Investigating the Attitudes of the d/Deaf Community Towards Genetic Counseling and the Utilization of Genetic Services

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Investigating the Attitudes of the d/Deaf Community Towards Genetic Counseling and the Utilization of Genetic Services

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by
Katie Baudoin, BS
Houston, Texas

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Finally, I would like to express my gratitude to the Deaf community for sharing their personal stories. I am immensely grateful for the emotional strength and vulnerability it must have taken to share their truth. This project would truly not have been possible with them.
Investigating the Attitudes of the d/Deaf Community Towards Genetic Counseling and the Utilization of Genetic Services

Katie Baudoin, B.S.
Advisory Professor: Jennifer Czerwinski, M.S., CGC

The Deaf community has previously expressed concerns about the process of genetic counseling/testing and the potential implications it can have for Deaf individuals. Prior studies have explored the motivations of Deaf individuals for pursuing genetic testing related to deafness; however, information regarding the interest and motivations for indications other than deafness is limited. Our study aims to characterize attitudes of individuals within the d/Deaf community towards genetic counseling and testing and to assess interest and motivations to seek genetic counseling for indications other than deafness.

Individuals were recruited through local and national d/Deaf organizations to participate in an anonymous, online survey. Of the 54 responses, 61% identified with the Deaf community. Thirty percent indicated having prior experience with genetic counseling and testing. Overall scores of satisfaction were consistent with most participants being satisfied with their sessions. Both individuals with prior experiences and individuals without experience expressed interest in genetic counseling about a variety of indications, although individuals still seemed to feel overall neutral towards genetic counseling and testing. Surprisingly, 60% of individuals who identified with the Deaf community agreed with the statement that deafness is a disability.

These findings indicate that despite literature and generalizations about the Deaf community and their beliefs, these views may not be representative of all Deaf patients and can further damage rapport and trust if wrongly assumed. To overcome the decades of distrust and injustices, healthcare providers need to engage in culturally competent, patient-centered care, especially in historically marginalized communities like the d/Deaf community.
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Introduction

Hereditary hearing loss can be categorized as either syndromic or non-syndromic. Non-syndromic causes of hereditary hearing loss are most often autosomal-recessive and account for up to 80% of pre-lingual hearing loss with a genetic etiology.\textsuperscript{1,2} Additionally, hearing loss can be found as part of over 400 genetic syndromes.\textsuperscript{3} While access to genetic testing for hereditary hearing loss/deafness is readily available, the motivations and desires of individuals and caregivers of individuals with hearing loss and/or deafness to undergo genetic testing and counseling varies widely. This is often dependent upon personal motivations, health literacy, access to care, and perceptions on what it means to be d/Deaf.\textsuperscript{4}

Historically, deaf (lower case “d”) individuals are those that identify their hearing loss as an impairment, disability, or functional loss and are often integrated into the hearing world. Deaf (upper case “D”) individuals identify as a part of a community and culture that has its own language (American Sign Language) and do not view deafness as an impairment, disability, or loss of function. The Deaf community is tight-knit and connected by shared beliefs, experiences, history, and language, while embracing deafness as part of their identity.\textsuperscript{4,5}

Many individuals in the Deaf community do not consider their deafness a disability, a sentiment that is often at odds with the medical model perception of “disability.” According to the Americans with Disability Act (ADA), disability is defined as having a physical or mental impairment that hinders one or more daily life activities, having a history of such impairment, or being perceived by others of having such impairment.\textsuperscript{6} Under this definition, Deaf individuals are considered to be, and often labeled as, “disabled” by the ADA, employers, and the non-Deaf community, even if they do not personally identify as being disabled.

Before, and even following, the passage of the ADA, the d/Deaf community has faced ostracization, intolerance, and discrimination on the basis of their deafness. The eugenics
movement included the sterilization of Deaf individuals and discouragement against Deaf individuals from marrying and having children with each other in an effort to “select against deafness”. These intolerant acts extended to education and school systems that once banned sign-language and forced d/Deaf individuals to adhere to strict oralism policies, such as lip reading and vocalization. These efforts further deepened the existing divide between the Deaf community and non-Deaf individuals, presenting unique challenges in gaining the trust of this marginalized community in a healthcare setting.

Fear, mistrust, and frustration has long been an undercurrent in interactions between the Deaf community and healthcare providers, often contributing disparities in care for Deaf individuals. Communication issues, language barriers, lack of provider knowledge regarding Deaf culture, and lack of appropriate resources all have been attributed to poorer health outcomes and decreased health literacy among the Deaf population. Many genetic counseling training programs incorporate d/Deaf culture awareness training into their curriculum; however, one recent study showed no evidence of increased competency, comfort level, or knowledge of genetic counseling graduate’s students regarding the d/Deaf community. Additionally, almost one third of participants indicated their training was insufficient.

