

5-2018

EXAMINING THE RELATIONSHIP BETWEEN GENETIC COUNSELORS' IMPLICIT ATTITUDES TOWARD DISABILITY AND THEIR PRACTICE METHODS

Helen W. Gould

Follow this and additional works at: https://digitalcommons.library.tmc.edu/utgsbs_dissertations



Part of the [Counselor Education Commons](#), [Genetics Commons](#), [Medicine and Health Sciences Commons](#), and the [Personality and Social Contexts Commons](#)

Recommended Citation

Gould, Helen W., "EXAMINING THE RELATIONSHIP BETWEEN GENETIC COUNSELORS' IMPLICIT ATTITUDES TOWARD DISABILITY AND THEIR PRACTICE METHODS" (2018). *The University of Texas MD Anderson Cancer Center UTHealth Graduate School of Biomedical Sciences Dissertations and Theses (Open Access)*. 862.

https://digitalcommons.library.tmc.edu/utgsbs_dissertations/862

This Thesis (MS) is brought to you for free and open access by the The University of Texas MD Anderson Cancer Center UTHealth Graduate School of Biomedical Sciences at DigitalCommons@TMC. It has been accepted for inclusion in The University of Texas MD Anderson Cancer Center UTHealth Graduate School of Biomedical Sciences Dissertations and Theses (Open Access) by an authorized administrator of DigitalCommons@TMC. For more information, please contact digitalcommons@library.tmc.edu.

EXAMINING THE RELATIONSHIP BETWEEN GENETIC COUNSELORS' IMPLICIT
ATTITUDES TOWARD DISABILITY AND THEIR PRACTICE METHODS

by

Helen Gould, B.S.

APPROVED:

Jennifer Czerwinski, M.S. C.G.C.
Advisory Professor

Syed Hashmi, Ph.D. M.D.

Victoria Wagner, M.S. C.G.C.

Katie Stoll M.S. C.G.C.

Kathryn K. Ostermaier, M.D.

APPROVED:

Dean, The University of Texas
MD Anderson Cancer Center UTHHealth Graduate School of Biomedical Sciences

EXAMINING THE RELATIONSHIP BETWEEN GENETIC COUNSELORS' IMPLICIT
ATTITUDES TOWARD DISABILITY AND THEIR PRACTICE METHODS

A

THESIS

Presented to the Faculty of

The University of Texas

MD Anderson Cancer Center UTHealth

Graduate School of Biomedical Sciences

in Partial Fulfillment

of the Requirements

for the Degree of

MASTER OF SCIENCE

by

Helen Gould, BS
Houston, Texas

May, 2018

EXAMINING THE RELATIONSHIP BETWEEN GENETIC COUNSELORS' IMPLICIT ATTITUDES TOWARD DISABILITY AND THEIR PRACTICE METHODS

Helen Gould, B.S.

Advisory Professor: Jennifer Czerwinski, M.S., C.G.C.

Genetic counselors serve as a link between the medical community and the disability community as they are regularly the first exposure families have following a new diagnosis in a pregnancy, infant or child. This role requires genetic counselors to be responsible and compassionate when approaching conversations about disability. With a lack of research on how the specific attitudes of genetic counselors toward disability impact clinical practice, we aimed to understand these attitudes, what factors affect implicit attitudes toward disability, and how these attitudes affect counseling. Case scenarios involving disability were used to examine different counseling content preferences within a genetic counseling session including medical and diagnostic information, lifestyle and social implications, psychosocial issues. Attitudes were measured using the Disability Implicit Association Test (DA-IAT), and personal and professional experience with disability was assessed. Results from the study reveal that genetic counselors have a stronger bias toward ability compared to the previous participants of the DA-IAT. Results reassure that personal experience with individuals with disabilities does not significantly impact DA-IAT scores or preferred counseling methods. The uniform bias observed across specialties may point to an underlying characteristic of the genetic counseling field either due to shared exposure to disability, self-selection or another factor still undetermined, but even more likely, may point to an inability of the available tool to assess implicit bias toward and individual or group of individuals.

TABLE OF CONTENTS

APPROVAL PAGE	i
TITLE PAGE	ii
ABSTRACT	iii
TABLE OF CONTENTS	iv
LIST OF ILLUSTRATIONS	v
LIST OF TABLES	vi
ABBREVIATIONS	vii
INTRODUCTION	1
MATERIALS AND METHODS	5
<i>Sample</i>	5
<i>Questionnaire</i>	5
<i>Implicit Association Test</i>	5
<i>Data Analysis</i>	6
RESULTS	8
<i>Demographics</i>	8
<i>Experience with Disability</i>	9
<i>Counseling Scenarios</i>	12
<i>Implicit Attitudes toward Disability</i>	13
DISCUSSION	15
<i>Strengths and Limitations</i>	19
Appendix A: Case Scenarios	22
BIBLIOGRAPHY	24
VITA	27

LIST OF ILLUSTRATIONS

Figure 1a Counseling About Disability by Specialty 10
Figure 1b Counseling Individuals with Disability by Specialty 10

LIST OF TABLES

Table 1: Participant demographics.....	8
Table 2: Professional experiences with disability.....	9
Table 3: Personal experiences with disability.....	11
Table 4: Time of one hour session spent on counseling topics.....	12
Table 5: Univariable analyses of DA-IAT score by Group	13

ABBREVIATIONS

IAT- Implicit Association Test

DA-IAT- Disability Implicit Association Test

IQR- Inner quartile range

NSGC- National Society of Genetic Counselors

ADA- Americans with Disabilities Act

ACGC- Accreditation Counsel for Genetic Counseling

INTRODUCTION

With advancing genetic technology, the ability to detect genetic disease earlier and with greater accuracy has grown significantly in recent years. Concern within the disability community has grown alongside these scientific advancements. The question has been raised as to whether or not better detection of conditions involving disability may cause discrimination and, eventually, dwindling numbers of people with disabilities due to genetic conditions (1).

