ASSESSING THE CURRNET STATE OF AFFAIRS SURROUNDING EDUCATION ON COUNSELING DIRECT-TO-CONSUMER TESTING PATIENTS THROUGH SURVEYING GENETIC COUNSELING PROGRAM DIRECTORS

By

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ABSTRACT OF THE THESIS

Assessing the Current State of Affairs Surrounding Education on Counseling Direct-to-Consumer Testing Patients through Surveying Genetic Counseling Program Directors

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Direct-to-consumer (DTC) genetic testing is highly popular but often met with skepticism. Consumers who purchase DTC genetic testing commonly have questions or concerns about their test. Even though they are often not sought out directly, genetic counselors (GCs) may be uniquely poised as the best health care professionals to interface with these consumers. Therefore, genetic counselors should be educated and prepared to counsel consumers of DTC genetic testing. However, most practicing genetic counselors do not feel confident discussing DTC genetic testing with patients. In an effort to evaluate how current genetic counseling students are being educated on DTC genetic testing and whether the next generation of genetic counselors may be better equipped to counsel these patients, we investigated current curricula for genetic counseling training programs by surveying genetic counseling program directors. We found that 95.65% of genetic counseling programs surveyed include some level of

education on DTC genetic testing in their programs' curriculum and about half of programs are assessing the effectiveness of their education. Students are being educated about DTC genetic testing through combinations of course lectures, optional guest lectures, journal clubs, grand rounds, clinical rotations, non-clinical industry rotations, professional meetings, and small group discussions. It appears that genetic counseling students are being exposed to multiple aspects of DTC genetic testing via a variety of methods and settings. However, the effectiveness of this education is unclear because most students are not being assessed on what they are taught. These results suggest that while education on DTC genetic testing is established at most genetic counseling programs, it is neither standardized nor proven effective for training future genetic counselors to advise DTC test consumers.

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Introduction

Direct-to-Consumer (DTC) genetic testing is defined as at-home DNA testing that provides access to one's genetic information without the need to involve health care professionals or insurance companies ("What is direct-to-consumer genetic testing?," 2019). Consumers can order the tests online, submit their samples, and receive their results without needing to visit their doctor's office. DTC testing has become extremely popular; as of 2018, over 12 million people have completed some form of DTC genetic testing in the U.S. (Regalado, 2018). There are many different tests available to consumers, but most include either ancestry, "fun" traits or quirks, or health traits. Depending on which test a consumer purchases, motivations for testing can range from wanting to learn about ethnic background to hoping for insight into health conditions.

Individuals who pursue DTC genetic testing can sometimes receive surprising or confusing results, or they may be curious and desire further information, and as such, genetic counselors and doctors have advocated to make genetic counseling available to customers both pre- and post-test (Middleton, Mendes, Benjamin, & Howard, 2017). Physicians and genetic professionals have concerns about patients' abilities to understand the implications of the information these tests uncover (Middleton et al., 2017). Additionally, various professional medical societies and organizations have released statements supporting pre- and post-test counseling and further education of healthcare professionals on DTC genetic testing (Skirton, Goldsmith, Jackson, & O'Connor, 2013). Only 28% of DTC genetic testing consumers follow up with a

healthcare professional after receiving their results (Kaufman, Bollinger, Dvoskin, & Scott, 2012).

Consumers who utilize genetic counseling to discuss their DTC genetic testing results report an improved understanding of their results and genetics in general (Darst, Madlensky, Schork, Topol, & Bloss, 2013). Most DTC customers who pursue genetic counseling seek help interpreting their results and do not question their results' validity or want further testing (Brett, Metcalfe, Amor, & Halliday, 2012). This is important for genetic counselors to know, as GCs often question validity of results of DTC genetic testing.

Currently, there are some genetic counselors that can be found through the National Society of Genetic Counselors' (NSGC) directory as specializing in "At-home/Direct-to-consumer genetic testing" ("Find a Genetic Counselor," 2020). Additionally, there are some independently-practicing genetic counselors who see patients to discuss DTC genetic testing ("Genetics Consult & Review of Direct-to-Consumer Test Results (NJ)," 2020; Kirkpatrick, 2019). However, most consumers will share their results with their primary care provider (PCP), not a genetic counselor (Koeller, Uhlmann, Carere, Green, & Roberts, 2017; van der Wouden et al., 2016). Of those who discuss with their PCP, only 35% were very satisfied with the experience (van der Wouden et al., 2016). If a patient is unsatisfied with the information their PCP gives them, a specialized genetic counselor would be a great place to turn, as these genetic counselors are the health-care providers most equipped to counsel these consumers (McGrath, Walton, Williams, Kim, & Bastola, 2019).

Some DTC genetic companies employ genetic counselors that are available to consumers at a cost, but most DTC genetic testing companies do not offer patient-facing GC services ("Ancestry Health," 2020). One large DTC genetic testing company states on its website that a consultation with a genetic counselor is recommended and includes a link to the National Society of Genetic Counselors' 'Find a Genetic Counselor' tool in several places on its website ("Test Info," 2020). Although most DTC test consumers do not consult a genetic counselor about their results, companies direct them to utilize GCs as a resource if they need it. Therefore, genetic counselors need to be prepared to discuss DTC genetic testing with a consumer especially given the growing number of consumers using DTC genetic testing over the past several years (Regalado, 2018).

