

Addressing the Lesbian, Gay, Bisexual and Transgender Cultural Competency Gap in Genetic

Counseling:

A Curriculum Pilot Study

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### Abstract

Previous studies have reported that 90.1% of genetic counselors know they have counseled a patient who identifies as Lesbian, Gay, Bisexual or Transgender (LGBT). Since unique health disparities exist within the LGBT population, studies have found significant benefit to LGBT patient care curriculum in medical training programs. Of genetic counselors surveyed in past studies, few (17%) had received LGBT specific training and most (61%) desired such training. This information suggests a need for LGBT topics to be implemented into the education of genetic counselors. This study tests this hypothesis by development, implementation and assessment of a replicable LGBT curriculum that was observed by 21 students currently enrolled in a genetic counseling training program. The curriculum was developed by review of literature regarding present LGBT issues in health care and genetic counseling, as well as methods of teaching cultural competency. The curriculum was assessed using participant completion of the adapted Sexual Orientation Counselor Competency Scale (SOCCS) pre- and post-curriculum observation. The SOCCS allowed for assessment of the change in sexual orientation competency of genetic counseling students in the areas of knowledge, attitudes and skills due to this curriculum. Additionally, a Knowledge-Based Survey specific to genetic counseling was used to further assess the benefits. The curriculum developed as a result of this study was shown to improve participants' total sexual orientation competency, knowledge and skills on providing genetic counseling to the LGBT population. Students reported that they believed the curriculum would serve as a useful reference in their careers and were, on average, overall satisfied with the content and presentation of content. Additional findings and methods for implementation and adaptation for use in future genetic counseling trainings are presented.

*Keywords: Genetic Counseling · Lesbian, Gay Bisexual and Transgender (LGBT) · Education · Cultural Competency · Sexual Orientation*

Addressing the Lesbian, Gay, Bisexual and Transgender Cultural Competency Gap in Genetic Counseling: A Curriculum Pilot Study

**Introduction & Background**

Genetic counselors encounter lesbian, gay, bisexual and transgender (LGBT) patients in all areas of genetic medicine. Specifically, 90.1% of genetic counselors know they have counseled a LGBT identified patient (Dean Glessner, Vanden-Langenber, McCarthy & LeRoy, 2012). Members of the LGBT community, an estimated 2.3% of the US population, have additional, significant health risks compared to the general population (National Center for Health Statistics [NCHS], 2014). These health risks include increased rates of alcohol consumption, smoking and drug use, increased risk for mental health conditions such as depression and increased development and death rates of some cancers (Brandenburg, Matthews, Johnson & Hughes, 2007; Fredrisken-Goldsen, Hyun-Jun, Barkan, Muraco & Hoy-Ellis, 2013; Laine-Austin & Irwin, 2010; Machalek et al., 2012). The LGBT population faces many barriers in access to health care, disease prevention methods or insurance coverage (Conron, Mimiaga & Landers, 2010; Diamant, Schuster & Lever, 2000; Johnson, Mimiaga, & Bradford, 2008). Even when health care is attainable, LGBT patients generally receive second-rate health care and experience stigma and mistreatment by healthcare professionals (Scherzer, 2000). Therefore, it is essential that genetic counselors develop attitudinal awareness, medical knowledge, and patient-first language to best meet the needs of their LGBT patients.

The health disparities seen in the LGBT population are reported to be due, in part, to the inadequate knowledge and insensitivity about the unique needs of the LGBT population among health care providers. This lack of cultural competency towards the LGBT population is likely because of minimal LGBT-specific education in health care professionals' training. Many

professional training programs have yet to implement LGBT cultural competency training into their curriculum.

Within the genetic counseling profession there is clear recognition of the need to prepare genetic counselors for working with minority and underserved clients. The Accreditation Council for Genetic Counseling (ACGC) states that a competent genetic counselor can “apply genetic counseling skills in a culturally responsive and respectful manner to all clients” (Accreditation Council of Genetic Counseling [ACGC], 2013). This is a practice-based competency for genetic counselors, meaning training programs must ensure students have the knowledge, skills and attitudes to meet this competency before entering practice. Thus, similar to other health care professions in North America, cultural competency training is required in education programs for genetic counseling. The training that does exist in the education of health care professional groups, however, varies dramatically within and between professions with regard to the minority groups being addressed and topics being taught (Priester et al., 2008). Despite the clear need for LGBT topics, lesbian, gay, bisexual or transgender populations are often not included in multicultural training. In the training standards for genetic counseling programs delineated by ACGC, there is no specific mention of LGBT topics and skills as a content area to cover or a competency to develop in students. In a self-report study of 213 genetic counselors, few (17%) reported ever receiving LGBT specific training and most (61%) desired such training (Dean Glessner et al., 2012).

As more research focuses on the disparities in health care and unique needs of the LGBT population, it is essential professional training programs respond with appropriate education to address these needs. Since 2012, the U.S. Department of Health and Human Services (HHS) encouraged all healthcare training programs to develop and implement LGBT cultural

competency curricula because “the lack of culturally competent providers is a significant barrier to quality health care for many LGBT people.” (U.S Department of Health and Human Services, 2012). Bidell (2013) demonstrated that 23 master-level counseling students enrolled in an LGBT counseling course had significantly higher knowledge, skills and attitudes for working with LGBT patients than a comparison group. Similarly, Rutter et al. (2008) reported 21 graduate students showed positive changes in sexual orientation competency as a result of an LGBT training program. As a consequence of studies demonstrating the benefit of LGBT training, a growing number of counseling and psychotherapy training programs, medical schools, pharmaceutical care programs and social work programs are evaluating their LGBT curriculum content, designing curriculums and implementing them (Bidell, 2013; Grezinski, 2009; Mandap, Carrillo & Youmans, 2014; Obedin-Maliver et al, 2011; Rutter, Estrada, Ferguson, & Diggs, 2008). This indicates an LGBT curriculum has great potential to be beneficial in genetic counseling training programs; however, this has yet to be studied within the genetic counseling profession.

