



# Does Children of Deaf Adults' (CODA) Cultural Integration in Deaf Culture Predict Prenatal Genetic Testing for Deafness?

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## 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 regarding prenatal genetic testing for deafness was not significant. The majority, 33 of the 39 participants, showed no interest in undergoing prenatal genetic testing for deafness.

As the sample size of participants was small, the results may not be representative of this population as a whole. Future research could obtain a larger sample size which may allow for determination if this result reflects the opinion of the larger CODA community. Participants' decision regarding prenatal genetic testing could also be affected by financial or personal reasons which could be studied further. Additionally, one could feel that deafness does not require immediate or urgent attention; therefore, invasive procedures and a risk to the pregnancy are not necessary.

## BACKGROUND

- Hearing loss, affecting three to four in every 1,000 newborns, is one of the most common birth defects in the United States
- Hearing loss is due to either genetic, environmental or a combination of both genetic risk and environmental exposures
- Genetic factors account for approximately 60% of profound hearing loss at birth or in early childhood, with a majority of them due to autosomal recessive traits
- Confirmed diagnoses of a genetic condition are often accompanied with social, psychological, educational, and medical implications
- Cultural integration, keeping the values and morals of one's own culture, but respecting and accepting the practices, beliefs and values of other cultures, can contribute to how an individual responds to confirmed diagnoses
- CODA have a unique cultural view as they are hearing individuals immersed in Deaf culture
- Medical providers, including genetic counselors, should understand a patient's level of cultural integration to better understand the reason behind the patient's decisions to pursue or not pursue prenatal genetic testing for deafness

## OBJECTIVES

- The relationship between CODAs' 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 from December-February 2015

A survey inquired CODAs' knowledge/understanding of deafness and genetic testing, thoughts/feelings about Deaf culture, perspectives on prenatal diagnosis for deafness, and demographics

Analyzed data via one-way ANOVA statistical analysis using SPSS

## RESULTS

- 106 individuals filled out the survey and, after exclusion criteria (no consent, non-CODA, and younger than 18 or older than 55) was applied, results from 39 surveys were analyzed
- The majority of the participants were female (87.2%), married (66.7%), white non-Hispanic (92.3%), and college educated (97.4%). All participants were employed. The mean age of the participants was 39 (range 22-55)
- Overall, the participants had a strong knowledge and understanding of deafness and genetic testing, as well as a positive outlook on Deaf culture
- When participants were asked if they would undergo prenatal genetic testing for deafness, 33 responded "no," 2 responded "yes," and 8 responded "maybe"

## 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

"Yes" and "No" and "Maybe" vs. Integration

	df	F	Sig.
Between Groups	2	1.92	.16
Within Groups	36		
Total	38		

F (2, 36) = 1.92, p = .16

"Yes and maybe" vs. Integration

	df	F	Sig.
Between Groups	1	2.82	.10
Within Groups	37		
Total	38		

F (1, 37) = 2.82, p = .10

"Yes and maybe" vs. "Knowledge of genetics" and "Knowledge of Application" and "Knowledge of Genetic Counseling and Counselors" and "Knowledge of Genetic Testing"

	df	F	Sig.	
Knowledge of Genetics	Between Groups	1	3.87	.06
	Within Groups	37		
	Total	38		
Knowledge of Application	Between Groups	1	.01	.91
	Within Groups	37		
	Total	38		
Knowledge of Genetic Counseling and Counselors	Between Groups	1	.83	.37
	Within Groups	37		
	Total	38		
Knowledge of Genetic Testing	Between Groups	1	.10	.75
	Within Groups	37		
	Total	38		

F (1, 37) = 3.87, p = .06; F (1, 37) = .01, p = .91; F (1, 37) = .83, p = .37; F (1, 37) = .10, p = .75

## CONCLUSIONS

- The results revealed that the relationship between CODAs' 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 a more specific relationship between the level of cultural integration in Deaf culture and decision making for prenatal genetic testing for deafness

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