In a 2011 survey of genetic counselors, 55% believed that genetic counselors have a professional obligation to be knowledgeable about DTC genetic testing (Hock et al., 2011). However, past studies have found that the general healthcare field is unprepared for the large influx of consumers using these products (Skirton, Jackson, Goldsmith, & O'Connor, 2013). In a survey of Australian-based genetic counselors, only 7% felt confident in interpreting and explaining DTC genetic test results (Brett et al., 2012). A 2017 survey of U.S.-based GCs showed that a majority (56%) felt negatively or very negatively towards DTC genetic testing (T. Braid, 2017). Additionally, while 90.9% of counselors thought that DTC genetic testing would be improved by adding genetic counseling, only 31.2% stated that they felt comfortable counseling a patient who had DTC genetic testing (T. Braid, 2017). Given the fast increase in popularity of DTC genetic testing, training for GCs took time to catch up; therefore, currently practicing genetic

counselors may not have had training on this topic when they were in graduate school. This lack of training surrounding DTC genetic testing may explain the negative sentiment and low preparedness of GCs to counsel DTC genetic testing consumers.

The field's problem lies in the lack of comfort and confidence genetic counselors have regarding working with consumers of DTC genetic testing. The large knowledge gap is concerning and needs to be addressed for several reasons: genetic testing companies advise consumers to consult with a GC, GCs recognize that DTC genetic testing would be better comprehended if a genetic counselor were involved, and GCs believe they have a professional obligation to be knowledgeable about DTC genetic testing. This knowledge gap can be rectified by either educating the current workforce or educating the students who will soon be entering the workforce. Currently practicing genetic counselors have a number of DTC genetic testing resources available to them, including webinars, lectures, and papers; however, studies have not been conducted to determine what resources and exposures are available to support education on this topic for graduate students (Counselors, 2017).

At this time, it is unclear whether genetic counseling graduate programs are incorporating education on DTC genetic testing, and if so, how they are providing this education. To the authors knowledge, no previous study has investigated the integration of education on of DTC genetic testing in genetic counseling training programs. This study aims to assess the addition of DTC genetic testing content into genetic counseling graduate program curricula and the perspectives of program directors on that integration. Since program directors and assistant program directors

determine the curriculum, the authors were interested in their opinions about DTC genetic testing and its impact on the practice of genetic counselors. We surveyed program directors and assistant program directors from all 49 accredited genetic counseling programs in the United States and Canada regarding the extent of implementing education on DTC genetic testing into their curricula as well as their attitudes on DTC genetic testing.

Methods

A survey-based study was conducted to assess the extent to which genetic counseling graduate programs have incorporated education on DTC genetic testing into their curricula. Data was collected using an anonymous survey of genetic counseling program directors during September-October 2019. The survey assessed whether programs had integrated education on DTC genetic testing, the methods used for education, and the program directors' attitudes on integration. The survey was created by the principal investigator and refined and edited by the co-authors, who guided survey formation based on professional experiences in genetic counseling. It was loosely modeled from survey instruments used in "Assessing the Integration of Genomic Medicine in Genetic Counseling Training Programs" by J. Profato and "Relieving the Bottleneck: An Investigation of Barriers to Expansion of Supervision Networks at Genetic Counseling Training Programs" by J. Berg (Berg et al., 2018; Profato, Gordon, Dixon, & Kwan, 2014). This study was reviewed and approved by the Rutgers University Institutional Review Board.

Participants

Program directors and assistant program directors from the 49 ACGC (Accreditation Council for Genetic Counseling) accredited genetic counseling programs were eligible to participate in the survey. Only one response per program was permitted.

Procedures

The anonymous survey (see Appendix) consisted of 25 items and included multiple-choice questions, which allowed either single or multiple answer selections, as well as open-ended questions. A link to the online survey, which was hosted on the Qualtrics platform, was distributed via email to all program directors and assistant program directors at the 49 ACGC accredited genetic counseling programs. The survey remained open for responses for one month, from September 23, 2019 until October 23, 2019. One follow-up reminder email was sent one week before the survey closed.

For the purpose of this study, DTC genetic testing was defined as, “at-home DNA testing that provides people with easy access to their genetic information without the need to involve their health care professional or health insurance company” ("What is direct-to-consumer genetic testing?," 2019).

Program directors were asked about a particular service called Test 2 Learn. This is a service that allows students to submit their own personal DNA samples to a DTC genetic testing service and receive and interpret their own results to better understand what a patient would experience by using a DTC genetic testing service ("Innovative Genomics Education," 2020).

Data Analysis

The survey data was collected and downloaded from the Qualtrics platform for analysis. Raw data were primarily analyzed using descriptive statistics such as percentages and frequencies. The data were stratified by both age of program (with 0-

14 years representing newer programs and 15 or more years representing older/more established programs) and geographic location of the program (with regions 1, 2, 3, and 6 representing coastal programs and regions 4 and 5 representing midwestern/southern programs). Because DTC genetic testing is relatively new and consumer demographics differ based on geographic location, it was hypothesized that age of the program and geographic location may impact the education being offered to students. Segregated data were analyzed utilizing the chi-squared test of independence and t-tests. Analysis was completed using Qualtrics analysis tools and Microsoft Excel.