While many forms of deafness have an underlying genetic etiology, many d/Deaf individuals do not pursue genetic testing and express negative feelings towards the process due to their interactions and experiences with healthcare providers. The Deaf community has expressed valid concerns about the process of genetic testing and counseling in the past and the possible impact and implications it can have for Deaf individuals. Previous studies have highlighted concerns that genetic testing may do more harm than good, aid in the devaluation of Deaf people, try to eliminate or “cure” deafness, contribute to discrimination, or be used to make pregnancy termination decisions based on hearing status. Despite these concerns, d/Deaf individuals have
expressed interest in genetic testing as a means to learn if there is a genetic etiology to their deafness, to help prepare for the educational needs of future children, and to help contribute to research.\textsuperscript{4,11}

Previous studies have investigated motivations for pursuing genetic testing related to deafness; however, there is limited information within the deaf/Deaf communities regarding interest and motivations for pursuing genetic counseling and/or testing for indications other than deafness. This study aimed to characterize past experiences of deaf/Deaf individuals with genetic counseling and testing as well as assess individuals’ interest and motivations to seek genetic counseling for a variety of indications. By characterizing the interest and motivations of d/Deaf individuals, genetic counselors can continue to build trust, further their cultural competency, and tailor their counseling to the specific needs of the individuals of this unique community.

**Methodology**

**Study Design**

A cross-sectional, mixed-methods survey was utilized to evaluate the attitudes of individuals within the d/Deaf community towards genetic counseling and assess its impact on their motivations and desire to pursue genetic counseling for indications other than their deafness. Survey responses were collected between September 2021 to January 2022. This study was approved by the Institutional Review Board at the University of Texas Health Science Center at Houston (HSC-MS-21-0511).

**Participants**

Participants included members of the d/Deaf community who identified as d/Deaf individuals, caregivers, family members, or advocates of the d/Deaf community. Individuals had to be 18 years or older and speak English and/or use American Sign Language (ASL) to be
eligible. Participants were recruited for the study through both local and national d/Deaf organizations. A total of 26 organizations were contacted for participation and six agreed to distribute the survey to their members. These organizations included: Louisiana Association of the Deaf (LAD); Kansas Association of the Deaf (KAS); Hearing Loss Association of America (HLAA) - St Louis; the Association of Medical Professionals with Hearing Loss (AMPHL); Deaf Empowerment Awareness Foundation (DEAF), Inc; and American Society for Deaf Children. Each organization distributed the survey to their members via a direct email link, social media, or recruitment flyers with QR codes. An initial call for participants was distributed via organizational channels and was followed by a second invitation to participate approximately 4-6 weeks afterwards.

Data Collection

A self-administered online survey was developed in Qualtrics XM (Qualtrics, Provo, UT) and provided to the participants via a QR code and direct website link. Questions were developed by investigators utilizing previous studies examining similar topics and reviewed by a d/Deaf community advocate prior to distribution. In an effort to increase accessibility and inclusion, the survey was provided in both English and ASL. The directions and questions were translated by a certified American Sign Language interpreter and recorded videos were embedded within the survey. Consent to participate was obtained prior to starting the survey. Participants did not have to complete all questions of the survey and could exit at any time. Additionally, a subset of questions were posed only to individuals who reported prior experience with genetic counseling. Responses were anonymous and personal identifiable information was not collected.

A brief definition of genetic counseling from the National Society of Genetic Counseling (NSGC) was provided for participants to review at the beginning of the survey. Demographic information collected included age, gender identity, race/ethnicities, primary language, education
level, state of residence, health insurance, community identity, and self-identity. Participants could self-identify any/all communities they identify with including: Deaf (“big D”), deaf (“little d”), hearing, multiple community identities, no community identity, or prefer not to say. Individuals also self-identified as any combination of: a d/Deaf person, parent, child, caregiver, friend, and/or advocate of a d/Deaf person. Subsequent questions aimed to assess participant’s previous experiences with genetic counseling, interest in genetic testing for deafness, interest in testing for indications other than deafness, and attitudes towards genetic counseling and genetic testing.

Attitudes towards genetic counseling and testing were assessed by providing a “check-all-that-apply” list of nine adjectives of emotion or feelings words. These words encompassed a spectrum of three positive words (excited, hopeful, positive), three neutral words (not bothered, mixed feelings, cautious), and three negative words (worried, concerned, negative). These words were modified from a previous study to assess feelings towards new discoveries in genetics. For analysis purposes, individual words were grouped into these three categories for characterization and comparison.