Genetic counselors serve as a link between the medical community and the disability community as they are both educators and medical providers but also aim to be advocates for their patients. This role requires genetic counselors to be responsible and compassionate when approaching conversations about disability (2). Genetic counselors must attempt to balance these, often times, paradoxical roles between supporting patients with disabilities or who have children with disabilities, and properly educating them on the condition and its implications (2).

While many models exist to characterize views on disability, two specifically describe this paradoxical relationship that the genetic counseling field has with the disability community. The social and medical models are discussed in contrast with one another throughout the disability literature and commentary. In the social model, disability is seen as a neutral difference in ability and as a product of the individual's interaction with their environment or society as a whole (3, 4). The key to remedy any conflict within the situation relies on changing the perspectives of society (3, 4). In the medical model, disability is seen as an abnormality or a deficiency within the individual, which requires correction or treatment from a professional (4, 5). These opposing models likely represent opposite ends of a larger spectrum but understanding where one falls is important in determining how one views disability and therefore how that could affect interactions with individuals with disabilities.

When genetic counselors educate families about the technical aspects of a disability including the recurrence risks and medical complications associated with a particular condition, they may speak from the medical model. When compassionately discussing patients' differing abilities and promoting positive self-image and empowerment even with a diagnosis, they are asking the patient to adopt the social model of disability. Understanding attitudes toward disability in the field of genetic counseling will help to further describe the vital role genetic counselors play as liaisons between the medical community and the patient advocacy community, and further understand their role in providing patient-centered education.

The 2017 National Society of Genetic Counselors mission statement on disability is as follows:

“The National Society of Genetic Counselors (NSGC) recognizes and celebrates a person’s inherent value including differences in one’s physical, cognitive, or psychiatric functioning. Individuals should be viewed holistically and not defined by others solely in terms of a single characteristic. Technological advancements in genetics may potentially benefit individuals with disabilities; however, they may also cause harm or stigmatize. Policies should be enacted around these technologies to ensure safeguards protect the rights of those with physical, cognitive, or psychiatric differences and their families. NSGC supports inclusive and nondiscriminatory policies that protect the rights and autonomy of all individuals, provide all individuals the opportunity for self-determination, and respect diversity (6).”

This statement is in line with the social model and its application to the field of genetic counseling; however, little qualitative research has been done to understand the underlying attitudes genetic counselors have toward disability.

As advocates and educators, genetic counselors are often the first medical professionals to describe a condition to a patient and their family (2). These initial discussions about a diagnosis can impact patient perception of prognosis and natural history (7). We can assume that every medical professional will not present information about a new diagnosis in exactly the same way, but presumably prioritizes communicating the information that they believe to be the most vital information about a new diagnosis. What may be important to the provider may not be what the patient would have prioritized if the roles were reversed or what an individual or a community with a given disability would elect to discuss.

Previous studies have found that medical providers including medical students, residents, and genetic counseling trainees generally reported explicit comfort with disability, but when asked about how they would explain diagnoses involving genetic disability, they reported focusing on medical complications over social and life style factors (8). In contrast to explicit attitudes, implicit attitudes are underlying biases which are thought to be subconscious and have been shown to affect behaviors (9, 10). Measuring implicit attitudes does not rely on self-reporting or self-awareness and may therefore eliminate the potential confounding factors of social desirability, or the attempt to manipulate attitudes to fit a more socially acceptable image (9, 11). Furthermore, studies exploring the opinions of individuals with disabilities toward genetic counseling and testing reported that individuals with disabilities feel counseling about conditions involving disability should focus on what individuals with those conditions can do rather than what makes them different (12, 13).

With a limited amount of research on the specific attitudes of genetic counselors toward disability and the impacts on clinical practice, we aimed to address this question. We examined different counseling content areas within a genetic counseling session including medical and diagnostic information, lifestyle and social implications, and psychosocial issues. In addition,

we aimed to determine whether or not there is an association between preferred counseling method and implicit attitudes toward disability along with what other factors affect genetic counselors' attitudes toward disability.

MATERIALS AND METHODS

Sample

The sample population for this project included listserv members of the National Society of Genetic Counselors (NSGC). Recruitment was completed through e-mail invitation which included a survey link to participate. Members of NSGC include genetic counselors, genetic counseling students, and other genetics professionals. For the purposes of this study, only genetic counselors and genetic counseling students were invited to participate.

Questionnaire

The survey included two sections: a questionnaire followed by a disability-specific psychometric tool measuring implicit attitudes. Participants were first directed to complete demographic questions assessing gender, age, years of experience as a genetic counselor, specialty, and experience with individuals with a disability. The Americans with Disability Act (ADA) definition of disability was provided for this section of the survey, “Disability is a physical and/or mental impairment that substantially limits one or more major life activity.”(14)

As part of the questionnaire, participants were asked about their counseling methods in three different case scenarios (Appendix 1). Counseling methods included four core content themes: medical complications, diagnostic information, social and lifestyle behaviors, and psychosocial counseling. Each of the scenarios involved counseling parents of a child with a new diagnosis involving disability and asked participants to report the number of minutes of an hour-long session they would plan to spend in each content theme.

