**ABSTRACT**

Hearing loss, being one of the most common birth defects in the United States, affects about four in every 1,000 newborns. The etiologies of hearing loss can be genetic, environmental or a combination of both. With genetic etiologies being responsible for approximately 60% of profound hearing loss at birth or in childhood, genetic evaluation and counseling is imperative. Genetic evaluation and counseling informs individuals and/or families about the etiology of the hearing loss, medical implications, recurrence risks, current diagnostic technologies and reproductive options.

Medical providers, such as genetic counselors, have a duty to provide information in a nondirective manner, allowing for patient autonomy. Patients have the option to pursue prenatal genetic testing. Cultural integration and affiliation can play a substantial part in making this decision. Cultures such as the hearing, hard-of-hearing, and Deaf have varied attitudes toward prenatal genetic testing for deafness. Therefore, it is important for medical providers to understand a patient’s level of cultural integration and what drives their decision-making.

Children of Deaf Adults (CODA), hearing individuals immersed in Deaf culture, have a unique cultural view as they straddle both Deaf and hearing cultures. This study hypothesized that the level of integration into Deaf culture of CODA affects decision-making regarding prenatal testing for deafness. The link for the anonymous online survey was sent to five organizations identified as having significant involvement with the Deaf and CODA communities. One hundred and six individuals responded to the survey. Thirty-nine participants met the criteria of being a CODA between the ages of 18 and 55, and their results were analyzed using One-way Analysis of Variance (ANOVA) via Statistical Product and Service Solutions (SPSS).

The results revealed that the relationship between CODA’s level of integration into Deaf culture and their decision whether or not to pursue prenatal genetic testing for deafness is important to understand.

This study aims to improve patient autonomy in the genetic counseling profession.

**OBJECTIVES**

- The relationship between CODA’s level of integration in Deaf culture and their decision whether or not to pursue prenatal genetic testing for deafness is important to understand
- This study aims to improve patient autonomy in the genetic counseling profession

**METHODS**

- **Long Island University-Post Institutional Review Board approved the study**

An e-mail describing the study/looking for assistance with distribution was composed. Five organizations were identified and asked to distribute the anonymous survey online. Surveys were analyzed from December-February 2015.

A survey inquired CODA’s knowledge/understanding of deafness and genetic testing, thoughts/feelings about Deaf culture, perspectives on prenatal diagnosis for deafness, and demographics.

Analysed data via one-way ANOVA statistical analysis using SPSS.

**RESULTS**

- Six ANOVAs were run comparing the results for prenatal genetic testing against either the level of cultural integration into Deaf culture or one of the knowledge factors

<table>
<thead>
<tr>
<th></th>
<th>Between Groups</th>
<th>Within Groups</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>df</td>
<td>2</td>
<td>38</td>
<td>40</td>
</tr>
<tr>
<td>F (2, 38) = 1.92</td>
<td>.16</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Knowledge of Genetics</th>
<th>Between Groups</th>
<th>Within Groups</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>df</td>
<td>1</td>
<td>35</td>
<td>35</td>
</tr>
<tr>
<td>F (1, 35) = 2.82</td>
<td>.10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*The END" and "Maybe* to "Knowledge of genetics" and "Knowledge of Application" and "Knowledge of Genetic Counseling and Translation" and "Knowledge of Genetic testing"

- **CONCLUSIONS**

- The results revealed that the relationship between CODA’s level of integration into Deaf culture and their decision regarding prenatal genetic testing for deafness was not significant.
- The participant’s level of cultural integration was self-reported so it was hard to measure this factor for data analysis and could have skewed the results obtained.
- There are factors other than the level of cultural integration in Deaf culture that affect decision making for prenatal testing for deafness, such as knowledge of deafness and/or genetic testing.
- Using a larger sample size in the future may allow us to see more specific relationships between the level of cultural integration in Deaf culture and decision making for prenatal genetic testing for deafness.

**NAME/ACKNOWLEDGEMENTS**

- Ashley Mills, MS, CGC, Jill Fischer, MS, CGC, Nancy Frye, PhD, and James Byrne, Lime Interpreting, LLC

---

*Jaime Tramontana, MS, Ashley Mills, MS, CGC, Jill Fischer, MS, CGC, Nancy Frye, PhD, and James Byrne, Long Island University-Post, Brookville, NY; Lime Interpreting, LLC, Selden, NY*