To explore the utilization of genetic counseling services, participants were asked if they had previously been referred for genetic counseling and their motivations for accepting or declining their referral. Those with prior genetic counseling experience were asked details about their prior appointment and given an additional set of validated questions from the Genetic Counseling Satisfaction scale (GCSS). The GCSS consists of six statements used to address patient satisfaction and the general goals of genetic counseling. Total satisfaction scores were calculated and reported across the entire GCSS, as well as average scores for each satisfaction statement according to original methodology by DeMarco 2004.
Analysis

Statistical analysis was conducted using STATA software (Stata Corp, v13.1) with a Type 1 error rate set at $p < 0.05$. Descriptive data analysis was used to report means and frequencies of categorical variables. Inferential statistics were used to compare demographics to motivations and attitudes towards genetic counseling. Genetic counseling experience was assessed along with interest in genetic counseling for indications other than deafness. To understand if one’s community identity impacted a person’s perspective toward genetic counseling, individuals’ attitudes were compared to their community identity. While a formal analysis of qualitative responses was not performed, quotes were used to further illustrate participants' motivations and attitudes towards genetic counseling and testing.

Results

A total of 72 responses were collected during the recruitment period. Responses that did not complete questions after the demographics section (n=13) or did not meet inclusion criteria (n=5) were excluded. After review, a total of 54 responses were included in the analysis, (Figure 1). Due to the multi-pronged recruitment approach through several organizations, it is unclear how many individuals were invited to participate and whether or not they were a part of multiple organizations; therefore, an accurate response rate could not be calculated.

Cohort Demographics

Participants' ages ranged from 23 to 67 years old, with a mean age of 41 years old. The majority of participants identified as female (63.0%, n=34/54), followed by male (35.2%, n=19/54), and one participant who preferred not to state their gender identity (1.9%). Thirty-eight (70.4%) participants indicated that their primary language was ASL, while the other 16 participants indicated their primary language as English (29.6%). When asked which community
they best identified with, 33 participants selected big “D” Deaf community (61.1%), four identified with the little “d” deaf community (7.4%), two identified with the hearing community (3.7%), six indicated they identified with more than one community (11.1%), six indicated they did not identify with any community (11.1%), and three preferred not to say their community identity (5.6%). Individuals who identified with more than one community were given the opportunity to specify their identities. A total of six participants selected multiple identities and their responses included: “Both deaf and hearing”, “Deaf and hearing community”, “Mexican-American and deaf community”, “d/Deaf”, “Oral, deaf & hearing”. For full cohort demographics, refer to Table 1.
Table 1: Cohort Demographics (n=54)

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<tr>
<th>Age Range, in years</th>
<th>Number of Responses</th>
<th>Percent</th>
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<tr>
<td>20-29</td>
<td>10</td>
<td>18.5</td>
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<tr>
<td>30-39</td>
<td>13</td>
<td>24.1</td>
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<tr>
<td>40-49</td>
<td>9</td>
<td>16.7</td>
</tr>
<tr>
<td>50-59</td>
<td>9</td>
<td>16.7</td>
</tr>
<tr>
<td>60-69</td>
<td>6</td>
<td>11.1</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>Blank</td>
<td>6</td>
<td>11.1</td>
</tr>
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</table>

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<thead>
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<th>Race/Ethnicity*</th>
<th>Number of Responses</th>
<th>Percent</th>
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<tr>
<td>White</td>
<td>44</td>
<td>-</td>
</tr>
<tr>
<td>Black or African American</td>
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<td>-</td>
</tr>
<tr>
<td>Hispanic, Latino, Latina, or Latinx</td>
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<td>-</td>
</tr>
<tr>
<td>Native American or Alaskan Native</td>
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<td>-</td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>Hawaiian Native or other Pacific Islander</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Some other race, ethnicity, or origin</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>1</td>
<td>-</td>
</tr>
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<th>Gender Identity</th>
<th>Number of Responses</th>
<th>Percent</th>
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<td>Female</td>
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<td>Male</td>
<td>19</td>
<td>35.2</td>
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<td>Non-binary / third gender</td>
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<td>0</td>
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<tr>
<td>Transgender</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Another option not listed</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>1</td>
<td>1.9</td>
</tr>
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</table>

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<th>Primary Language</th>
<th>Number of Responses</th>
<th>Percent</th>
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<tbody>
<tr>
<td>English</td>
<td>16</td>
<td>29.6</td>
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<td>American Sign Language (ASL)</td>
<td>38</td>
<td>70.4</td>
</tr>
<tr>
<td>Spanish</td>
<td>0</td>
<td>0</td>
</tr>
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<td>Mandarin</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Arabic</td>
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<td>0</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>0</td>
<td>0</td>
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<tr>
<th>Education</th>
<th>Number of Responses</th>
<th>Percent</th>
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<tr>
<td>No schooling completed</td>
<td>4</td>
<td>7.4</td>
</tr>
<tr>
<td>Up to 8th grade</td>
<td>2</td>
<td>3.7</td>
</tr>
<tr>
<td>Some high school, no diploma</td>
<td>4</td>
<td>7.4</td>
</tr>
<tr>
<td>High school graduate, diploma, or GED</td>
<td>9</td>
<td>16.7</td>
</tr>
<tr>
<td>Some college credit, no degree</td>
<td>9</td>
<td>16.7</td>
</tr>
<tr>
<td>Trade/technical/vocational training</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>College degree</td>
<td>13</td>
<td>24.1</td>
</tr>
<tr>
<td>Graduate/Professional degree</td>
<td>12</td>
<td>22.2</td>
</tr>
</tbody>
</table>