Some health care professional governing bodies have published specific practice standards/guidelines/competencies for working with LGBT populations. Professional psychologists have significantly contributed to the LGBT competency movement with the American Psychological Association (APA) being one of the first professional governing bodies to release practice guidelines specific to sexual orientation (American Psychological Association [APA], 2012). APA used an evidence-based approach to develop 21 broad guidelines established to outline the topics of attention and knowledge psychologists should have when working with LGBT patients and how to appropriately use this knowledge in practice.

Other governing bodies of health care professions have also produced standardized guidelines to develop LGBT competency in trainees and professionals. (ALGBTIC LGBTQIA Competencies Taskforce, 2013; Society of Teachers of Family Medicine, 2013). The American Counseling Association (ACA) and the American Academy of Family Physicians (AAFP) are among these groups, both using a consensus-driven approach. ACA and AAFP publications together define over 170 measurable or observable knowledge, skills, abilities, and behaviors/attitudes critical to providing appropriate and respectful care to LGBT clients. Many of the universal themes within the ACA, APA and AAFP publications are directly applicable to genetic counseling and can provide a framework for development of learning objectives for a genetic counseling LGBT curriculum. Developing and assessing the benefits of a genetic counseling curriculum using this framework is an important step towards standardizing LGBT training in genetic counseling and effectively leading to more consistent care and positive health outcomes for LGBT patients.

### **Purpose of Current Study**

The purpose of this study is to determine whether implementation of an LGBT cultural competency curriculum into a genetic counseling training program impacts students' competence respective to providing genetic counseling services to this population. This study sought to develop, implement and assess a replicable LGBT curriculum into the current curriculum of the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College. Second year genetic counseling students were assessed in terms of changes in LGBT knowledge, counseling skills and general attitudes to determine if changes in any of these categories was correlated to the implementation of the curriculum. This analysis allowed for further delineation of beneficial

LGBT topics and learning objectives for genetic counselor training and makes suggestions on effective methods for teaching LGBT topics.

## **Materials and Methods**

### **Participants**

All participants were second year graduate students in the genetic counseling program at Sarah Lawrence College.

### **Instrumentation**

**Education Questionnaire.** A short questionnaire was developed to determine the number of hours of previous LGBT cultural competency training participants have received, the format of this training and if it occurred during their current genetic counseling education.

**Sexual Orientation Counselor Competency Scale (SOCCS).** The Sexual Orientation Counselor Competency Scale is a widely used, psychometrically valid tool (Bidell, 2013; Rutter et al., 2008) developed to assess the lesbian, gay and bisexual (LGB) cultural competency of counselors. The SOCCS assesses three areas identified as necessary to be a culturally competent counselor, particularly knowledge, awareness and skills. The SOCCS was adapted to better reflect the role of the genetic counselor. The adapted SOCCS consisted of 27 items separated into three subscales: skills for counseling LGB patients (11 questions), attitudes towards the LGB population (10 questions) and knowledge of specific LGB healthcare-related issues (six questions) (Bidell, 2005). Calculation of overall scores involves an exploratory factor analysis, taking into account principal-axis factors with oblique rotation. Bidell (2005) reports ranges of

scores that indicate low (1.00-2.00), moderate (3.00-5.00) and high (6.00-7.00) levels of sexual orientation competency.

**Knowledge-Based Survey.** A questionnaire was developed to assess knowledge of LGBT-specific healthcare and genetics issues. Consisting of 7 multiple choice and 8 true/false questions on terminology, pedigree notation, health disparities and best practice for LGBT patients, it assessed specific learning objectives established for the workshop.

**Workshop Evaluations.** Evaluations were created for the three workshop components including two guest speakers and the “Coming Out” Panel. Evaluations for the guest speakers contained 12 Likert-scale measures in the areas of content, presentation and audiovisual aids. Additional written feedback was encouraged. The 2014 version of the American College of Health Executive’s Education Panel Discussion Form was used for evaluation of the “Coming Out” Panel (American College of Health Executives [ACHE], 2014).

## **Procedure**

The LGBT cultural competency workshop was conducted as two, three-hour sessions as part of a professional issues course. Attendance at the workshop was mandatory for completion of the course. The SOCCS, Knowledge-Based Survey and Education Questionnaire were administered to the participants at the beginning of the first session of the workshop and then the SOCCS and Knowledge-Based Survey again at the completion of the final session of the workshop. The Workshop Evaluations were administered at the end of each day of the workshop. The participants were asked to assign themselves a code to maintain anonymity and pair pre-workshop with post-workshop results and consent forms.

## Curriculum Development

Learning objectives were created within four main themes: (1) attention to relationship and family structure, (2) inclusive and respectful communication, (3) self-awareness, and (4) continued education and professional development (see Table I). The themes were based on issues described in existing literature, published guidelines and competencies in fields similar to genetic counseling. The four themes were universally represented in the established practice guidelines and standards for LGBT cultural competency by three organizations (ALGBTIC LBQQIA Competencies Taskforce, 2013; APA, 2012; Society of Teachers of Family Medicine, 2013).

Learning objectives surrounding areas of attention to the coming out process, self-actualization and family history or family building were all created based on the common theme of attention to relationships and family structures. ACA, APA and AAFP emphasize the importance for healthcare professionals to understand the unique family structures that may exist for LGBT individuals and how these may change over time. One example mentioned by ACA is that many LGBT individuals adopt a “family of choice,” comprised of supportive people who may not be biological relatives. It is thus important to consider barriers to communication with biological relatives and how these may affect the gathering and dissemination of information, such as obtaining family history information, medical records and preventative care recommendations, in a genetic counseling setting. Additionally, all three organizations highlight the necessity of providers to respect the validity and normalcy of same-sex attraction and same-sex parenting. Genetic counselors should understand family structures and dynamics for the purposes of taking family histories and addressing psychosocial concerns associated with relationships and family structure.

