training and professional life. Through our discussions, a prominent theme of support emerged, and it was agreed that adequate support was lacking for us. We presumed this would also be true for other individuals of minoritized backgrounds, whether genetic counseling students or professionals. As we considered the expansion of our group and the support that could be offered, we recognized that race was only one form of diversity and wanted to offer support to individuals who felt isolated in the field of genetic counseling for a variety of reasons, while also acknowledging that the space should feel safe and connected through shared, intersectional, marginalized identities. After much discussion via teleconference meetings, emails, and shared electronic documents, we established a definition for ‘social minority’:

> *A social minority background includes individuals who feel that characteristics of their (born, inherited, or developed) identities are not equally represented, supported, or opportune compared with other identities in their profession and/or society.*

Through this definition, we empower any prospective participant to consider whether their identity impacts their feelings of representation and support or lack thereof. Although males are a statistical minority in the genetic counseling profession, our definition of social minority made the assumption that access to community and support is part of the lived experience of heterosexual, able-bodied, white, cis men and that the experience of lifelong marginalization is not. We cannot assume that heterosexual, able-bodied, white, cis men who are genetic counselors do not have unique support needs; however, we felt that the BMGC was unlikely to be a space to fulfill those potential needs.

Another point of discussion that arose was whether the mission of our group should include efforts to increase minority recruitment for the field or efforts to improve health across communities of social minority identities. While these were initiatives that many of us were passionate about, we unanimously decided that such efforts and responsibilities should not be included in the overarching mission of our group. Participation in these initiatives may resonate for some individuals of social minority backgrounds; however, it is important to note that minority recruitment and health equity improvement are responsibilities that should not be placed solely on individuals of social minority backgrounds. We therefore felt that our group members should not be required or expected to work on initiatives aimed to improve diversity disparities and inequity. There was also discussion around emphasizing inclusion rather than diversity alone. Through much discussion, we adopted the following mission statement:

> *This group is comprised of genetic counselors with social minority identities. Our mission is to promote individual wellbeing of members and create a community of interconnection and support. We hope to provide a safe space to discuss professional issues and concerns related to minority status; a place where we can breathe, behave naturally, and receive support and guidance from peers and colleagues.*

The creation of two ongoing process groups—one for genetic counseling graduate students and one for professional genetic counselors—was identified as a feasible approach to address our mission. We plan to have regularly scheduled (e.g., monthly) teleconference meetings (audio and video). We will also convey the opportunity to participate in the student process group via email to all Program Directors of the GC training programs in New England requesting that the Program Directors forward the email to students enrolled in the program. We anticipate that word-of-mouth recruitment will further expand the professional process group. In-person meetups are anticipated to occur as well with structure for such meetups to be decided at a later time.

In consideration of how to maximize the safe space of the process groups, we knew we would need to gather some preliminary information on prospective process group participants. This led to the creation of an onboarding survey to distribute to prospective members (Figure S1). The survey first asks incoming participants about their interests and current activities. These questions are aimed to ascertain possible needs, skills, and interests of new group members. The subsequent questions in the survey are meant to organize the individual process groups. For example, the prospective participant is asked whether they are a genetic counseling student or professional in order to take into account confidentiality issues and to alleviate situations where a participant might feel uncomfortable sharing school and/or workplace incidents. We additionally ask about race, gender, sexual orientation, disabilities, and other social minority identities. For all of these questions we offer an 'other' option with optional free-text and a 'prefer not to answer' option, as we feel it is important to ensure participants have space to provide their own identifiers and the option to not disclose their own identifiers.