Implicit Association Test

The Implicit Association Test (IAT) is a validated psychometric tool designed to assess underlying bias (15). The Disability Implicit Associated Test (DA-IAT) is a modified version of the IAT initially expected to assess respondent’s bias toward “abled” or “disabled”

individuals. The tool consists of visual stimuli that are intended to represent individuals with and without disabilities as well as words that are characterized as “good” and “bad”.

Respondents are instructed to place visual stimuli in “abled” and “disabled” categories, followed by categorizing the words in “good” and “bad” categories. In the next section, respondents are given pairings of the categories as either “disabled/good” and “abled/bad” or “disabled/bad” and “abled/good”. In this section they are asked to categorize both images and words under the paired categories. Respondents are randomly assigned one of the two pairings first. In the following section the pairings are switched, depending on which pairing they received in the previous section. Respondents are instructed to complete these activities as quickly as possible, thereby using differences in response time to assess implicit bias (16).

Time to make congruent pairings, or stimuli that are correctly categorized as good or bad, were compared to incongruent pairings. This comparison is used to measure the strength of the association between congruent and incongruent pairings. The effect size of this comparison is called the D score. Negative D scores indicate a preference for disability over ability and positive D scores indicate a preference for ability over disability (16).

Data Analysis

Data was collected using Qualtrics software and exported for analysis. Frequencies (with percentages) and medians (with interquartile ranges, IQR) were utilized to describe categorical and continuous variables, respectively (17). Comparisons between categorical variables were performed using contingency tests (Fisher exact or Chi-square). Distribution of continuous variables across groups were performed using a Mann-Whitney test or Kruskal-Wallis with a post-hoc Dunn's test. Separate multivariable regression models were tested to identify factors associated with the IAT and the time spent on each of the four counseling components. Additionally, multivariate multiple regression models were assessed to identify

factors associated with time spent on all four counseling components. All analyses were performed using STATA (v.13, College Station, TX) (18). Statistical significance was assumed at $p < 0.05$.

RESULTS

Demographics

Of the 3,560 NSGC listserv members that received the survey, 406 elected to respond to at least a portion of the survey. Respondents who did not complete questions beyond the demographic sections were excluded, as well as duplicate responses and responses not completed by a currently practicing genetic counselor or genetic counseling student. After excluding these responses, 382 complete surveys were considered for analysis. An overall estimated response rate of 10.7% was obtained, however this response rate is likely an underestimate as the NSGC listserv contains recipients who were not part of the target study population of practicing genetic counselors and genetic counseling students.

Participant demographic and professional information is summarized in Table 1. Counselor primary specialties were categorized as prenatal, cancer, medical genetics (including pediatric, adult, cardiology, and neurology), and other (including research, industry, laboratory, education, and multiple specialties when no single primary was selected). Participant demographic and professional information was compared to the National Society of Genetic Counselors 2016 Professional Status Survey and found to be appropriately representative (19).

Table 1: Participant demographics

Variable	n	%
Gender		
Female	364	95
Male	16	4
Other/No answer	2	<1
GC/Student		
GC	319	84
Student	63	16
Ethnicity		
Non-Hispanic White	348	91
Asian	9	2
Mix ethnic	9	2
Hispanic	8	2
African American	3	1
Other	5	1
Religion		
Nonreligious	135	35
Christian	120	31
Catholic	49	13
Jewish	24	6
Poly-Religious	19	5
Other	18	5
No response	17	4
Primary Specialty		
Medical Genetics	95	30
Cancer	90	28
Prenatal	67	21
Other	67	21

Experience with Disability

Complete information on responses regarding counseling *about* disability as well as counseling individuals *with* disabilities can be found in Table 2. Nearly half (48%) of all participants reported that they counsel *about* disability at least once per week, while approximately one-third (34%) of respondents reported that they never counsel *about* disability. Thirty-five percent reported that they never counsel individuals *with* a disability, while 21%

reported that they counsel individuals *with* a disability at least once per week. Prenatal and medical genetics counselors most frequently reported counseling *about* disability at least once per week (96% and 73%, respectively), while cancer genetic counselors most frequently reported never counseling *about* disability (79%) (Figure 1a). The majority of counselors who reported counseling patients who have a disability at least weekly are medical genetics counselors (71%) (Figure 1b).

Table 2: Professional experiences with disability

Frequency	Counseling About Disability		Counseling Individuals with Disabilities	
	N	%	n	%
Never	129	34	135	35
Less than once per month	21	6	90	24
Once or twice per month	47	12	78	20
Once or twice per week	59	15	46	12
More than twice per week	126	33	33	9