In addition to attention to relationship and family structure, knowledge about the coming out process, importance of disclosure, use of inclusive language and development of practical skills were also included in the learning objectives based on the significant focus of these by the other organizations. All three groups placed strong emphasis on correct terminology and inclusive language within practice, medical forms and patient-friendly information. More specifically, ACA encourages the use of the term “partner,” as opposed to more narrow terms, and also encourages space on intake forms for patients to self-identify gender and sexual orientation. Due to the constant evolution of accepted terminology, the organizations encourage health care professionals to seek out frequent updates through research or continuing education. Use of inclusive terminology is important within genetic counseling in order to respectfully communicate with patients, record medical facts and convey these facts to other professionals where required.

The third theme of self-awareness surrounded awareness on the part of the health care professional towards themselves, their profession and society as a whole. Learning objectives were developed based on these concepts as self-awareness through self-reflection was encouraged by all three organizations. Self-reflection allows for the recognition of how attitudes, identities and biases of health care providers influence patient care and relationships with patients. The importance of dedicated time to explore these issues, allowing for their recognition, was outlined in the publications. This theme is also supported by the genetic counseling practice-based competency of self-awareness, which states genetic counselors should be aware of their personal biases in order to provide culturally competent care (ACGC, 2013).

Finally, the theme of continued education and professional development was incorporated into learning objectives by addressing the role of cultural competency and its

recommended uses in genetic counseling. Continued education and professional development is encouraged by the ACA, APA and AAFP to maintain an acceptable level of competency in LGBT care in the context of ever-evolving research, terminology and understanding of this population. The publications suggest consultation with other health care providers, continuing education programs and exploration of current research to fulfill this need. Genetic counselors are required to engage in continuing education (ACGC, 2013) and therefore this is applicable within the context of genetic counseling for the LGBT population.

After the exploration of common themes amongst the ACA, APA and AAFP publications, unique aspects of genetic counseling were considered and three themes arose, which included being able to: (1) provide genetic counseling to LGBT identified individuals about reproductive and family building options; (2) take an appropriate family/medical/pregnancy history with proper pedigree notation; and (3) recommend appropriate disease screening and prevention strategies for LGBT identified individuals.

A genetic counselor's role in LGBT family building and consideration of associated issues were also included in the curriculum learning objectives. AAFP recommends family physicians have the skills to counsel LGBT couples about reproductive choices and the resources available to aid them (Society of Teachers of Family Medicine, 2013). This is consistent with another practice-based competency for genetic counselors, which states genetic counselors must have expertise in the area of human reproduction, including assisted reproductive technologies (ACGC, 2013).

Family, medical and pregnancy histories are essential components of the genetic counseling session. All genetic counselors must be capable of “construct[ing] relevant, targeted and comprehensive personal and family history and pedigrees” (ACGC, 2013). To accomplish

this, a genetic counselor must conduct a session in an inclusive manner, irrespective of a patient's gender identity or sexual orientation. Learning objectives were therefore developed around issues of inclusivity and differences that exist pertaining to the medical, pregnancy and family histories for LGBT identified individuals.

Lastly, learning objectives regarding identifying and discussing preventative care were included in the workshop since genetic counselors often discuss preventative care methods with patients (ACGC, 2013) and these differ for transgender individuals. This requires genetic counselors to be knowledgeable in transgender healthcare, as gender affirmation takes many forms and transgender individuals may retain organs specific to their sex assigned at birth. For example, it is crucial genetic counselors recognize the importance of gathering correct anatomical information to make recommendations for cancer screening.

Once learning objectives addressing all seven themes were established, they were organized into relevant categories to allow for workshop development (Table I).

### **Workshop Format and Structure**

The workshop was divided into discrete modules. Several authors suggest ways LGBT cultural competency training could be implemented, including devoting a set class or interspersing content within other courses (Biaggio, Orchard, Larson, Petrino, Mihara, 2003; Bidell, 2013; Carroll & Gilroy, 2001). Both methods have advantages. Allotting for a separate class ensures training will be provided by integrating content into an existing core curriculum thereby helping to normalize the topic. Consequently, our curriculum was developed as distinct modules designed to either stand alone, or be integrated into pre-existing courses. Table I lists

the modules and their titles, learning objectives for each module, educational activity type and which main theme each module addresses.

One of the educational activities included a “Coming Out” panel, which consisted of two LGBT identified individuals telling their personal stories, followed by a question and answer segment. A panel of gay and lesbian individuals exposes students to this population and dispels stereotypical beliefs (Biaggio, Orchard, Larson, Petrino, Mihara, 2003). Panel discussions also aid LGBT cultural competency training by promoting awareness and knowledge of LGBT issues and student interest in such matters (Bidell, 2013). Another activity included a reflection exercise students completed between the two sessions of the workshop. Participants were instructed to assess their current clinical rotation sites for LGBT inclusiveness and to brainstorm methods for creating better environments to foster disclosure of sexual orientation and gender identity to health care professionals.

An additional educational activity was a role-play session with the goal of demonstrating incompetency within a genetic counseling session and identifying techniques to improve patient care. Peer role-play has been shown to improve patient care performance, increase a student’s perception of their ability and increase empathy (Bosse et al., 2012). Due to the large number of students in the second year genetic counseling class at Sarah Lawrence College, vignette analysis was used in place of peer role-play and two pre-recorded vignettes were shown. One addressed appropriate intake of a transgender individual whose identified gender and name did not match their medical record. The other involved a gay couple, one of whom had tested positive for MUTYH-associated polyposis, and the couple’s reaction to how surgery would affect their sex life. Students watched the vignettes and then discussed the differences between the two

situations, what techniques were employed to provide better patient care and brainstormed additional improvements that could be made.

### **Ethical Considerations**

The investigators obtained ANDRUS Institutional Review Board (IRB) approval. Participants were given an information sheet that outlined the study, risks and benefits, measures taken to protect confidentiality, and instructions for opting out of having their scores used in the study.