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<th>Insurance</th>
<th>Number of Responses</th>
<th>Percent</th>
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<td>I do not have insurance</td>
<td>3</td>
<td>5.6</td>
</tr>
<tr>
<td>Medicare/Medicaid</td>
<td>22</td>
<td>40.7</td>
</tr>
<tr>
<td>Private insurance</td>
<td>25</td>
<td>46.3</td>
</tr>
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</table>
Marketplace insurance 3 5.6
Other 1 1.9

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<th>Community Identity</th>
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<tr>
<td>Deaf community</td>
<td>33</td>
<td>61.1</td>
</tr>
<tr>
<td>deaf community</td>
<td>4</td>
<td>7.4</td>
</tr>
<tr>
<td>Hearing community</td>
<td>2</td>
<td>3.7</td>
</tr>
<tr>
<td>I identify with more than one community</td>
<td>6</td>
<td>11.1</td>
</tr>
<tr>
<td>I do not identify with any community</td>
<td>6</td>
<td>11.1</td>
</tr>
<tr>
<td>I prefer not to say</td>
<td>3</td>
<td>5.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Self-Identity*</th>
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<tbody>
<tr>
<td>I am a d/Deaf person</td>
<td>51</td>
<td>-</td>
</tr>
<tr>
<td>I am a parent of a d/Deaf person</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>I am a child of a d/Deaf person</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>I am a caregiver of a d/Deaf person</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>I am a friend of a d/Deaf person</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td>I am an advocate for a d/Deaf person</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>None of the above</td>
<td>0</td>
<td>-</td>
</tr>
</tbody>
</table>

*Participants could select all that applied

Participants With Prior Genetic Counseling Experience

The majority of participants (70.4%, n=38/54) reported no prior experience with genetic counseling, while 16 participants (29.6%) indicated they did have prior experience. Those with prior genetic counseling experience were then prompted to answer questions regarding their experience and to complete the validated Genetic Counseling Satisfaction Scale (GCSS).

Using the GCSS, overall genetic counseling satisfaction in individuals that reported prior GC experience (n=16/54) was assessed. Statements were scored on a five-point Likert scale from strongly disagree (1 point) to strongly agree (5 points). The overall mean of each individual’s average score was 3.7 (SD=0.8, range 2.5-5.0). The average of the total score for all of the satisfaction statements was 22.1 out of 30 (SD=4.4, range 15-30). The statements with the highest degree of satisfaction among respondents were: The genetic counseling session was valuable to me (mean=3.9, range 2-5); My genetic counselor seemed to understand the stresses I was facing (mean=3.8, range 2-5); My genetic counselor was truly concerned about my well-being (mean=3.8, range 2-5).
The indications for individuals who underwent prior genetic counseling were varied and included reasons such as: to learn more about the risk of developing cancer due to personal or family history, to better understand their overall health, and to learn more about their deafness. Of these individuals (n=16), nine were referred to genetics based on their personal or family history of deafness and six followed through with the session. The three individuals who did not attend this session indicated their reason for declining their appointment was their previous knowledge about their form of deafness.

Participants were then asked about their interest in seeing a genetic counselor again based on their previous experience for various indications including: the genetic causes of deafness, the chance to pass deafness to future children, testing during pregnancy for genetic conditions, personal or family history of cancer, and personal or family history of other health conditions. The majority of individuals with prior genetic counseling experience indicated a strong interest in seeing a genetic counselor again for all indications (87.5%, n=14/16). See Figure 2 for comprehensive results.

*Participants Without Prior Genetic Counseling Experience*

Thirty-eight individuals (70.4%, n=54) indicated they had no prior genetic counseling. Notably, 58% (n=22/38) of these individuals were found to have not been referred to genetic counseling before but would qualify based on their responses indicating they had a personal or family history of: multiple miscarriages, intellectual disabilities, birth defects, known genetic conditions, or cancer diagnosed under the age of 50. Despite this reported personal and family history, over half of these respondents (51.0%, n=19/37) indicated they had not heard of genetic counseling prior to taking the survey.

The cohort with no prior genetic counseling experience was asked about their interest in seeing a genetic counselor for a variety of indications. Responses between the group with prior
Figure 2: Interest in Genetic Counseling for Various Indications by Prior Experience

A) The genetic causes of deafness (n=53)

B) The chance for potential future children to also have deafness (n=52)

C) Testing during pregnancy for genetic conditions (n=52)

D) Personal and/or family history of cancer (n=52)

E) Personal and/or family history of medical conditions (n=51)
GC experience and no prior GC experience were compared, (Figure 2). Indications that had the most overall interest between both groups were: personal and/or family history of medical conditions (92.2%, n=47/51), the genetic causes of deafness (86.7%, n=46/53), and personal and/or family history of cancer (86.5%, n=45/52). The indications that had the least interest were: the chance for potential future children to also have deafness (65.4%, n=34/52) and testing during pregnancy for genetic conditions (67.3%, n=35/52).