Choosing an appropriate name for our group was paramount to the unity and longevity of our efforts and to potentially widen the possibilities for funding and additional structure in the future. For example, the possibility of legalizing our group as a non-profit organization was raised. More importantly, creating a name for our group brought unity and consensus between us regarding the words we used to describe our group and its mission. In the time period prior to selecting a name, for example, we would often use quotation marks around the words New England or Boston and would have backslashes or commas to depict our identities as diverse, minority, and underrepresented individuals. The process of deliberating and selecting a name for the group symbolically enhanced our sense of connection to the mission of BMGC. We generated a list of ten ideas; over the course of three weeks, we shared our preferences and opinions on these possible names. Ultimately, we came to a consensus on a name that would depict our geographical location and the minority identities of the group's membership: Boston Minority Genetic Counselors (BMGC). While we do not anticipate that all members of the BMGC will reside in the city's geographical zip code regions throughout the entire duration of their involvement with the group, we felt it important to pinpoint the geographical location where in-person meetups would likely be.

3 | CONCLUSIONS

We formed the Boston Minority Genetic Counselors as a support system for geographically close genetic counselors and genetic counseling students with social minority backgrounds in the Boston area. The goal of the BMGC is to increase support and feelings of inclusion. Diversity without inclusion can lead to those of social minority backgrounds having to conform to dominant norms, reinforcing their minoritization, and putting them at risk of losing their authenticity (Center for Talent Innovation, 2012, 2013). According to a 2018 survey of Women in the Workplace, women of color, and especially Black women, receive less support from managers than White women Thomas, 2018), further underscoring the need for support. Feelings of exclusion have already been reported in studies specific to the genetic counseling profession (Kass and Veres, 2016; Mittman and Downs, 2008; Schoonveld et al., 2007). The creation of affinity groups can serve as a mechanism for genetic counselors to feel a sense of belonging. To date, all of us involved in the BMGC unanimously report feeling a sense of relief and comfort, sentiments that are voiced during numerous teleconference meetings and outside of the meetings.

Research has shown that mentorship is an effective method of retaining professionals of underrepresented minorities (Beech et al., 2013; Rodriguez, Campbell, Fogarty, & Williams, 2014). By providing opportunities for genetic counselors and genetic counseling students to facilitate process groups, it is possible that there will be greater retention and recruitment of genetic counseling professionals with social minority backgrounds. By creating, facilitating, and nurturing the group process, genetic counselors and students will also have an opportunity to deepen connections and gain leadership experience within the BMGC network.

4 | FUTURE DIRECTIONS

We believe the formation of the Boston Minority Genetic Counselors is replicable for genetic counselors and trainees in other geographical areas who desire support around topics of social minority identities. Additional research is desired to better elucidate the effect of affinity groups and process groups on inclusion within the genetic counseling profession. In addition to the mechanism of inclusion and support enhancement proposed here, other inclusion initiatives should be assessed and explored. For example, formal curricular changes that value students' life experiences, promote student mental health and wellness, and ensure access to multiple mentorship opportunities for minoritized students are strategies that have been proposed by medical students of minority backgrounds (Fergus, Teale, Sivapragasam, Mesina, & Stergiopoulos, 2018). Such ideas should be assessed for feasibility and utility in genetic counseling training.

AUTHOR CONTRIBUTIONS

Tala Berro, Fatima Amir, Gayun Chan-Smutko, Janette Lawrence, and Nadine Channaoui contributed substantially to the conception and design of the work, drafting and revising intellectual content, and final approval of the version to be published. All five authors agree to be accountable for all aspects of the work ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

COMPLIANCE WITH ETHICAL STANDARDS

Conflict of interest

Tala Berro, Fatima Amir, Gayun Chan-Smutko, Janette Lawrence, and Nadine Channaoui declare that they have no conflicts of interest.

Human studies and informed consent

Additional informed consent was obtained from all participants for which identifying information is included in this article.

Animal studies

No non-human animal studies were carried out by the authors for this article.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Berro T, Amir F, Chan-Smutko G, Lawrence J, Channaoui N. Creation and utility of 'Boston Minority Genetic Counselors'. *J Genet Couns*. 2020;00:1–6. https://doi.org/10.1002/jgc4.1268