## **Results**

### **Respondents**

Twenty-one students participated in the curriculum and consented for their test and survey responses to be used for research purposes.

### **Education Questionnaire**

Two percent (2%) of respondents reported never having received any education related to LGBT topics and 52% of respondents reported having received less than 2 hours of education related to LGBT related topics in their current or previous education. The average amount of education reported was 1.94 hours. On average, of those who reported having received any LGBT education, approximately 25% was reported to be during their current genetic counseling training.

### **SOCCS**

When comparing average pre-workshop and post-workshop scores, students' skills score changed from within the low competency range to within the moderate range and knowledge

changed from moderate to high range. There was no change in attitude range. Similar results were found when a paired sample t-test analysis was performed on SOCCS scores to compare scores pre-workshop and post-workshop. There were significant increases in scores in the Total Sexual Orientation Counselor Competency Scale score after the training ( $t(20) = 5.78, p < .001$ ) and in the Skills ( $t(20) = 7.42, p < .01$ ), and Knowledge Subscales ( $t(20) = 5.09, p < .001$ ). There were no increases in the Attitude subscale ( $t(20) = -.48, n.s.$ ). The mean SOCCS pre-workshop and post-workshop scores and subscale scores are presented in Table II.

The Sexual Orientation Counselor Competency Scale and subscales pre-workshop scores were not found to be related to the number of previous hours of education in LGBT issues. The number of previous hours in genetic counseling training on LGBT issues was positively correlated with the total SOCCS pre-workshop scores ( $r(18) = .53, P < .01$ ), the Skills subscale ( $r(19) = .47, P < .05$ ) and the Knowledge subscale ( $r(18) = .57, P < .01$ ) pre-workshop scores. The only part of the pre-workshop SOCCS that was not related to the percentage of hours in genetic counseling was the Attitudes subscale ( $r(18) = -.14, P = .28$ ).

### **Knowledge-Based Survey**

Paired sample t-test analysis was performed on Knowledge-Based Survey scores to compare scores pre-workshop and post-workshop. There was a significant increase from pre-workshop score to post-workshop score ( $t(20) = 3.48, p < .01$ ). The test scores increased from 78% ( $SD = 0.13$ ) before the training to 87% ( $SD = 0.08$ ) after the training. Knowledge-Based Survey scores are summarized in Table II.

Pre-workshop scores on the knowledge test were not correlated with either the number of hours of education on LGBT topics ( $r(18) = -.01, P = .48$ ) or the percentage of hours in genetic counseling training on LGBT issues ( $r(18) = .10, P = .34$ ).

The Knowledge-Based Survey created for this study had scores that were positively correlated to the Sexual Orientation Counselor Competency Scale scores ( $r(19) = .63, p < .01$ ) and the Skills ( $r(19) = .46, p < .05$ ), Attitudes ( $r(19) = .52, p < .01$ ) and Knowledge ( $r(19) = .50, p < .05$ ) subscale scores.

The most common question answered incorrectly upon pre-workshop testing was in regard to identifying specific health disparities that exist for the lesbian population. Pre-workshop, 14 out of 21 participants answered this question incorrectly, while after the workshop three students answered incorrectly. A question addressing the need for prostate cancer screening for transgender women who have undergone gender-affirming surgery was also commonly answered incorrectly, with 10 out of the 21 students answering incorrectly pre-workshop and two students post-workshop.

Two questions were answered incorrectly more frequently after observation of the workshop than before. These questions dealt with colon cancer screening for gay men and the use of reproductive lawyers by the LGBT community.

### **Workshop Evaluation**

*Knowledge of Terms, Genetic and Legal Issues* received average overall performance evaluations within the good-excellent range. One participant commented that “[the lecture] provided us with information we would not learn elsewhere.” Many participants expressed a desire for more information regarding the intersex population and disorders of sexual

development/differentiation. Participants ranked the module highly in the categories of presentation, content and visual aid quality, with the lowest ranking being for active participation/critical thinking.

*Transgender Health in Genetic Counseling* received overall reviews in the excellent range, with a mean ranking of 5 out of 5 for content, presentation and visual aids. The majority of comments mentioned the speaker's excellent and engaging presentation skills.

*Medical and Family History Taking for LGBT-Identified Individuals* was called a "nice, concise overview [of the topic]" by a participant. The majority of participants ranked the module as overall excellent, and content, presentation and visual aids were, on average, ranked 5 out of 5.

*The 'Coming Out' Panel* panelists and moderator were, on average, ranked between 4 and 5 out of 5 for knowledge of subject and presentation of content. The majority of participants believed the panel was beneficial and relevant to their learning. Multiple participants expressed a desire for more time for questions.

### **Workshop Execution**

Based on content covered at the time of implementation, the workshop did not successfully address learning objectives related to previous barriers to health care LGBT people have faced (such as the HIV/AIDS epidemic), nor did it address the legal issues that gay and lesbian couples may encounter when family building.

## **Discussion**

The results of this study indicate the implementation of an LGBT curriculum improves genetic counseling students' sexual orientation and gender identity cultural competency. The overall SOCCS scores showed a statistically significant increase after completion of the workshop from a moderate competency range to a moderate-high competency range (Bidell, 2005). This finding is consistent with previous studies that analyzed the effectiveness of an LGBT curriculum for graduate-level counseling students (Bidell, 2013; Rutter et al., 2008). In addition, there was a significant increase in the Knowledge-Based Survey scores in our study. Together this demonstrates our curriculum increased the LGBT cultural competency of genetic counseling students who participated in our study.