**Attitudes Towards Genetic Counseling**

All participants were asked to categorize their feelings towards genetic counseling/testing by selecting words from a provided list of nine words categorized as positive, negative, or neutral. Participants could select all that applied. The average number of selections per participant was 1.6 (range 1-6). A total of 83 selections were made by 52 participants, (Figure 3). Overall, 40 neutral words were selected, 37 positive words were selected, and six negative words were selected. Three individuals selected only negative terms. The remaining participants selected either exclusively positive (36.5%, n=19/52) exclusively neutral (44.2%, n=23/52), or a combination of emotions (13.5%, n=7/52). Two of the individuals that selected a combination of emotions selected an emotion in each category (28.6%).

Participants were asked to rate on a five-point scale of strongly agree to strongly disagree their opinions on five statements regarding deafness and genetic counseling, (Figure 4). In response to the statement “Genetic counseling/testing aims to rid society of d/Deaf individuals,” 46.2% of participants overall disagreed (n=24/52), 34.6% felt neutral (n=18/52), and 19.2% overall agreed (n=10/52). When asked their opinion on the statement “Genetic counseling can help me understand causes for my deafness,” 17.3% of participants overall disagreed (n=9/52), 36.5% felt neutral (n=19/52), and 46.2% overall agreed (n=24/52). Majority of participants (57.7%, n=30/52) overall agreed with the statement, “Genetic counselors can help me better
understand my personal or family medical history,” while 13.5% overall disagreed (n=7/52) and 28.8% felt neutral (n=15/52).

Responses to these statements were described between individuals that self-identified as deaf versus Deaf. In response to the statement “Deafness is a disability,” 61.3% (n=19/31) of participants who identify with the Deaf community overall agreed, and 50% (n=2/4) of participants who identify with the deaf community agreed. A large percent of the Deaf community (38.7%, n=12/31) indicated that they felt neutral to the statement: “Genetic counseling/testing aims to rid society of d/Deaf individuals.” The remaining individuals either overall disagreed (38.7%, n=12/31) or overall agreed (22.6%, n=7/31) to this statement. Within the deaf community, individuals either disagreed (50%, n=2/4) or felt neutral (50%, n=2/4).

Free Responses

Free response questions were available after individual sections of the survey to allow participants to expand on their prior experience with genetic counseling (n=5), factors influencing
**Figure 4:** Attitudes about Genetic Counseling and d/Deafness by Community Identity

A) Community stance on "Deafness is a disability" (n=51)

B) Community stance on "Deafness is a medical condition" (n=50)

C) Community stance on "GC aims to rid society of d/Deaf individuals" (n=51)

D) Community stance on "GC can help me understand the causes of my deafness" (n=51)
their choices of emotion words (n=31), and overall attitudes regarding genetic counseling and testing (n=18). Responses ranged from positive, negative, and neutral perspectives.

Some participants with prior genetic counseling experience pointed out possible barriers and considerations for the Deaf community.

“The meeting should be cordial and professional. Take more account of the patient's difficulties and wishes.” (ASL user, identifies with the deaf community, age 34, female)

“Worth the test but very expensive. Don't think many of our community members can afford it.” (English speaker, identifies with Mexican-American and deaf community, age 64, female)

When asked about factors that influenced the emotion words they selected, one participant felt positive about genetics and its future:
“I think it is fascinating! It will be very helpful to know our genetic predispositions & mutations so that we can modify our lifestyles, and/or prevent/screen for any potential issues, and treat (if treatable).” (ASL user, identifies with the Deaf community, age 38, female. Emotion words: excited, hopeful, and positive)

Although there were many responses that expressed positive outlooks regarding genetic testing, many individuals had reservations on the intended use and implications of genetic testing:

“Potential for misuse to select/deselect traits in utero. We’ve seen this in cases of down syndrome, where virtually all down syndrome babies are aborted in Nordic countries.” (English speaker, identifies with both deaf and hearing communities, age 46, female. Emotion words: mixed feelings)

“Humanity. Information gathered and later to be used for purposes of eliminating genetic disorders that are 'deemed' harmful.” (English speaker, self-describes as a d/Deaf person, parent, child, caregiver, friend, and advocate, age 44, female. Emotion words: mixed feelings, cautious)

**Discussion**

With the many current and historical challenges the Deaf community has faced, it is vital for genetic counselors to respect, acknowledge, and appreciate Deaf patients’ views and values. This study explored the attitudes of the d/Deaf community toward genetic counseling and testing with the goal of better understanding Deaf patients’ motivations, trepidations, and desires surrounding genetic counseling and testing. This study also evaluated the utilization of genetic services within the d/Deaf community and characterized areas of interest for future genetic counseling encounters.
Individuals with prior genetic counseling experience indicated overall satisfaction with their genetic counseling appointment (average score of 22.36/30). While no participants selected “strongly disagree” out of any of the GCSS statements, the lowest average satisfaction score was for the statement “the genetic counseling session was about the right length of time needed” (average of 3.44/5). This lower satisfaction score could be an indicator of previously established variables that play a role in the satisfaction and health literacy of Deaf individuals, including provider knowledge about deafness and/or language barriers and communication issues. The use of interpreters and limited or no resources in preferred patient language (ASL) can limit the amount of meaningful time spent in sessions addressing educational and psychosocial needs of these patients. It is important that genetic counseling appointments take into account these variables which can affect the amount of time needed for these patients and to consider the creation or accessibility of resources and information in the patient’s preferred language.