Figure 1a Counseling About Disability by Specialty

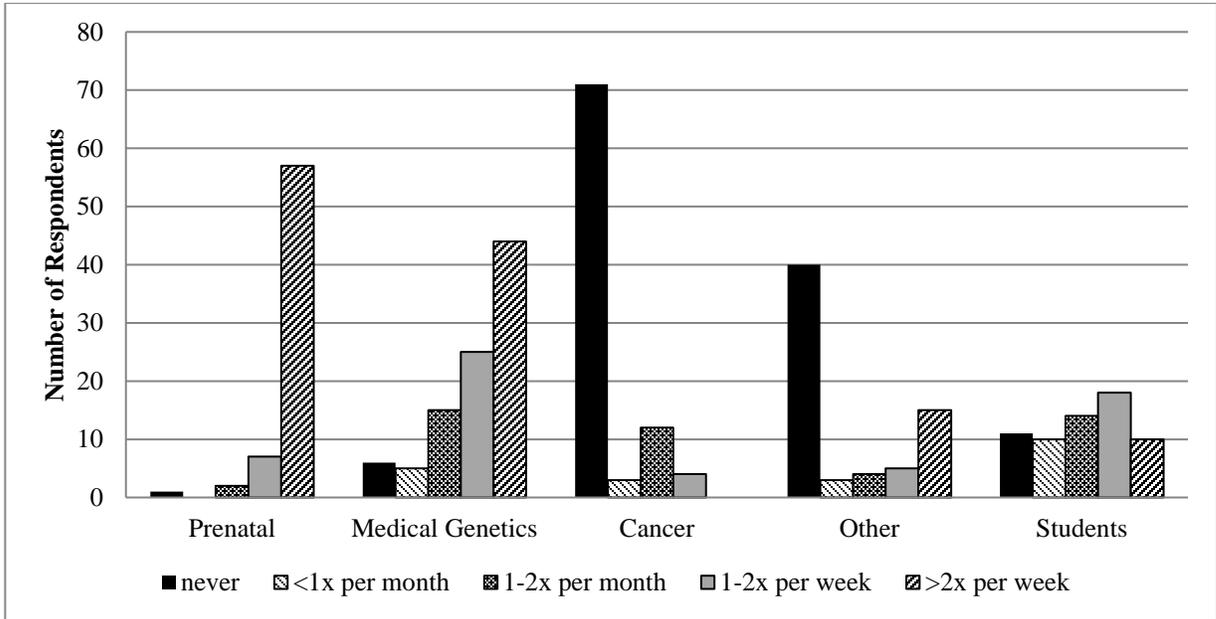
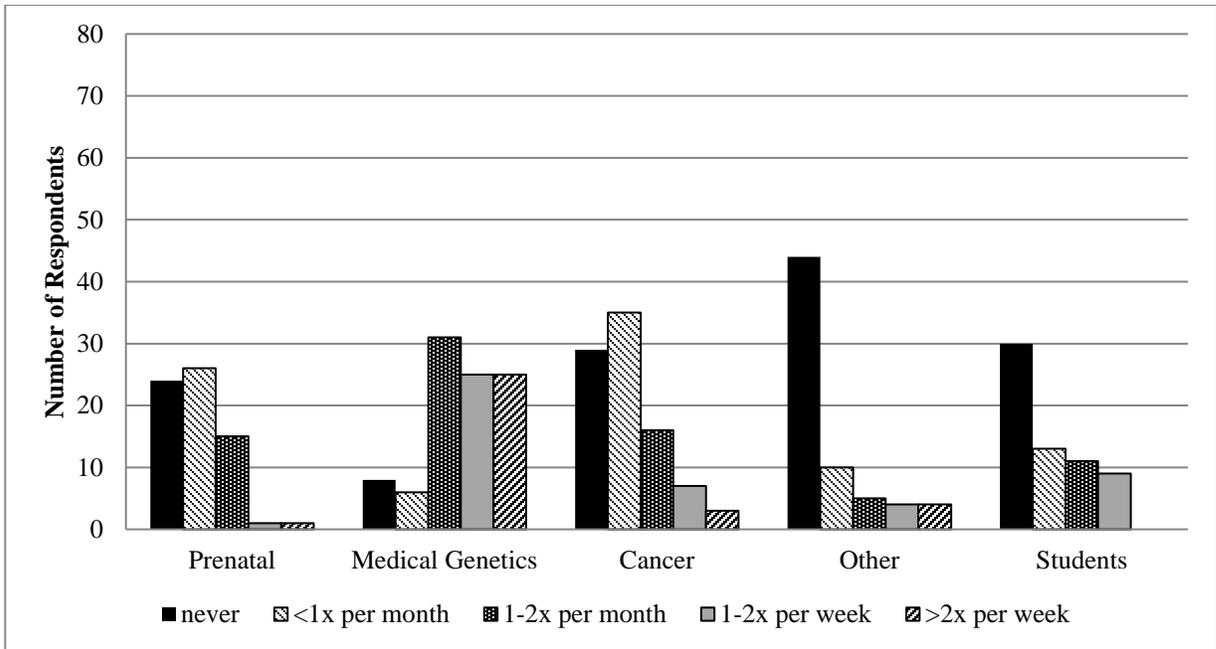


Figure 1b Counseling Individuals with Disabilities by Specialty



Free-response answers regarding personal experience with individuals with disabilities were categorized by type of relationship to an individual with disabilities and type of disability experienced. Relationships to an individual with a disability were categorized into personal disability, first degree relatives and spouses, other family members, friends, genetic counseling experiences, and volunteering. Types of disability were categorized into intellectual disability,

autism, physical disability, mental illnesses, “other”, and unspecified. “Other” included diabetes, dementia, and cancer. Of 382 survey respondents, approximately two-thirds (68%) reported some type of personal experience with an individual with a disability. Nearly half (45%) of respondents who reported personal experience with an individual with a disability, reported relationships with more than one individual with a disability, with eight percent of respondents reporting three or more different relationships with an individual with a disability (Table 3). Intellectual disability was the most frequently reported type of disability experienced (n=135), followed by unspecified (n=102), and physical disability (n=84).