### **Awareness, Knowledge and Skills**

Through the use of the psychometrically valid SOCCS and the Knowledge-Based Survey developed for this study, we established that our LGBT Cultural Competency Workshop improved the awareness, knowledge and skills of genetic counseling graduate students. Within the SOCCS, the most significant average score increase was seen on the skill subscale (from 2.27 to 3.59). This finding mirrors those of previous studies (Bidell, 2013; Rutter et al., 2008) and suggests an overall lack of LGBT education prior to curriculum implementation. The significant increase in scores on the Knowledge-Based Survey (78% pre-workshop to 87% post-workshop score) and the significant increase in the knowledge subscale of the SOCCS (4.40 pre-workshop to 5.35 post-workshop score) indicate a positive impact of our curriculum. A previous study found an increase in the scores of the knowledge subscale (Bidell, 2013) while another study saw no significant increase in this domain (Rutter et al., 2008). This may be due to the fact that the latter study utilized only two hours of training, one hour of lecture and another hour of role-play.

Therefore, less time was devoted to knowledge dissemination (Rutter et al., 2008). Our results suggest the didactic lectures, reflection activities, panel discussion, and vignette analysis, which comprised our workshop, were important factors that increased LGBT cultural competency of the genetic counseling students in this study.

The attitudes subscale of the SOCCS had no significant change from pre-workshop to post-workshop score. In contrast to the current study, Bidell (2013) found a significant increase in the attitudes subscale of the SOCCS with implementation of an LGBT course into a counseling curriculum. The participants in both the current study and Bidell (2013), however, had similar post-workshop scores (6.74 and 6.80 respectively), indicating the insignificant change in our study was likely due to higher pre-workshop awareness scores (6.79). Rutter et al. (2008) had similar findings with attitude scores and proposed an inclusive environment at the training program of study as an explanation for the lack of a significant change in these scores (Rutter et al., 2008). Other studies also suggest an inclusive environment and LGBT identified colleagues and professors improve attitudes and LGBT cultural competency (Biaggio et al., 2003; Israel & Selvidge, 2003). The Princeton Review currently ranks Sarah Lawrence College amongst the top 20 LGBT-friendly colleges in the United States (Princeton Review, 2015) and, therefore, may be expected to have an overall LGBT-positive environment. It is thus possible the inclusive environment at the Joan H. Marks Graduate Program in Human Genetics, in addition to daily interactions with LGBT identified colleagues, resulted in the high pre-workshop awareness subscale scores. The environment of our program may not be reflective of the environment of all genetic counseling programs and, therefore, this curriculum has the potential to significantly improve attitudes of graduate students in other genetic counseling programs.

### **Curriculum Revisions and Implications for Replication and Further Adaptation**

While this curriculum was developed with the intent for it to be shared with and implemented at other genetic counseling programs in a uniform manner, certain aspects of the workshop will need to be uniquely adapted for different programs. Standardization of sections of the curriculum was achieved by the use of pre-recorded lectures and activities that can be easily adapted to other settings. The following is an analysis of each workshop module and suggestions for improvement and/or adaptation.

The Cultural Competency Awareness module was effective and can be easily adapted by other programs. While student evaluations were not completed, a reflective critique indicated this mini-lecture and self-reflection activity led to increased awareness of self-identity and what influences it. This was demonstrated through class discussion and a high level of engagement of the students. This activity can be used to initiate the discussion of cultural competency in any class setting.

The module, Knowledge of LGBT Terms, Genetic and Legal Issues, was successfully implemented via a pre-recorded lecture by a guest speaker. Student evaluations were very positive and it is likely this lecture contributed to the increase in knowledge of LGBT terms and issues seen in our study. This module did not cover the use of reproductive lawyers by the LGBT community as hoped, which likely resulted in a high incorrect response rate on the question pertaining to this topic on the Knowledge-Based Survey. Our plan is to include this topic as we revise this module for future uses. In addition, we would suggest genetic counseling programs schedule a talk regarding disorders of sexual development (DSDs) to complement this workshop, as this was an area where students wished for more information.

A “Coming Out” panel turned out to be a powerful way to present the Experiences and Challenges of the Coming Out Process module. Students rated this portion of the workshop very highly, and many responded with a desire for additional time for panelists to tell their stories and for questions. We would recommend between one and one and a half hours for the “Coming Out” Panel instead of the 45 minutes initially scheduled. This module likely increased participants’ knowledge of the issues faced by LGBT patients. While the attitudes subscale score did not increase in our study, this module could potentially help to increase attitudes in other genetic counseling programs. Other genetic counseling programs could draw upon their students and local LGBT groups to recruit individuals willing to discuss their stories and answer questions about coming out. The learning objectives and goals for this module should be reviewed with all panelists. Students and panelists should be made aware that this module requires a safe space and although all questions should be encouraged, the panelist for personal reasons can decline to answer any question.

The module that addressed Medical and Family History Taking for LGBT-Identified Individuals took the form of a lecture and practice activity. This module received positive student evaluations and likely contributed to the increase in the knowledge and skills subscale scores seen in this study. This portion of the workshop took longer than expected, however, we suggest additional time be allotted, as it is a topic that needs to be covered in adequate depth. Due to scheduling constraints, the “Developing LGBTQ Cultural Competency Family History Taking Skills” lecture was pre-recorded and students were instructed to watch the lecture and do the practice pedigree problems independently. It cannot be guaranteed all participants undertook this portion of the workshop, which may have influenced some of our results related to the workshop’s desired learning objectives (See Table I). The development of this lecture led to the

realization that there is a need for a consensus within the genetic counseling profession for standardized nomenclature of LGBT related symbols on pedigrees. This could be a future area of research.

A guest speaker, a nurse with expertise in LGBT related health care issues, lead an interactive presentation addressing the following modules: Transgender Health in Genetic Counseling, Health Disparities and the Importance and Facilitation of Sexual Orientation Disclosure. This content covered in this session likely contributed to the increase in the skills and knowledge of the participants in our study. The question on the Knowledge-Based Survey, which saw the greatest increase in correct responses post-workshop pertained to health disparities, a topic covered by the guest speaker. One question, which saw a decrease in correct answers, had to do with screening for colon cancer in the gay male population. Although the guest speaker reviewed this topic, it is possible content covering the increased risk for anal cancer in this population was confused with colon cancer during the post-workshop test, leading to incorrect answers. This section of the curriculum will need to be individually coordinated by each program that implements our curriculum. A subject matter expert can be identified using local LGBT health centers or advocacy groups. Student evaluations indicate the importance of a guest speaker who is engaging and open to answering questions. The detailed learning objectives and other components of the curriculum can be used to aid these individuals when building their lecture for this portion of the curriculum.