Results

Of the 49 eligible ACGC accredited genetic counseling programs, representatives from 23 programs (46.94%) responded to and completed the survey. Table 1 shows the demographic breakdown of the survey respondents. Respondents tended to be from more established programs; 52.2% of represented schools have been accredited programs for 15 or more years. The tenure of program directors was more evenly distributed, with an average of 6-8 years. The majority of genetic counseling programs (56.5%) were housed within the medical school at their home college or university, and 26.1% were housed within the main university (graduate school). Responses came from programs in all six geographic regions, and region 4 (the midwest) was the most represented, with 8 programs.

Table 1. Demographic data of study population

Variable	Property	N (%)
Program age	0-2 years	5 (21.7%)
	3-5 years	2 (8.7%)
	6-8 years	2 (8.7%)
	9-11 years	1 (4.3%)
	12-14 years	1 (4.3%)
	15 or more years	12 (52.2%)
Program director tenure	0-2 years	4 (17.4%)
	3-5 years	6 (26.1%)
	6-8 years	2 (8.7%)
	9-11 years	3 (13%)
	12-14 years	4 (17.4%)
	15 or more years	4 (17.4%)
Program location within university	Medical school	13 (56.5%)
	School of public health	0 (0%)
	Main university (graduate school)	6 (26.1%)
	Other	4 (17.4%)
Program geographic location	Region 1: CT, MA, ME, NH, RI, VT, Canada	4 (17.4%)
	Region 2: DC, DE, MD, NJ, NY, PA, VA, WV	3 (13%)
	Region 3: AL, FL, GA, KY, LA, MS, NC, SC, TN (Puerto Rico, virgin islands)	4 (17.4%)
	Region 4: AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI	8 (34.8%)
	Region 5: AZ, CO, MT, NM, TX, UT, WY	3 (13%)
	Region 6: AK, CA, HI, ID, NV, OR, WA	1 (4.3%)

The vast majority of schools, 95.65%, are already incorporating some type of education on DTC genetic testing in their curriculum. The sample had a slightly higher representation of GC programs >15 years old. When comparing the two age groups

separately, new vs. established programs, there is a difference in the timing of the content being incorporated. For the older, established programs, only three of twelve (25%) started including DTC genetic testing into their curriculum within the past five years; the rest have been including DTC genetic testing content for an average of 8.83 years (Table 2). When deciding to include this topic in their curriculum, most (75%) directors were motivated by both current industry/society trends and personal beliefs that it is important for genetic counseling students to learn about DTC genetic testing.

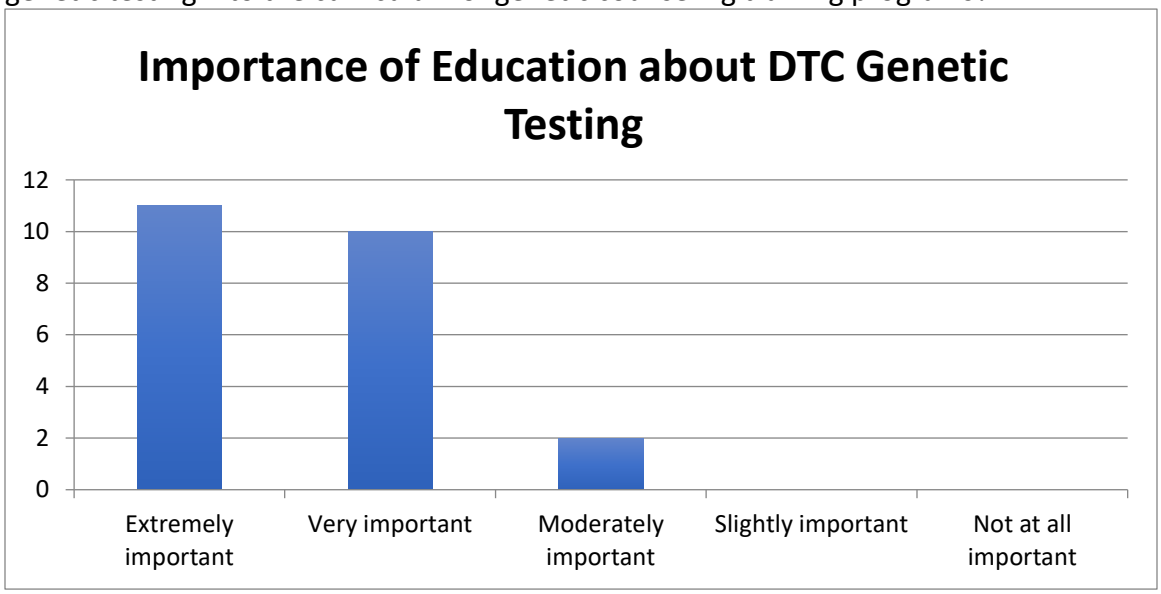
Table 2. Years when programs established programs began including DTC genetic testing in their curriculum.

School	Year of Inclusion
1	2006
2	2008
3	2010
4	2010
5	2013
6	2014
7	2017
8	2017
9	2018
Average	2012.556

All but one director (95.65%) responded that it was somewhat or extremely likely that their programs' recent graduates would counsel patients about DTC genetic testing in the next 10-15 years of their careers. The vast majority of program directors (87.5%) thought it was very important or extremely important to include education on DTC genetic testing in a genetic counseling training program (Figure 1). However, just

over half of program directors (59.1%) think that this topic should be added to the ACGC practice-based competencies or accreditation standards in the next 5-10 years. Neither age of program nor geographic location were determining factors in whether program directors were more likely to agree that DTC genetic testing education should be added to the ACGC practice-based competencies or accreditation standards.