Table 3: Personal experiences with disability

Relationship to Individual with Disability	>1 type of relationship	Single Relationship (n= 142, excluding None)
Personal	14	3
First degree relative/spouse	30	16
Other family member	64	37
Friend	49	18
As a GC	38	20
As a Volunteer	73	48
None	-	123
Type of Disability Reported	n	
Intellectual Disability	135	
Autism	49	
Physical Disability	84	
Mental Illness	19	
Other	45	
Unspecified	102	

Counseling Scenarios

Two-hundred and sixty-four respondents completed all three counseling scenarios (69%). Summaries of mean time spent on each topic within a session for the counseling scenarios are depicted in Table 4. On average, cancer genetic counselors reported spending more time counseling on social and life style factors ($p= 0.0045$), by approximately three minutes, when compared to prenatal and “other” counselors and by a minute and a half when compared to medical genetics counselors. In addition, medical genetics counselors reported

spending significantly more time counseling about medical complications than prenatal and “other” counselors on average ($p= 0.0408$). Of note, because increasing time in any one content area would require the decreasing of time spent in the other areas, they are considered dependent variables. To assess the effect of counseling methods on each other, multivariate analyses were completed, in which the significant difference in medical genetics counselors was not found. Statistically significant differences were still found, however, for time spent on social and life style factors among cancer counselors when compared to prenatal and “other” specialties ($p= 0.004$). All four counseling methods were incorporated into the multivariate model.

Table 4: Time of one hour session spent on counseling topics

Counseling Methods	Average minutes of a one-hour session spent over three counseling scenarios				p-value
	Prenatal (n=55)	Medical Genetics (n=78)	Cancer (n=74)	Other (n=57)	
Medical Complications (common clinical symptoms)	15.0	16.0	16.0	15.0	0.0408
Diagnostic Information (Testing methods and techniques, radiographic features, genetic changes, inheritance, recurrence risk & future testing)	11.7	11.2	11.0	10.0	0.7649
Social & Life Style Factors (Options for school and work later in life, relationships, life expectancy, developmental milestones)	11.7	13.3	14.7	11.7	0.0045
Psychosocial Counseling	17.3	17.7	16.7	18.7	0.0845

Implicit Attitudes toward Disability

Two-hundred and ninety participants completed the disability implicit association test (DA-IAT) (76%). Scores ranged from -0.843 to 1.621 with a median of 0.70 (IQR 0.61).

Twenty-eight respondents (10%) had scores less than or equal to zero, indicating either no bias ($D=0$) or bias toward disability, while 90% had positive scores, indicating the majority of

participants had bias toward ability. In comparing DA-IAT scores from this study ($D_{(\text{mean})} = 0.62$) with those reported for all previous participants of the DA-IAT ($D_{(\text{mean})} = 0.45$), genetic counselors' scores were found to be significantly higher ($p < 0.005$) (20). No significant differences were found when comparing DA-IAT scores between practicing genetic counselors and those of students, differing religious affiliations, and years of experience (those with less than five years in practice and those with five or more years). In addition, DA-IAT scores by primary practice setting, whether one counsels *about* disability, counsels individuals who *have* disabilities, or has personal experience with an individual(s) with a disability were not found to be significantly different. There were also no statistically significant differences found in DA-IAT scores between different types of relationships to an individual with a disability or between the different types of disabilities reported in personal experiences. Univariable analyses, median DA-IAT scores, and p-values can be found in Table 5. Multivariable regression adjusting for all the variables also failed to yield any statistically significant associations.

Table 5: Univariable analyses of DA-IAT score by Group

Group	GC/ Student	Primary Field of Practice	Type of Relationship	Years of experience in GC ($<5, \geq 5$)	Ethnicity	Religion	Type of Disability
p-value	0.8384	0.5723	0.6819	0.2407	0.4274	0.5376	0.1417

DISCUSSION

In considering the role genetic counselors play in delivering diagnoses and educating patients, it is important to understand the potential subconscious biases that could be affecting these conversations. Results from this study help in understanding what these underlying biases are and what factors they may influence in daily counseling sessions.

Within the study cohort, counseling *about* disability was experienced most frequently in prenatal and medical genetics specialties. These results are expected as prenatal counselors routinely discuss risks for chromosome abnormalities and medical genetics counselors routinely see individuals with indications involving intellectual disability, autism, and physical disabilities. Time spent counseling individuals *with* a disability was also significantly different across specialties. As expected, medical genetics counselors have the most frequent exposure to counseling individuals *with* a disability. Interestingly, cancer genetic counselors, as well as those in the “other” category, reported counseling individuals with disabilities most infrequently; even though cancer is often considered a disability under the ADA definition of disability, as it can limit one or more major life activity (14). This discrepancy, along with the free response answers regarding personal experience with disability, highlight the important concept that individuals’ interpretation of disability varies greatly and may or may not be consistent with the technical definition determined by the ADA or other associations. Therefore, it is always imperative to verify how a patient perceives a given diagnosis before assuming whether they would categorize it as a disability.

In assessing the preferred counseling methods by specialty, it was found that cancer genetic counselors reported spending significantly more time on social and lifestyle factors when averaging time for all case scenarios. This difference in time amounted to a minute and half longer than medical genetics counselors and three minutes longer than both prenatal and

“other” counselors, of the one-hour session allowed in the case scenarios. These results are consistent with the previously completed Genetic Counseling Video Project, which reported cancer genetic counselors showed a preference for a psycho-educational teaching approach in sessions, including social and lifestyle factors (21). This may reflect either a personal preference for discussing this information or what these counselors believe is most important to the patient. Considering the context of a cancer genetic counseling session, topics such as living with a genetic predisposition to cancer, family dynamics and relationships, communicating test results, and self-image may regularly be covered by cancer genetic counselors and thus may explain a tendency toward social and lifestyle factor discussion. Cancer genetic counselors in this study may have chosen methods utilized in typical cancer sessions when considering their methods for these scenarios involving disability in a pediatric setting. However, case scenarios assessed in this study were hypothetical, where participants were estimating the time they would spend in each counseling content area and the significant differences in time range from one and a half minute to three minute differences. While statistically significant, these incremental differences may not affect the counselor or patient experience in a meaningful way.