This study supports previous claims of d/Deaf individuals' interest in genetic testing. The majority of individuals indicated wanting to learn more about the genetic causes of deafness, in addition to hereditary risks related to personal or family history of cancer and other medical conditions. With an increase of genetic awareness and direct-to-consumer testing, society’s interest in learning more about one’s health has become increasingly more common. Although there is interest in learning about these things, individuals still seemed to feel overall neutral toward genetic counseling and testing. This neutrality could indicate that there still seems to be hesitancy with regards to genetic counseling and testing within the Deaf community, even with demonstrated interest. Quotes gathered from participants suggest that some of these reservations may be caused by the perception of genetic knowledge being used for deselecting traits and eliminating genetic disorders. Given past experiences with healthcare providers, and with society as a whole, the trust in genetics has not yet been earned back, and to overcome the injustices of
the past, healthcare providers need to engage in culturally competent care, especially in historically marginalized communities like the d/Deaf community.

A key characteristic of the Deaf community is the belief that their deafness is not a disability or impairment. Interestingly, only 60% of individuals who identify with the Deaf community in our cohort indicated that they agreed with this statement. This is surprising given the central values cited consistently throughout literature and our understanding of the Deaf community as a whole. This finding may indicate that individuals within the Deaf community have differing views on what they consider to be a disability and how this defines their self-identity. Some individuals of the non-Deaf community have previously argued that the Deaf community takes a “paradoxical stance” of rejecting the label of disability while also claiming the rights and protections granted by the ADA to those with a disability. Our findings provide possible evidence to the notion that the Deaf community prefers to subscribe to the social model of disability and may only regard their deafness as a disability due to the medical model of disability that is readily accepted by society. If society followed a social model of disability instead, there would be no need for the members of the Deaf community to take this “paradoxical stance” in order to justify their rightful claims to the protections and truths that are afforded to all other individuals. These discordant views within the Deaf community can create confusion for healthcare providers, including genetic counselors. This surprising finding highlights the necessity of genetic counselors actively engaging in rapport building, contracting, and tailoring with each individual patient. Despite literature and generalizations about the Deaf community and their beliefs regarding deafness and disability, these views may not be representative of all Deaf patients and if wrongly assumed, can further damage rapport and trust with patients.

This study also highlighted barriers and access to healthcare concerns within the d/Deaf population. The majority of participants who did not have prior genetic counseling experience
would have actually qualified for genetic counseling based on their reported personal or family history but were never referred. This raises questions as to why these individuals did not receive a referral to genetic counseling. Prior studies have attributed decreased health literacy levels, lack of available medically experienced interpreters, and stressful healthcare experiences as significant barriers for the Deaf community. As patient advocates, genetic counselors can help break down these barriers. More interactions between the Deaf and healthcare communities are needed to help gain a better understanding and respect for each other. Outreach events where healthcare professionals can speak with Deaf organizations about genetics, translating information and resources into ASL, partnering with a medically certified translation service, or incorporating Deaf culture educational opportunities for providers are all ways genetic counselors can help increase accessibility.

Notably, recruiting d/Deaf individuals to this study was difficult. Only six out of the 26 organizations contacted agreed to participate. Other attempts to partner with several prominent Deaf educational schools were declined. General feedback from non-participating organizations is that the Deaf community is an already marginalized community that is further marginalized when research is done without Deaf individuals, stakeholders, or advocates involved. This logic is not without merit, and has been echoed by other marginalized communities that must bear the burden of educating the majority, at a personal, emotional, and physical cost. Recent discussions within the genetic counseling field have also highlighted the lack of diversity within the profession, especially in regards to the representation individuals with a disability. Active assessment of barriers and recruitment for these individuals to enter the field of genetic counseling should be considered to amplify the voices of historically marginalized communities and begin to bridge the gap between an “us” versus “them” mentality.

This study is not without its limitations. Participants self-selected to complete the survey,
which may result in response bias. Individuals with positive views or experiences of genetic counseling and testing may have been more likely to complete the survey than those who have negative views or experiences. This study also represents only a small population of the d/Deaf communities and may not be representative of all d/Deaf individuals. Participants were recruited through d/Deaf organizations, limiting the study to only those with an active membership. Deaf individuals who are not a member of the participating organizations may have differing views than those who are an active member. Additionally, this study recruited participants from the AMPHL, an organization of healthcare professionals with hearing loss. These individuals likely have a higher education level than that of the general population and may be biased in their attitudes toward genetic technology and testing. Despite these limitations, this study yielded novel information about motivations and attitudes towards genetic counseling and testing in the d/Deaf population.