The self-reflection homework assignment was an aspect of the Importance and Facilitation of Sexual Orientation Disclosure module. While students were given this exercise, there was not adequate time to discuss it on the last day of the workshop. Additional time should be added to this module for discussion of the assignment.

The final module of the workshop, Skills of an Effective LGBT Genetic Counselor utilized viewing of videotaped vignettes and discussion. Thirty minutes were allotted for this module, however, more time was needed for discussion. The large class size at Sarah Lawrence College resulted in difficulty implementing a role-play component of the workshop. Others suggest role-playing is integral to developing cultural competency (Kocarek & Pelling, 2003). When feasible in future implementation of this curriculum, the situations outlined in the vignettes can be used in role-play activities.

### **Limitations**

The instruments used to measure cultural competency have several restrictions. The SOCCS relies on self-reporting; therefore, it cannot measure the unconscious attitudes and beliefs that inform participants' way of thought (Bidell, 2013). The SOCCS and Knowledge-Based Survey do not assess how the education gained during the workshop translates into clinical practice or patient satisfaction changes (Bidell, 2013). An additional restriction of the SOCCS is the lack of assessment of transgender cultural competency. To protect anonymity of participants, demographic information, including sexual orientation, was not collected. It is possible participants who identify as LGBT may have had higher pre-workshop scores, affecting the overall average.

### **Conclusion**

The results of this study indicate our LGBT Cultural Competency Workshop improved genetic counseling students' awareness, knowledge and skills for providing genetic counseling services to LGBT identified individuals. Further research is needed to assess the effect of this curriculum on students' attitudes. This workshop achieved a positive change through the use of

didactic lectures, workshops, interactive activities and vignette analysis. Other genetic counseling training programs can adopt this replicable curriculum to address the gaps that currently exist within the training of genetic counseling professionals (Glessner et al., 2012; VandenLangenberg et al., 2012). It is imperative LGBT-identified individuals receive culturally competent genetic counseling services. This not only results in better patient care, but also works towards reducing health disparities in this underserved population.

Katie Gallagher, Thomas Ward and Amber Gamma declare that they have no conflicts of interest.

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

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**Table I:** Curriculum development and workshop modules for the LGBT cultural competency workshop.

<b>WORKSHOP MODULE</b>	<b>EDUCATIONAL ACTIVITY</b>	<b>LEARNING OBJECTIVES<sup>(Theme)</sup></b>
<b>PART 1</b>		
Cultural Competency Awareness (30 minutes)	<ul style="list-style-type: none"> <li>• Self-reflection activity</li> <li>• Discussion</li> <li>• Didactic lecture</li> </ul>	<ul style="list-style-type: none"> <li>• Explore personal identities<sup>(3)</sup></li> <li>• Understand individuals may identify with more than one identity or culture<sup>(3)</sup></li> <li>• Define cultural competency and its importance<sup>(4)</sup></li> <li>• Summarize recommendations for cultural competency<sup>(4)</sup></li> <li>• Know the prevalence of LGBT individuals in the population<sup>(2)</sup></li> </ul>
Knowledge of Terms, Genetic and Legal Issues (30 minutes)	<ul style="list-style-type: none"> <li>• Didactic lecture</li> </ul>	<ul style="list-style-type: none"> <li>• Understand and use correct LGBT terminology<sup>(2)</sup></li> <li>• Differentiate between sex and gender<sup>(2)</sup></li> <li>• Appreciate that LGBT terminology varies and changes with time<sup>(2)</sup></li> <li>• Describe reproductive options for LGBT individuals<sup>(5)</sup></li> <li>• Assess the role of the genetic counselor in LGBT family building<sup>(5)(1)</sup></li> <li>• Understand challenges associated with insurance coverage<sup>(3)(5)</sup></li> <li>• Identify legal issues faced by LGBT individuals with family building<sup>(1)(3)</sup></li> <li>• Refer LGBT individuals to appropriate resources and legal aid<sup>(1)(3)</sup></li> </ul>
Medical and Family History Taking for LGBT-Identified Individuals (20 minutes)	<ul style="list-style-type: none"> <li>• Didactic lecture</li> <li>• Question activity</li> </ul>	<ul style="list-style-type: none"> <li>• Use appropriate notation and symbols when constructing pedigrees of LBGT individuals and their families<sup>(6)</sup></li> <li>• Correctly notate biological and social relationships when constructing pedigrees<sup>(6)</sup></li> <li>• Use inclusive language when collecting family history and medical information from LGBT identified individuals</li> </ul>
Experiences and Challenges of the Coming Out Process (45 minutes)	<ul style="list-style-type: none"> <li>• Panel discussion</li> </ul>	<ul style="list-style-type: none"> <li>• Have knowledge of the personal stories about the coming out process<sup>(1)(2)</sup></li> <li>• Recognize the coming out process is a variable, constant process<sup>(1)(2)</sup></li> <li>• Realize the influence of other identities in LGBT identified individuals<sup>(2)</sup></li> <li>• Assess the psychosocial issues related to the coming out process<sup>(2)</sup></li> </ul>