Surprisingly, results of the Disability Implicit Association Test were found to be overwhelmingly biased toward ability among the genetic counselors in the study cohort ($D_{\text{mean}}=0.62$). This was found to be significantly higher than the aggregate data reported by the Project Implicit website for all previous participants of the DA-IAT ($p<0.005$) (20, 22). This significant disparity is consistent with findings from a 2012 study by Aaberg et al., analyzing the implicit attitudes of nurse educators toward disability. Similar to findings of the present study, Aaberg et al. found that nurse educators experienced a significantly higher level of implicit bias toward individuals without disabilities when compared to the aggregate DA-IAT data (22). Genetic counselors and nurse educators share a number of similarities in their roles as

patient educators and advocates, however the scores from the DA-IAT fail to explain the values of patient-centered care that these professions aim to practice (22). For these reasons, consideration was placed into how the DA-IAT truly assesses implicit bias towards disability and whether this is the most appropriate measure for this population.

Individual experience with disability may often serve as a motivating factor to pursue genetic counseling as a profession. Somewhat surprisingly, results of this study suggest that personal experience with disability does not have a significant effect on implicit bias toward ability/disability. This was found both when comparing the type of disability experienced as well as type of relationship(s) to the individual(s) with a disability, suggesting that having personal experience with individuals with a disability does not impact how genetic counselors view disability. What was not captured in this study was the timing of these exposures. Therefore, it is difficult to determine what impact genetic counseling training had on individual perspectives of those with prior experience with individuals with disabilities.

In addition to DA-IAT score comparisons between personal experiences, implicit attitude score comparisons between students and practicing genetic counselors were not significantly different. It is hypothesized that an exposure or a predisposition to becoming a genetic counselor may be sufficient to effect attitudes toward disability. Further supporting this hypothesis, there were not significant differences identified in counseling methods or DA-IAT scores between new counselors and those with more experience in the field. Both of these findings indicate that the exposure affecting attitudes toward disability occurs early in graduate training or before graduate training altogether. Shared factors that attract people to a career in genetic counseling may further explain this relationship. For example, if the DA-IAT was performed prior to graduate training, would significant differences in bias be found between those with disability experience and those without? Is there something about training that

allows for a bias against disability because counselors are so knowledgeable about attributes of genetic disease and the challenges they bring while presumably still being able to exhibit positive regard towards patients, both with and without disability? Although not assessed by this study, it is clear that counselors provide compassionate care to their patients with disability while, apparently, having a bias toward ability.

Demographically, genetic counselors are a relatively homogeneous group when considering gender, race, and, educational background (19). Perhaps this homogeneity extends farther than demographics, into personality traits and explains both the implicit biases revealed in this study, as well as the similarity in counseling methods regardless of bias. For example, within the Lesch-Nyhan case scenario, time spent in differing counseling methods was not found to be statistically significant between specialties. This may point to an underlying uniformity in the way genetic counselors are trained to counsel in scenarios involving little clinical variability and a more severely disabling condition. Tenets of genetic counseling encourage that, while counselors may have underlying bias about disability, these biases should not be brought into sessions, and patients are treated and counseled based on individual needs (6). Therefore, counselors may be able to compartmentalize those biases, if present, when counseling these patients and reflect the needs and attitudes of the patients in front of them rather than succumbing to their own implicit biases. It is important to note that this is a generalization made based on the results of this study, not all counselors are able to hide underlying biases and self-awareness of implicit biases is a crucial part of nondirective counseling.

Perhaps this ability to provide patient centered, nondirective counseling can be traced back to graduate training for genetic counseling. Interestingly, in 2012 Sanborn et al. studied the involvement of disability training in genetic counseling graduate programs and found that just

10% of programs require experience with disability as a prerequisite (23). Although the majority of programs did not appear to require disability experience at that time, many programs are likely to prioritize exposure to disability in a prospective student application. While there are not specific guidelines for disability education or training in the ACGC practice-based competencies, they do mention that genetic counselors should be able to describe how disability affects the genetic counseling encounter. This is included as part of cultural competency in genetic counseling as outlined by ACGC practice-based competencies (24). This may explain why results of this study do not show a strong impact of implicit bias on counseling methods.

Strengths and Limitations

One important distinction, and potential underlying rationale for results obtained from the DA-IAT in this study, is that participants are asked to categorize visual stimuli associated with ability versus disability. For example, a handicapped-parking figure and a stick figure skiing, rather than pictures of individuals with and without disabilities were utilized by the tool. Although results of the DA-IAT claim to report a bias toward individuals with disabilities versus individuals without disabilities, it appears that the tool actually measures bias towards ability or disability. Interestingly, a study by Falugi et al. found that traditional clinical pictures of patients with visible genetic conditions had negative impacts on student's perceptions of conditions, while more natural photographs of individuals with these conditions improved these perceptions. These perceptions change when depictions are more natural and more human. Therefore, these biases may lie in the disability itself rather than the person or group of people with disabilities and more positive depictions and exposure during training may help to improve perceptions (25).

While counselors may feel that disability, as a concept is negative, they are unlikely to have bias feelings against a person with disabilities as genetic counselors routinely fulfill the

role of compassionate advocates for their patients. This distinction is important as it remains imperative to always assess a patients' view of their own diagnoses and not project personal feelings or attitudes toward the diagnoses themselves. Another interesting realization is the DA-IAT includes images representative of physical disability and therefore limits the generalizability of the results to other types of disability, for example intellectual disability.