Figure 1. In your opinion, how important is it to incorporate education about DTC genetic testing into the curriculum of genetic counseling training programs?



Eighty-seven percent of program directors felt somewhat comfortable or extremely comfortable addressing questions from students about DTC genetic testing (Figure 2). Program directors and assistant program directors are very involved in teaching DTC concepts to students (Figure 3). Instructor roles did not differ between newer and established programs or coastal and midwestern/southern programs.

Figure 2. Program directors'/assistant program directors' personal comfort level addressing concerns/questions from students about DTC genetic testing.

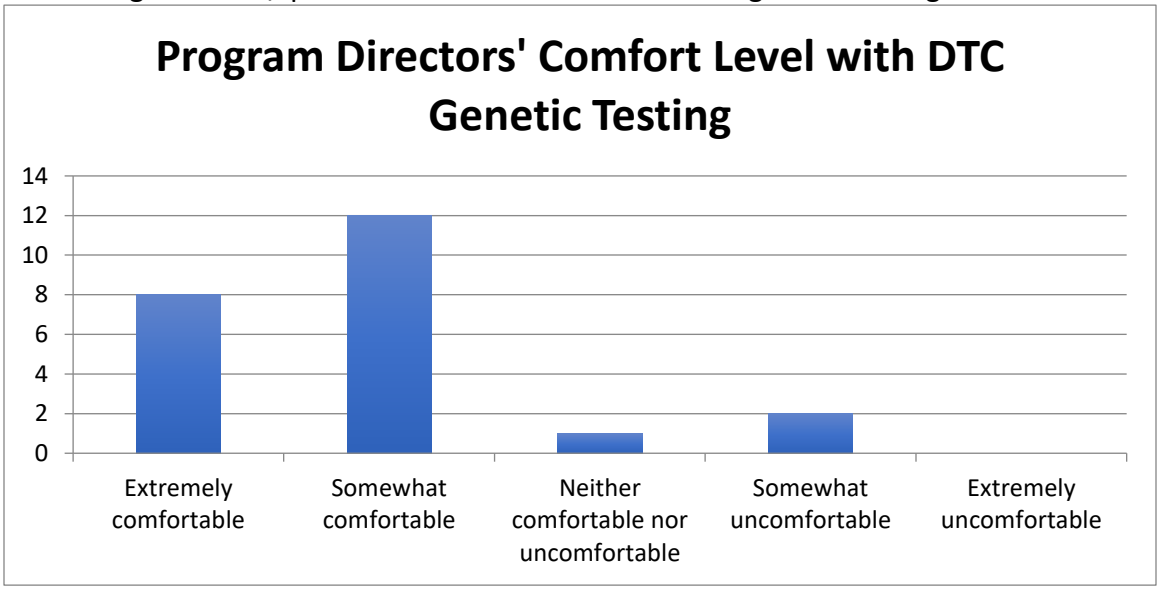
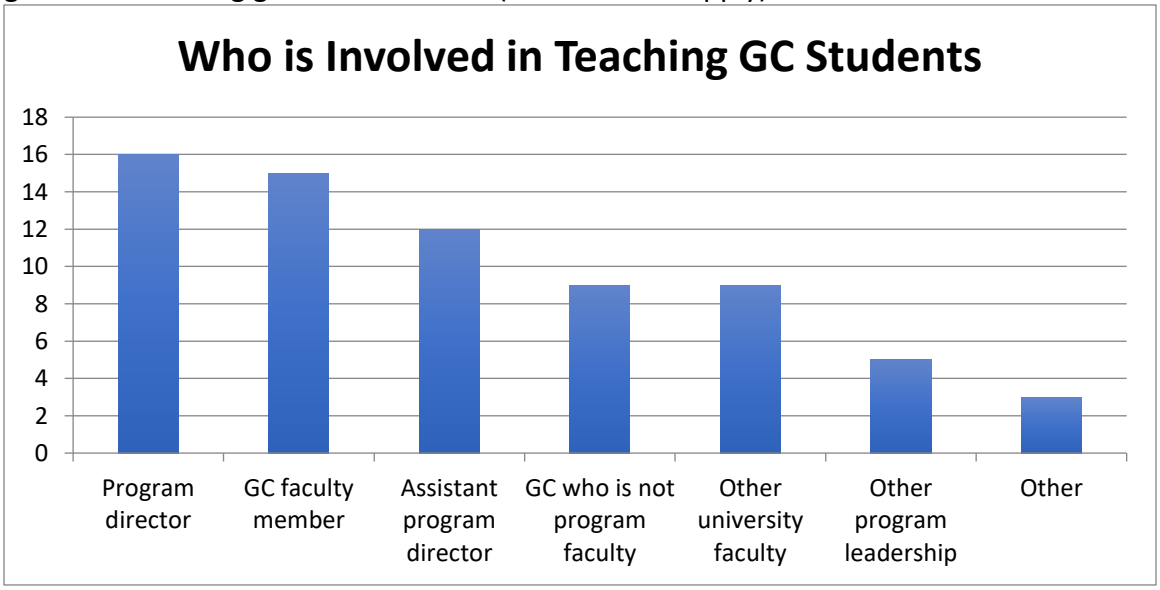


Figure 3. Faculty who are involved in teaching concepts about DTC genetic testing to genetic counseling graduate students (select all that apply).