Future directions should include designing specific strategies to aid in resolving the barriers and tensions between the healthcare field and d/Deaf communities. This may include gathering input directly from d/Deaf individuals to create a formal Deaf culture awareness curriculum to include in genetic counseling training. Practicing genetic counselors should consider accessibility of resources for Deaf individuals in their clinics to mitigate barriers that contribute to decreased health literacy and exacerbate communication and language barriers in a healthcare setting. Genetic counseling laboratories, organizations, or patient advocacy groups should consider the funding of, or direct translation, of materials into ASL to reduce the marginalization of this community from medical resources. These are all steps in the right direction to improve the relationship, respect, and acknowledgment of the d/Deaf community as valuable patients worthy of the same degree of tailoring, cultural competency, and access as any other genetic counseling patient.
Appendix

Supplemental Document 1: Survey Questions

Definition

Genetic Counseling: is the process of helping people understand and adapt to the medical, psychological and familial effects of genetic contributions to disease. This process includes the following:

- Review of family and medical histories to assess the chance of developing a condition.
- Education about inheritance, testing, management, prevention, resources and research.
- Counseling to promote informed choices and adapting to new information about a condition.

1. I understand the above information and understand that my participation in this survey is completely voluntary. By choosing "I agree" and continuing, I consent to have my responses included in the study.

   **Bulleted options:** I agree or I do not wish to participate

   If no → skip to end of survey

   If yes → go to Q2

2. How old are you?

   **Empty text box**

   Less than 18 → skip to end of survey

3. What is your gender?

   **Bulleted options:**
   - Female
   - Male
− Non-binary / third gender
− Transgender
− Another option not listed (please specify), empty text box
− Prefer not to say

4. What is your race(s)/ethnicity(ies)? (Check all that apply)

**Bulleted options:**

− Asian
− Black or African American
− Hispanic, Latino, Latina, or Latinx
− Hawaiian Native or other Pacific Islander
− Native American or Alaskan Native
− White
− Some other race, ethnicity, or origin (please specify), empty text box
− Prefer not to say

5. What is your primary language?

**Bulleted options:**

− American Sign Language (ASL)
− Arabic
− English
− Mandarin
− Spanish
− Vietnamese
− Other (please specify), empty text box

6. What is the highest degree or level of school that you have completed?
Bulleted options:

- No schooling completed
- Up to 8th grade
- Some high school, no diploma
- High school graduate, diploma or GED
- Some college credit, no degree
- Trade/technical/vocational training
- College degree
- Graduate/Professional degree

7. What state do you currently live in?

Empty text box

8. What type of health insurance do you have?

Bulleted options:

- I do not have insurance
- Medicare/Medicaid
- Private insurance
- Marketplace insurance
- Other (please specify), empty text box

9. Which community do you most identify with?

Bulleted options:

- Deaf community
- deaf community
- Hearing community
- I do not identify with any community
- I identify with more than one community (please specify), empty text box
- I prefer not to say

10. Which of the following best describes you? (Check all that apply)

**Bulleted options:**
- I am a d/Deaf person
- I am a parent of a d/Deaf person
- I am a child of a d/Deaf person
- I am a caregiver of a d/Deaf person
- I am a friend of a d/Deaf person
- I am an advocate for a d/Deaf person
- None of the above

11. Do you have a personal or family history of cancer diagnosed under the age 50?

**Bulleted options:** Yes or No

12. Do you have a personal or family history of birth defects or intellectual disabilities?

**Bulleted options:** Yes or No

13. Do you have a personal or family history of more than 2 miscarriages/stillbirths?

**Bulleted options:** Yes or No

14. Do you have a personal or family history of a known genetic condition? (unrelated to deafness)

**Bulleted options:** Yes or No

15. Have you met with a genetic counselor before?

**Bulleted options:** Yes or No
   - If no → skip to Q23
   - If yes → go to Q16
16. What is your understanding of why you met with a genetic counselor?

Empty text box

17. How long ago was your most recent genetic counseling appointment?

Bulleted options:

- Less than 1 year ago
- 1-5 years ago
- 6-10 years ago
- More than 10 years ago

18. Who provided the genetic counseling?

Bulleted options:

- Genetic Counselor
- Doctor (MD)
- Physician Assistant (PA)
- Nurse
- Other (please specify)
- I am unsure
Please rate the following regarding your satisfaction of your most recent genetic counseling appointment:

<table>
<thead>
<tr>
<th>Strongly Disagree (1)</th>
<th>Disagree (2)</th>
<th>Neutral (3)</th>
<th>Agree (4)</th>
<th>Strongly agree (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>My genetic counselor seemed to understand the stresses I was facing.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>My genetic counselor helped me to identify what I needed.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I felt better about my health after meeting with my genetic counselor.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The genetic counseling session was about the right length of time I needed.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>My genetic counselor was truly concerned about my well-being.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The genetic counseling session was valuable to me.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
20. Other comments about your genetic counseling session you would like to share:

**Empty text box**

21. Please use the scale to rate the following question: Based on your past experience, if needed, how likely would you be to attend genetic counseling for a different reason?