Literature assessing the validity of the IAT has found little correlation between explicit attitudes and implicit attitudes, specifically regarding bias toward disability (11, 20, 26). This may be expected given the social desirability of being neutral in one's attitudes toward disability. In contrast, critiques of the IAT have suggested that the tool measures a single response to a visual stimuli rather than the more complex response that humans might experience (26, 27). De Houwer explains an example of this concept in which one may have conflicting attitudes towards a friend displaying a negative facial expression. While reacting positively to the familiar person, one may react negatively to the facial expression (27). For this reason, the IAT may not capture the complexity of genetic counselors' relationship to individuals with disabilities.

Additionally, the population that makes-up the aggregate DA-IAT data may experience selection-bias as those that experience disability themselves and/or have an interest in the conversation surround disability are those most likely to have sought out the DA-IAT and taken it unprompted. Therefore, scores of aggregate data may not be representative societal implicit attitudes toward disability. Eliciting responses to the DA-IAT from an unselected, general population cohort is needed to further define the range of bias.

Information provided about personal experience with disability was given via free response which did not specifically elicit information about frequency of personal exposure to disability, time spent in the experiences, and degree of relationship to individuals with

disabilities. This study was also not designed to elicit timing of personal experience with disability but rather what experiences counselors had with individuals with disabilities. It may be helpful, in future studies, to understand chronology of experience with disability and its relationship to graduate studies and “in the field” experiences. This information may shed light on how prior personal experiences may affect implicit bias to disability and genetic counseling practice.

This study had a large sample size and while participants may have self-selected for those who have a particular interest in disability, the demographic stratification is consistent with the National Society of Genetic Counselors professional status survey and may be considered representative of the genetic counseling population as a whole.

In conclusion, this study revealed that genetic counselors show a uniform bias toward ability that is higher than expected compared to the available, aggregate data. In addition, this study did not find significant correlations between practice methods and implicit biases. It can be inferred that, while there may be an underlying factor affecting biases in the genetic counseling profession, biases are not significantly impacting how counselors are choosing to counsel about disability. While there were other factors, like primary specialty, associated with different counseling methods, it is difficult to understand the exact origin of these differences and if the differences can be perceived by the counselors and/or patients. This study helps to understand what the implicit attitudes of genetic counselors are toward disability but still begs the question, what factors are influencing these biases?

Appendix A: Case Scenarios

For the following case scenarios, please consider how much of a typical 1 hour-long counseling session you would likely spend on each of the content topics listed. (All cases provided are pediatric case scenarios, regardless of reported specialty).

Case 1:

You are seeing first-time parents of a two day old infant with a new diagnosis of Down syndrome. They have a high school education and limited knowledge of genetics. They have told you that they “have heard of Down syndrome” but do not know much about it. There is no apparent heart defect. Diagnosis was suspected at birth based on dysmorphic features.

(Down syndrome - Trisomy 21, characterized by global developmental delay, moderate intellectual disability, can also include congenital anomalies and medical concerns, shortened life expectancy [60 years])

Medical complications: [Ex: sleep apnea, seizures, hearing and vision problems, developmental delay, intellectual disability]

Diagnostic process: [Testing methods and techniques, dysmorphic features, chromosomes, inheritance, recurrence risk & future testing]

Social and lifestyle behaviors: [Options for school and work later in life, relationships, life expectancy, developmental milestones]

Psychosocial Counseling

Case 2:

You are seeing first-time parents of a one week old infant with a new diagnosis of achondroplasia. They are of average stature, with a high school education. They have mentioned that they "have seen people with dwarfism on TV" but do not know much about it.

(Achondroplasia- skeletal dysplasia caused by a mutation in the FGFR3 gene, characterized by disproportionate short stature, dysmorphic features, developmental delay, no intellectual disability, typical life expectancy)

Medical complications: [Ex: spinal stenosis, hydrocephalus, kyphosis, GI reflux]

Diagnostic Process: [Testing methods and techniques, radiographic features, genetic changes, inheritance, recurrence risk & future testing]

Social and lifestyle behaviors: [Options for school and work later in life, relationships, life expectancy, developmental milestones]

Psychosocial Counseling

Case 3:

You are seeing first-time parents of a three month old boy with Lesch-Nyhan syndrome. They have a high school education and no prior knowledge of Lesch-Nyhan syndrome.

(Lesch-Nyhan syndrome- X-linked metabolic condition caused by buildup of uric acid, characterized by typical perinatal course with involuntary muscle movements developing in the first year of life, inability to walk or sit on one's own, cognitive impairment expected along with, behavioral disturbances, including self-injurious behavior beginning at 2-3 years of life. Shortened life expectancy [20s-30s])

Medical complications: [Ex: severe intellectual disability, self-injurious behaviors, motor dysfunction, etc.]