Genetic counseling students are being educated about several common themes related to DTC genetic testing (Table 3). Most commonly, curricula include discussions on the methodologies of DTC genetic tests, ethical issues and/or concerns, raw data

interpretation, and common consumer misconceptions as educational concepts in DTC genetic testing. About half of programs spend time teaching their students about DTC-specific psychosocial issues or using role-play exercises to act out possible counseling scenarios. All programs checked that they were including three or more educational concepts in their DTC curricula, with six programs (26%) indicating that they were including all eight listed educational concepts. Several differences were observed in the educational concepts programs include when broken down by age and geographic location. Although these differences were not significant, newer programs were more likely to include raw data interpretation (p-value = 0.09), common misconceptions held by consumers (p-value = 0.09), and common misconceptions or biases held by health care professionals (p-value = 0.068) as educational concepts (data not shown). Notably, although not significant, coastal programs were more likely to include discussion on DTC-specific psychosocial issues (p-value = 0.09) than programs located in the midwest or south (data not shown).

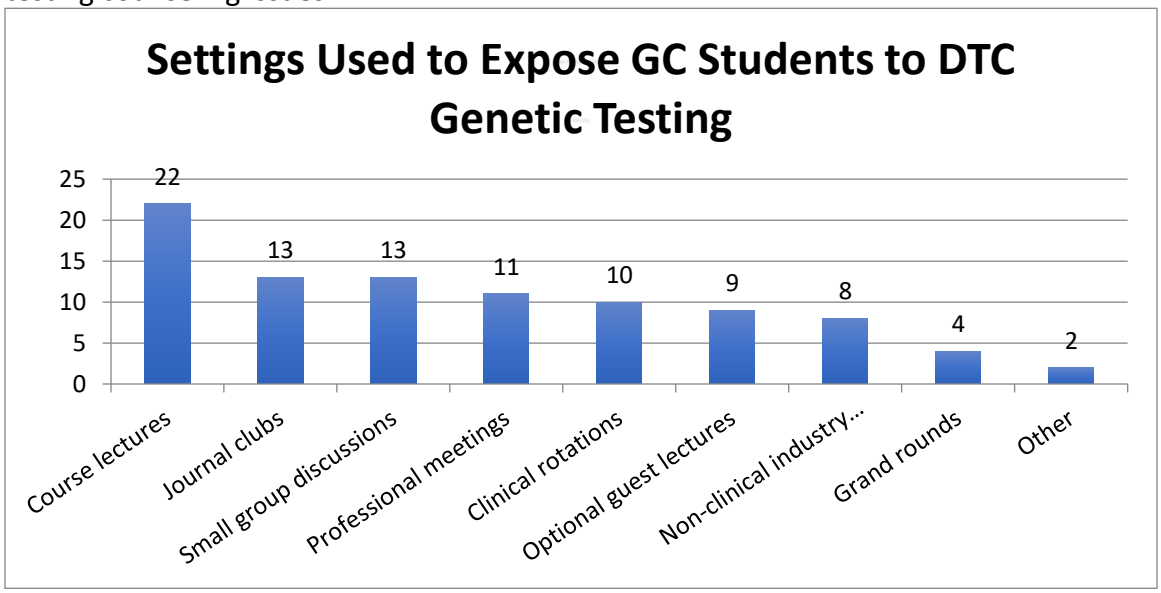
Table 3. Sub-topics that programs choose to include in their education on DTC genetic testing

Educational Concept	Count
Discussion of common methodologies behind DTC tests	20
Exploring ethical issues surrounding DTC testing	20
Discussion about raw data interpretation	18
Discussion of common misconceptions held by consumers	18
Discussion of common misconceptions/ biases held by health professionals	16
Developing skills to critically evaluate reported associations between SNP's and disease	16
Exploring DTC-specific psychosocial issues	13
Hands on exercises or role-plays	8
Other	1

There were several common themes regarding the methods being utilized to educate genetic counseling students about DTC genetic testing and how to counsel consumers (Figure 4). All programs (100%) utilize course lectures to expose students to this topic. Journal clubs and small group discussions are used by about half (54.2%) of schools. The most hands-on/active learning option utilized by schools are rotations, both clinical (41.7%) and non-clinical industry (33.3%). Other exposure routes include student presentations and thesis projects. There was no statistically significant difference between the exposure strategies used in newer versus established programs (data not shown). In an effort to reanalyze the data unique to the challenges of finding

clinical rotation sites for genetic counseling programs, the age cutoff was adjusted to programs less than six years old. With that readjust, there were no differences observed in what settings are used. Programs located in the midwest and/or southern United States were more likely to utilize professional meetings as an exposure method for students than programs located on the east or west coast (p-value = 0.0861; data not shown). Twenty out of twenty-two schools expose students to DTC genetic testing issues during both the first and second year of the program.

Figure 4. Settings used to expose genetic counseling graduate students to DTC genetic testing counseling issues.