INDEPENDENT LEARNING ACTIVITY		
Barriers to Healthcare in the Clinic Setting	<ul style="list-style-type: none"> <li>• Clinical Assessment</li> <li>• Self-Reflection</li> <li>• Discussion</li> </ul>	<ul style="list-style-type: none"> <li>• Observe and reflect on common barriers to access to healthcare by the LGBT population<sup>(2)</sup></li> <li>• Brainstorm and develop methods to create and improve an LGBT inclusive atmosphere in a health care setting<sup>(2)(4)</sup></li> <li>• Recognize the different barriers that exist between clinical settings and appreciate different approaches to promoting LGBT inclusivity<sup>(2)(4)</sup></li> <li>• Realize clinical applications of inclusive language to promote disclosure of sexual orientation and gender identity<sup>(2)(4)</sup></li> </ul>
PART 2		
Transgender Health in Genetic Counseling (30 minutes)	<ul style="list-style-type: none"> <li>• Interactive workshop</li> </ul>	<ul style="list-style-type: none"> <li>• Define gender identity and gender expression<sup>(2)</sup></li> <li>• Explain the medical/surgical options and psychological processes of gender transition<sup>(2)</sup></li> <li>• Recommend appropriate screening and prevention methods<sup>(7)</sup></li> <li>• Understand psychosocial issues that are faced by transgender individuals<sup>(1)(2)</sup></li> <li>• Characterize the reproductive and family building options available for transgender individuals<sup>(5)</sup></li> </ul>
Health Disparities (30 minutes)	<ul style="list-style-type: none"> <li>• Interactive workshop</li> </ul>	<ul style="list-style-type: none"> <li>• Differentiate past and current barriers LGBT individuals encounter accessing health care<sup>(3)</sup></li> <li>• Chronicle the origin of health disparities faced by the LGBT community<sup>(3)</sup></li> </ul>
The Importance and Facilitation of Sexual Orientation Disclosure (30 minutes)	<ul style="list-style-type: none"> <li>• Interactive workshop</li> </ul>	<ul style="list-style-type: none"> <li>• Describe the value of sexual orientation disclosure to a health care professional<sup>(2)</sup></li> <li>• Appreciate the importance of an inclusive atmosphere in a health care setting<sup>(2)</sup></li> <li>• Know ways to facilitate disclosure including use of language, inclusive intake forms and clinical environment<sup>(2)</sup></li> </ul>
Skills of an Effective LGBT Genetic Counselor (30 minutes)	<ul style="list-style-type: none"> <li>• Vignette analysis</li> <li>• Interactive workshop</li> <li>• Discussion</li> </ul>	<ul style="list-style-type: none"> <li>• Use necessary skills to elicit a complete family and medical history in a culturally competent fashion.<sup>(2)(3)</sup></li> <li>• Recognize psychosocial issues that are unique to the LGBT population<sup>(1)(2)(3)(5)(6)</sup></li> <li>• Counsel regarding psychosocial issues unique to the LGBT population<sup>(1)(2)(3)(5)(6)</sup></li> <li>• Brainstorm solution strategies for psychosocial issues unique to the LGBT population<sup>(1)(2)(3)(5)(6)</sup></li> </ul>

Legend: Seven themes identified via review of the American Counseling Association (ACA), American Psychological Association (APA) and American Academy of Family Physicians (AAFP) publications: (1) – Attention to relationships and family structure (2) – Knowledge and inclusive communication (3) – Self-awareness (4) – Continued education and professional development (5) – Counseling regarding family building (6) – Family, medical and pregnancy histories (7) – Prevention Strategies

**Table II:** Scores on SOCCS and Knowledge-Based Survey pre-workshop and post-workshop. Post-workshop means with \* indicate significant mean differences at  $p < .01$ .

	Pre-Workshop			Post-Workshop			Change in mean (p-value)
	Mean	Grade	SD	Mean	Grade	SD	
<b>SOCCS - Overall</b>	4.42	Moderate	0.61	5.15	Moderate-High	0.72	0.73 ( $p < 0.01$ )
<b>Skills</b>	2.27	Low-Moderate	0.91	3.59	Moderate	1.18	1.32 ( $p < 0.01$ )
<b>Attitude</b>	6.79	High	0.54	6.74	High	0.52	-0.05 (p-value)
<b>Knowledge</b>	4.40	Moderate	0.94	5.35	Moderate-High	1.01	0.95 ( $p < 0.01$ )
<b>Knowledge Based Survey</b>	78%	N/A	0.13	87%	N/A	0.08	9% ( $p < 0.01$ )

## Reference List

- Accreditation Council of Genetic Counseling. (2013). *Practice based competencies for genetic counselors*. Retrieved from [http://genetics.emory.edu/gc\\_training/docs/ACGC%20Practice%20Based%20Competencies\\_13-Final-Web-1-1.pdf](http://genetics.emory.edu/gc_training/docs/ACGC%20Practice%20Based%20Competencies_13-Final-Web-1-1.pdf).
- ALGBTIC LGBQQA Competencies Taskforce, Harper, A., Finnerty, P., Martinez, M., Brace, A., Crethar, H.C., Loos, B., et al. (2013). Association for lesbian, gay, bisexual, and transgender issues in counseling competencies for counseling with lesbian, gay, bisexual, queer, questioning, intersex, and ally Individuals. *Journal of LGBT Issues in Counseling*, 7(1), 2-43.
- American College of Healthcare Executives. (2014). *ACHE face-to-face education panel discussion evaluation form*. Retrieved from [http://www.ache.org/chapters/downloads/chapter\\_education/PanelDiscussionEvaluation.pdf](http://www.ache.org/chapters/downloads/chapter_education/PanelDiscussionEvaluation.pdf).
- American Psychological Association. (2012). Guidelines for psychological practice with lesbian, gay, and bisexual clients. *The American Psychologist*, 67(1), 10-42.
- Biaggio, M., Orchard, S., Larson, J., Petrino, K., Mihara, R. (2003). Guidelines for gay/lesbian/bisexual-affirmative educational practices in graduate psychology programs. *Professional Psychology Research and Practice*, 34(5), 548-555.
- Bidell, M. P. (2005). The sexual orientation counselor competency scale: Assessing attitudes, skills, and knowledge of counselors working with lesbian, gay, and bisexual clients. *Counselor Education & Supervision*, 44, 267-279.
- Bidell, M. P. (2013). Addressing disparities: the impact of a lesbian, gay, bisexual, and transgender graduate counselling course. *Counselling and Psychotherapy Research*, 13(4), 300-307.
- Bosse, H. M., Schultz, J-H., Nickel, M., Lutz, T., Moltner, A., Junger, J., ... Nikendei, C. (2012). The effect of using standardized patients or peer role play on ratings of undergraduate communication training: A randomized controlled trial. *Patient Education and Counseling*, 87(3), 300-306.
- Brandenburg, D. L., Matthews, A. K., Johnson, T. P., & Hughes, T. L. (2007). Breast cancer risk and screening: A comparison of lesbian and heterosexual Women. *Women & Health*, 45(4), 109-131.
- Carroll, L., Gilroy, P.J. (2001). Teaching 'outside the box': Incorporating queer theory in counselling education. *Journal of Humanistic Counseling, Education and Development* 40I(1), 49-58.