Diagnostic Process: [Testing methods and techniques, genetic changes, inheritance, recurrence risk & future testing]

Social and lifestyle behaviors: [Options for school and work later in life, relationships, life expectancy, support groups]

Psychosocial Counseling

BIBLIOGRAPHY

1. Skotko, B. G. 2009. With new prenatal testing, will babies with Down syndrome slowly disappear? *Archives of disease in childhood* 94: 823-826.
2. NSGC. 2018. Who Are Genetic Counselors? 2018 National Society of Genetic Counselors, nsgc.org.
3. Oliver, M. 1996. *Understanding disability: From theory to practice*. St Martin's Press.
4. Nicolaisen, J., B. S. Blichfeldt, and F. Sonnenschein. 2012. Medical and social models of disability: a tourism providers' perspective. *World Leisure Journal* 54: 201-214.
5. Barnes, C., and M. Oliver. 1993. *Disability: a sociological phenomenon ignored by sociologists*.
6. 2017. Position Statement: Disability. N. Headquarters, ed. National Society of Genetic Counselors (NSGC), nsgc.org.
7. Kellogg, G., L. Slattery, L. Hudgins, and K. Ormond. 2014. Attitudes of mothers of children with down syndrome towards noninvasive prenatal testing. *Journal of genetic counseling* 23: 805-813.
8. Ormond, K. E., C. J. Gill, P. Semik, and K. L. Kirschner. 2003. Attitudes of health care trainees about genetics and disability: issues of access, health care communication, and decision making. *Journal of genetic counseling* 12: 333-349.
9. Blair, I. V., J. F. Steiner, and E. P. Havranek. 2011. Unconscious (Implicit) Bias and Health Disparities: Where Do We Go from Here? *The Permanente Journal* 15: 71-78.
10. Greenwald, A. G., T. A. Poehlman, E. L. Uhlmann, and M. R. Banaji. 2009. Understanding and using the Implicit Association Test: III. Meta-analysis of predictive validity. *Journal of personality and social psychology* 97: 17-41.

11. Pruet, S. R., and F. Chan. 2006. The development and psychometric validation of the Disability Attitude Implicit Association Test. *Rehabilitation Psychology* 51: 202-213.
12. Ward, L., J. Howarth, and J. Rodgers. 2002. Difference and choice: exploring prenatal testing and the use of genetic information with people with learning difficulties. *British Journal of Learning Disabilities* 30: 50-55.
13. Enns, E. E., P. Boudreault, and C. G. Palmer. 2010. Examining the relationship between genetic counselors' attitudes toward deaf people and the genetic counseling session. *Journal of genetic counseling* 19: 161-173.
14. (ADA), T. A. t. D. A. N. N. What is the definition of disability under the ADA? The Americans the Disabilities Act National Network (ADA), ADA National Network.
15. Greenwald, A. G., B. A. Nosek, and M. R. Banaji. 2003. Understanding and using the implicit association test: I. An improved scoring algorithm. *Journal of personality and social psychology* 85: 197-216.
16. Greenwald, A. G., D. E. McGhee, and J. L. Schwartz. 1998. Measuring individual differences in implicit cognition: the implicit association test. *Journal of personality and social psychology* 74: 1464-1480.
17. 2016. Qualtrics Software. May 2016 of Qualtrics ed. Qualtrics. Copyright ©. (2015). Qualtrics. Qualtrics and all other Qualtrics product or service names are registered trademarks or trademarks of Qualtrics, Provo, UT, USA.
18. StataCorp. 2013. Stata statistical software release 13. Copyright ©. Stata Corp, LP, College Station, TX.
19. (NSGC), N. S. o. G. C. 2016. 2016 Professional Status Survey: Work Environment.
20. Nosek, B. A., F. L. Smyth, J. J. Hansen, T. Devos, N. M. Lindner, K. A. Ranganath, C. T. Smith, K. R. Olson, D. Chugh, A. G. Greenwald, and M. R. Banaji. 2007.

- Pervasiveness and correlates of implicit attitudes and stereotypes. *European Review of Social Psychology* 18: 36-88.
21. Roter, D., L. Ellington, L. H. Erby, S. Larson, and D. W. 2006. The Genetic Counseling Video Project (GCVP): Models of Practice. *American journal of medical genetics. Part C, Seminars in medical genetics* 142C: 209-220.
 22. Aaberg, V. A. 2012. A path to greater inclusivity through understanding implicit attitudes toward disability. *J Nurs Educ* 51: 505-510.
 23. Sanborn, E., and A. R. Patterson. 2014. Disability training in the genetic counseling curricula: bridging the gap between genetic counselors and the disability community. *American journal of medical genetics. Part A* 164A: 1909-1915.
 24. Counseling, A. C. f. G. 2015. Practice-Based Competencies for Genetic Counselors. ACGC, gceducation.org.
 25. Falugi, C., S. S. Hashmi, S. H. Elsea, C. N. Singletary, A. D'Angelo, J. Nguyen, M. Ashfaq. 2016. Effect of Photographs of Visible Genetic Conditions on Quality of Life Perceptions. The University of Texas Health Science Center at Houston and The University of Texas MD Anderson Cancer Center Graduate School of Biomedical Sciences, Unpublished Master's Thesis Dissertation.
 26. Wilson, M. C., and K. Scior. 2015. Implicit Attitudes towards People with Intellectual Disabilities: Their Relationship with Explicit Attitudes, Social Distance, Emotions and Contact. *PLoS One* 10: e0137902.
 27. De Houwer, J. 2001. A Structural and Process Analysis of the Implicit Association Test. *Journal of Experimental Social Psychology* 37: 443-451.

VITA

Helen Gould was born in Newark, Delaware to Dr. John Gould Jr. and Dr. Sharon Gould. After completing her work at Avon Grove High School, Avondale, Pennsylvania in 2011, she entered The Pennsylvania State University in University Park, Pennsylvania. She received the degree of Bachelor of Science majoring in biology with a concentration in Genetics and Developmental Biology from Penn State in May, 2015. For the next year, she worked as a research assistant in the Department of Research and Development at Lambert Spawn & Co in Coatesville, Pennsylvania. In August of 2016 she entered The University of Texas MD Anderson Cancer Center UTHealth Graduate School of Biomedical Sciences Genetic Counseling Training Program.

Permanent address:

6301 Almeda Road, Apartment 749

Houston, Texas 77021