When designing the DTC education for their program, most programs (71.4%) used more than one resource. Published, peer-reviewed literature was the most commonly utilized resource (Figure 5). Established programs were more likely than newer programs to utilize resources from NSGC, 60.0% versus 27.3% respectively; however, this difference was not statistically significant (p-value = 0.198). No other

differences between resources used based on age of program were observed. Programs located in the Midwest or southern United States were significantly more likely (p-value = 0.0124) to have used industry-sponsored presentations or resources when developing their DTC genetic testing curricula than programs located on the east and west coast (Table 4).

Figure 5. Resources used by programs when designing curriculum to include DTC genetic testing into their program.

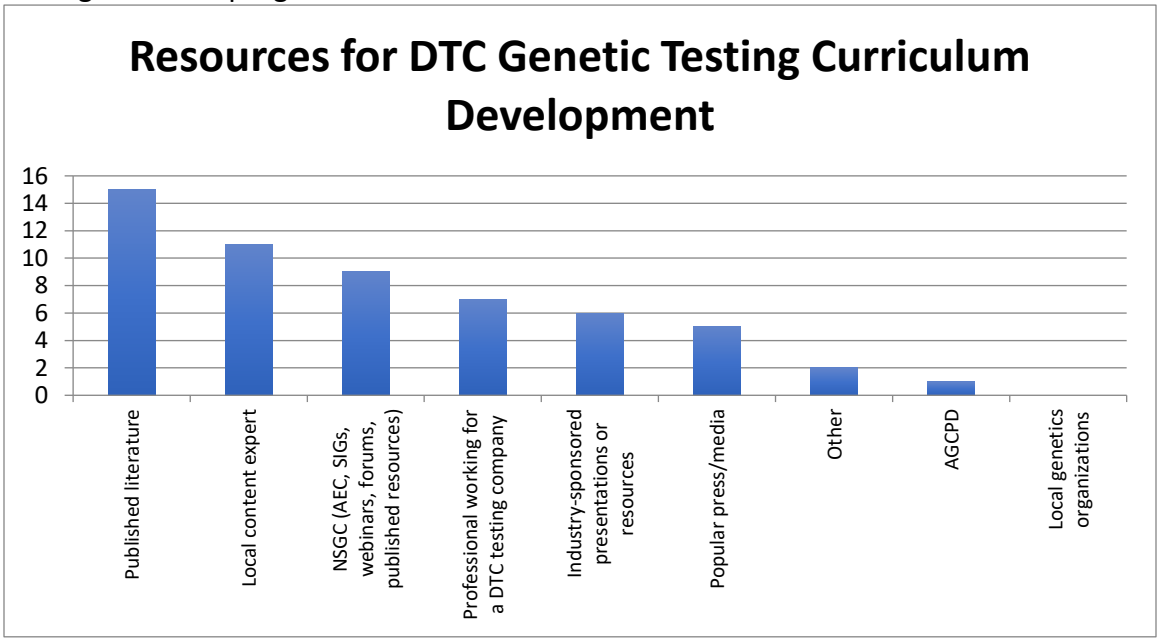


Table 4. Count of programs that utilized industry-sponsored presentations or resources as a resource when developing their DTC genetic testing curriculum - segregated by geographic location.

Geographic Location	Coastal	Midwest/South
Utilized industry-sponsored presentations or resources	0	6
Did not utilize industry-sponsored presentations or resources	10	5
Total	10	11

Less than half of the programs (40.9%) have evaluated the effectiveness of their program's DTC education components by assessing their students' understanding. Additionally, of those that have evaluated their curricula, seven of nine are using course evaluations or student feedback to determine if their methods of education are effective. Two programs use active learning (role plays, written assignments) or exam questions to assess the skills/knowledge that students have gained. Established programs were more likely than newer programs to evaluate the effectiveness of their teaching methods, 77.8% versus 30.8% respectively. However, this difference was not statistically significant (p-value = 0.0805). Evaluation practices did not differ based on the geographic location of the program.

When asked about having students use a service such as Test 2 Learn to simulate the DTC genetic testing process for themselves, 60.9% of participants responded that they would not use it as a part of their program's curriculum. Consideration of Test 2 Learn did not differ between established and newer programs or between coastal and midwestern/southern programs. The main concerns that program directors cited for declining to use a service like Test 2 Learn were related to consent and coercion, use of personal data, and student autonomy.

When asked what they would like education about DTC genetic testing to include in an ideal world, program directors expressed a desire for more hands-on experiences for their students. Specifically, they would like to include role playing in controlled classroom settings as well as exposure to patients in clinical situations. For example, one participant responded, "It would be great if students had more actual experience

meeting with patients who have undergone DTC testing [during training].” Several others expressed hope for students to “have the opportunity to role play a patient scenario and gain comfort in this setting.” These common themes were echoed by multiple program directors in their responses.

Discussion

This study focused on how genetic counseling students enrolled in accredited genetic counseling training programs across the United States and Canada are learning about the subject area of DTC genetic testing as well as program directors' attitudes about DTC genetic testing issues. To our knowledge, no study analyzing training programs' curricula surrounding DTC genetic testing has previously been conducted. Our sample size is representative of just under half of all accredited genetic counseling training programs in the United States and Canada. All data analysis was completed on self-reported survey responses; no external investigation of the curricula by any other means was conducted.