<table>
<thead>
<tr>
<th>Unlikely</th>
<th>Neutral</th>
<th>Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>9</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

22. If you saw a genetic counselor again, how interested would you be in learning about the following?

<table>
<thead>
<tr>
<th></th>
<th>Not interested (1)</th>
<th>Somewhat interested (2)</th>
<th>Very interested (3)</th>
<th>Not Applicable (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The genetic causes of deafness</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The chance for potential future children to also have deafness</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Testing during pregnancy for genetic conditions (Ex: Down syndrome, sickle cell disease, cystic fibrosis)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Personal and/or family history of cancer</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Personal and/or family history of medical conditions (Ex: heart conditions, seizures, bleeding disorders)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

23. Have you heard of genetic counseling prior to this survey?

**Bulleted options:** Yes or No
Display This Question If: Have you met with a genetic counselor before? = No

24. How interested would you be in learning about the following?

<table>
<thead>
<tr>
<th></th>
<th>Not interested (1)</th>
<th>Somewhat interested (2)</th>
<th>Very interested (3)</th>
<th>Not Applicable (4)</th>
</tr>
</thead>
<tbody>
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<td>Personal and/or family history of cancer</td>
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<tr>
<td>Personal and/or family history of medical conditions (Ex: heart conditions, seizures, bleeding disorders)</td>
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</tbody>
</table>
25. Please rate the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree (1)</th>
<th>Disagree (2)</th>
<th>Neutral (3)</th>
<th>Agree (4)</th>
<th>Strongly agree (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deafness is a disability</td>
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<tr>
<td>Deafness is a medical condition</td>
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<td>Genetic counseling/testing aims to rid society of d/Deaf individuals</td>
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<td>Genetic counselors can help me understand causes for my deafness</td>
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<td></td>
</tr>
<tr>
<td>Genetic counselors can help me better understand my personal or family medical history</td>
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<td></td>
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<td></td>
</tr>
</tbody>
</table>

26. Which word(s) best describe how you feel about genetic testing technology? (Please select all that apply)

**Bulleted options:**

- Excited
- Hopeful
- Positive
- Not bothered
- Mixed feelings
- Cautious
- Worried
- Concerned
27. Please share the factors that influenced your response(s) to the previous question.

Empty text box

28. Based on your experiences and/or from the information in this survey, is there anything else you would like to share about your attitudes towards genetic counseling/testing?

Empty text box

29. Do you have a personal history of deafness?

Bulleted options: Yes or No

30. Do you have a family history of deafness?

Bulleted options: Yes or No

Display This Question If: Do you have a family history of deafness? = Yes

31. How many people in your family have a history of deafness?

Bulleted options:

− I am the only person in my family with a history of deafness

− There is more than one person in my family with a history of deafness

32. How old were you when you were diagnosed with deafness?

Bulleted options:

− Age at diagnosis: empty text box

− Not applicable

33. Do you utilize a cochlear implant or hearing device?

Bulleted options:

− Yes

− No

− I'm considering
34. Do you have a genetic diagnosis for your deafness?

**Bulleted options:**
- Yes (If yes, please describe), **empty text box**
- No
- Not applicable

35. Have you ever been referred to genetic counseling for your personal or family history deafness?

**Bulleted options:** Yes or No

*Display This Question If: Have you ever been referred to genetic counseling for your personal or family history deafness? = Yes*

36. Did you attend this session?

**Bulleted options:** Yes or No

37. What factors influenced your decision to not attend the genetic counseling appointment? Select all that apply.

**Bulleted options:**
- Did not want to know
- Already knew
- Did not matter to me
- Family member already had genetic counseling
- Testing concerns
- Cost of appointment or testing
- Other (please specify), **empty text box**

38. How did you hear about this survey?
**Bulleted options:**

- Social Media
- Email
- Advocacy Organization
- Family/Friend
- Other
Bibliography


Vita

Katie Baudoin attended high school at Walker High School in Walker, Louisiana. Upon graduating in 2015, she attended the University of Louisiana at Lafayette, where she received her Bachelor of Science degree in Biology in 2019. She moved to Dallas, Texas, after graduation and worked as a genetic counseling assistant in a comprehensive cancer center at the University of Texas Southwestern Medical Center. In August of 2020, she moved to Houston, Texas, to begin her graduate degree of a Master of Science at the University of Texas MD Anderson Cancer Center UTHealth Graduate School of Biomedical Science Genetic Counseling Program.

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