- Conron, K. J., Mimiaga, M. J., & Landers, S. J. (2010). A population-based study of sexual orientation identity and gender differences in adult health. *American Journal of Public Health, 100*(10), 1953-1960.
- Dean Glessner, H., VandenLangenber, E., McCarthy Veach, P., & LeRoy, B. S. (2012). Are genetic counselors and GLBT Patients “on the same page”? an investigation of attitudes, practices and genetic counseling experiences. *Journal of Genetic Counseling, 21*, 326-336.
- Diamant, A. L, Schuster, M. A, & Lever, J. (2000). Receipt of preventive health care services by lesbians. *American Journal of Preventive Medicine, 19*(3), 141-148.
- Fredrisken-Goldsen, K. I., Kim, H-J., Barkan, S. E., Muraco, A., & Hoy-Ellis, C. (2013). Health disparities among lesbian, gay, and bisexual older adults: Results from a population-based study. *American Journal of Public Health, 103*(10), 1802-1809.
- Grezenski, L. (2009). Addressing sexual minority issues in social work education: A curriculum framework. *Advances in Social Work, 10*(1), 103-113.
- Israel, T., Selvidge, M. M., (2003). Contributions of multicultural counseling to counselor competence with lesbian, gay, and bisexual clients. *Journal of Multicultural Counseling & Development, 31*(2), 84-98.
- Johnson, C. V., Mimiaga, M. J., & Bradford, J. (2008). Health care issues among lesbian, gay, bisexual, transgender and intersex (LGBTI) populations in the United States: introduction. *Journal of Homosexuality, 54*(3), 213-224.
- Kocarek, C. E., Pelling, N. J., (2003). Beyond knowledge and awareness: Enhancing counselor skills for work with gay, lesbian, and bisexual clients. *Journal of Multicultural Counseling & Development, 31*(2), 99-112.
- Laine-Austin, E., Irwin, J. A. (2010). Health behaviours and health care utilizations of southern lesbians. *Women's Health Issues, 20*, 178-184.
- Machalek, D.A., Poynten, M., Jin, F., Fairley, C.K., Farnsworth, A., Garland, S.M., Hillman, ... Grulich, A. E. (2012). Anal human papillomavirus infection and associated neoplastic lesions in men who have sex with men: a systematic review and meta-analysis, *The Lancet Oncology, 13*(5), 487-500.
- Mandap, M., Carrillo, S., Youmans, S. L. (2014). An evaluation of lesbian, gay, bisexual and transgender (LGBT) health education in pharmacy school curricula. *Currents in Pharmacy Teaching and Learning, 6*(6), 752-758.
- National Center for Health Statistics (NCHS). (2014). *2013 National health interview survey (NHIS)* [Data File]. Retrieved from,

[ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Dataset\\_Documentation/NHIS/2013/samadult\\_freq.pdf](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHIS/2013/samadult_freq.pdf).

- Obedin-Maliver, J., Goldsmith, E. S., Stewart, L., White, W., Tran, E., Brenman, S., ... Lunn, M. R. (2011). Lesbian, gay, bisexual, and transgender-related content in undergraduate medical education. *The Journal of the American Medical Association*, 306(9), 971-977.
- Priester, P. E., Jones, J. E., Jackson-Bailey, C. M., Jana-Masri, A., Jordan, E. X., & Metz, A. J. (2008). An analysis of content and instructional strategies in multicultural counseling courses. *Journal of Multicultural Counseling and Development*, 36(1), 29-39.
- Princeton Review. (2015). *The best 379 colleges*. (2015 Ed.). New York, NY: The Princeton Review.
- Rutter, P. A., Estrada, D., Ferguson, L. K., & Diggs, G. A. (2008). Sexual orientation and counselor competency: the impact of training on enhancing awareness, knowledge and skills. *Journal of LGBT Issues in Counseling*, 2(2), 109-125.
- Scherzer, T. (2000). Negotiating health care: the experiences of young lesbian and bisexual women. *Culture, Health and Sexuality*, 2(1), 87-102.
- Society of Teachers of Family Medicine. (2013). *Recommended curriculum guidelines for family medicine residents: lesbian, gay, bisexual, and transgender health*. Retrieved From [http://www.aafp.org/dam/AAFP/documents/medical\\_education\\_residency/program\\_directors/Reprint289D\\_LGBT.pdf](http://www.aafp.org/dam/AAFP/documents/medical_education_residency/program_directors/Reprint289D_LGBT.pdf)
- U.S. Department of Health and Human Services. (2012). Health objectives 2011 | HHS.gov. Retrieved April 23, 2015 from <http://www.hhs.gov/lgbt/resources/reports/health-objectives-2011.html>
- VandenLangenberg, E., McCarthy Veach, P., LeRoy, B. S., Dean Glessner, H. (2012). Gay, lesbian and bisexual patient's recommendations for genetic counselors: A Qualitative Investigation. *Journal of Genetic Counseling*, 21, 741-747.