Our findings indicate that the curricula at the vast majority of genetic counseling training programs include education on DTC genetic testing, as well as training for working with these patients. This was expected due to the recent increase in popularity of DTC genetic testing in the past several years (Regalado, 2018). Following this trend, we found that several established programs began including education on DTC genetic testing into their curriculum within the past five years, correlating with the timing of the increase in the popularity of DTC testing. However, several programs began incorporating the topic nine or more years ago. The DTC genetic testing landscape has changed sharply within the past 10 years, suggesting that genetic counseling programs need to constantly change and adapt to trends in the field, as they have been known to do in the past with other new and emerging topics (Noss, Mills, & Callanan, 2014; Profato et al., 2014). This is highly important if students are to be well-equipped to

transition into the workforce. It is encouraging that most schools are already including education on this topic, as this will hopefully help to increase the comfort level of GCs practicing in the field, and because program directors believe that it is likely their students will interact with and counsel patients who have had DTC genetic testing within the next 10 years of their careers. This correlates well with the fact that all but two program directors agree it is extremely important or very important to include education on DTC genetic testing in training program curricula.

Most genetic counselors do not feel confident and comfortable counseling patients about DTC genetic testing (T. Braid, 2017). In contrast, program directors expressed high levels of comfort addressing concerns or questions from students about DTC genetic testing. This may reflect self-report bias, as even on an anonymous survey, program directors may not want to admit they feel less confident about a subject matter they are teaching to their students. The portion of genetic counselors who report high levels of comfort about DTC genetic testing are typically younger, less experienced counselors (McGrath et al., 2019). This is contradictory, as program directors are typically seasoned genetic counselors. However, they are also a group with high motivation to self-educate and stay up to date on current trends, since they are instructing students, so it is not surprising that they may feel more comfortable than other genetic counselors in this topic area. If this collective self-report is an accurate reflection of program directors' comfort with DTC genetic testing, it would be encouraging, as they are the ones most often directly lecturing to or teaching their students on the topic.

It stood out that only about half of programs spend time discussing psychosocial issues specific to DTC genetic testing consumers. Managing and anticipating psychosocial issues is integral to the genetic counseling process; ACGC practice-based competency I2a states that genetic counselors should be able to "demonstrate an understanding of psychosocial, ethical, and legal issues related to genetic counseling encounters" (*Practice-Based Competencies for Genetic Counselors*, 2019). It is possible that program directors do not address DTC-specific psychosocial issues because they feel they address similar psychosocial issues, such as non-paternity and unexpected positive results, in other parts of the curriculum.

The age of the genetic counseling program played a role in which educational components on DTC genetic testing are included in curricula. Newer programs were more likely to include discussions on several sub-topics of DTC genetic testing, indicating that the discussion on DTC genetic testing at newer genetic counseling programs is more robust and includes more topics than the discussion at established programs. This could be because established programs started including DTC genetic testing in their curriculum earlier than newer programs and may not have updated what their curriculum includes. The discrepancy demonstrates the importance of continuously updating and validating curriculum material.

All programs reported including at least three or more different educational concepts in their DTC curricula, indicating that education on DTC genetic testing is multi-dimensional. This suggests that there is some foundational "essential" content and some content that is above and beyond what is normally taught. Based on the topics

most selected in the survey, we propose that foundational content includes discussion of common methodologies, ethical issues, raw data interpretation, and common misconceptions held by consumers and health professionals. Advanced content includes discussion of DTC-psychosocial issues, developing skills to critically evaluate SNPs and relation to disease, and using hands on or role play exercises. We suggest that a consensus may be needed to further establish the foundational concepts that all programs should be teaching.

Most programs are utilizing lectures or other lecture-based learning styles, including journal clubs, grand rounds, professional meetings, or small group discussions to expose students to DTC genetic testing issues. Traditionally, genetic counseling students are exposed to material in both lectures and clinical rotations. Clinical rotations that give direct exposure to patients have been the gold standard for genetic counseling students to become comfortable in counseling patients in pediatric, prenatal, and cancer genetics (Masunga, Wusik, He, Yager, & Atzinger, 2014). One could argue that observation of experienced genetic counselors and supervision during live patient interactions would also be ideal for promoting competence with DTC genetic testing. Currently, less than half of programs are utilizing this method. Program director comments indicate that many schools want to offer this experience to their students.

Schools are limited in access to clinical rotation sites and patients coming through those sites. One program director stated, “Surprisingly our large university medical center has not seen too much with regard to inquiry about these tests.” Another director echoed this comment by saying that “not very many of these people

are actually coming to be seen in genetics clinics. When we know in advance that this is the reason they are coming, we do try to assign a student to the case." Additionally, if currently practicing genetic counselors do not feel comfortable counseling DTC genetic testing consumers, they may be turning down referrals and thus further limiting opportunities for students to gain practical experience. This lack of patient volume can be a difficult limitation to overcome. Perhaps part of the answer lies in finding other routes than the traditional hospital setting to find DTC genetic testing consumers. Some of those exposures may include non-traditional industry rotations, partnering with DTC genetic testing companies, community outreach and education, or supplementing lecture-based content with in-class role plays.

It was unsurprising that most programs relied on published literature when designing their DTC curriculum. The use of peer-reviewed sources is contingent upon recent and relevant papers being written and published. This is most likely why most programs utilized other resources as well, such as local "DTC experts" and NSGC published resources. Established programs utilized NSGC resources more than newer programs for reasons that are unclear. The significantly higher use of industry-sponsored presentations or resources by midwestern/southern programs could be due to the lack of in-person "experts" that are available in these geographic locations, as well as these areas of the country being later adopters of new genetic technology than the coasts. This could be concerning, as any resource that is industry-sponsored is not without bias and could influence what and how students learn. When designing

curricula, directors must take care to draw from a balanced set of resources and be skeptical about any industry-sponsored content.

Program directors are divided on whether or not this is a topic that should be added to the ACGC practice-based competencies in the next 5-10 years. Directors consider it an important topic to teach to students, but not important enough to warrant that a governing body of genetic counseling training programs make it a requirement. This response was not influenced by age of the program or geographic location. This could be because DTC genetic testing is a relatively narrow topic, and some may feel that it does not merit inclusion, as most topics on the practice-based competencies are broader and more encompassing (*Practice-Based Competencies for Genetic Counselors*, 2019). Similar up-and-coming topics in genetics include pharmacogenomics, telecounseling, and tumor versus germline testing, which have yet to be added to the list themselves. Additionally, DTC genetic testing is a quickly changing, emerging, and growing area; thus, it may be difficult to pinpoint exactly what students need to know, as those requirements may change year to year.

Whether or not the sub-topics, methods, and personnel being utilized to teach students about DTC genetic testing are effective in increasing their comfort with the topic and confidence working with DTC genetic test consumers is unclear. Only two programs assess their students' learning through either classroom activities, assignments, or exam questions. So, while we know students are learning about DTC genetic testing, we do not know if they will be entering the workforce with competence in this subject or whether they will be equipped with the necessary tools to counsel DTC

test consumers. Thus, it is unclear if the current education we are providing to genetic counseling students will help increase the comfort level of genetic counselors as they meet with patients about their DTC genetic testing.

The lack of assessment of student competence on DTC genetic testing issues seems a bit contradictory in light of other findings in our study. Program directors expressed a high level of comfort with teaching and talking to students about DTC genetic testing and a clear sentiment that it is an important and necessary area of instruction for genetic counseling students. However, all but two of them believe that it is important and necessary enough to evaluate students' understanding and competence on the subject. Traditionally, if a topic is important to a student's future success in their career, the student's competence in that topic will be assessed through tests, quizzes, or assignments prior to graduation. However, this is not the case with DTC genetic testing issues in genetic counseling training programs. It seems that program directors have deemed this topic important enough to dedicate valuable time in the curriculum to, but not important enough to give homework, quizzes, or test questions to assess students' knowledge and understanding.

The reasons for this discrepancy are unclear. We can speculate that program directors are hesitant to add an additional test, quiz, or assignment to their students' already lengthy core coarse load and evaluations. Alternatively, it could be due to the absence of DTC genetic testing from ACGC practice-based competency standards or accreditation standards. Since no governing organization has dictated that students are required to be proficient in this subject, program directors are not obligated to assess

their students' competency. We can speculate that DTC genetic testing is unlikely to be incorporated into the ACGC practice-based competencies in the short term, given program directors' disagreement on the issue and the relatively narrow scope of the subject.

The results of this study prompted several questions and directions for future research. This study did not assess program leaderships' opinions about what specific components need to be included in education about DTC genetic testing. Having an established consensus on this topic would help to guide program leadership in effectively designing their curricula. Future research may also be needed in order to explore the best way to expose students to interactions with DTC genetic testing consumers to gain hands-on experience, as exposure to relevant cases is currently limited. Additionally, since genetic counseling students are not currently being assessed on their knowledge surrounding DTC genetic testing, future research is necessary to determine the best way to assess students' understanding. It may be reasonable for an assessment tool to be created and piloted. If successful, such a tool could be distributed to accredited genetic counseling training programs to assist program directors in assessing the effectiveness of their instructional methods.

The major limitation of this study is ascertainment bias, such that the program directors who have an interest in DTC genetic testing and believe that it is important for their students were more likely to fill out the survey. A reasonable assumption is that these programs are more likely to already be including education on this topic in their curriculum. Also, the survey is based on self-reported data, which means that we are

unable to verify the responses we received. Additionally, only about half of all eligible programs answered the survey, which provides a small sample size for this study. Programs with differing views from those presented here may be underrepresented.

Program directors believe that teaching genetic counseling students about DTC genetic testing is important and relevant. Many expressed a desire to offer their students more active learning opportunities that would expose them to DTC genetic testing and its consumers. It is clear that program directors want students to be well-equipped to counsel on DTC topics when they enter the workforce. However, right now it remains unclear whether students are competent and confident with DTC genetic testing. It may be helpful for programs to learn from each other by sharing what they are doing and what has and has not been successful, which is why we felt it was important to undertake this research. At the same time, the effectiveness of different teaching methods for DTC genetic testing cannot be evaluated until more programs begin to assess their students' competency on this topic. A collaborative effort to collect and share meaningful outcomes with each other will enable us to more effectively train competent and confident genetic counselors. As DTC genetic testing becomes more popular, we believe education and training on this topic needs to continue to grow and expand from this solid starting point.

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