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Attitudes of the broader hearing, deaf, and hard-of-hearing community toward genetic testing for deafness

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Purpose: To assess attitudes in a nonmedically and nonculturally influenced setting of reproductive-age adults toward genetic testing for deafness in newborns. **Methods:** Hearing, deaf, and hard-of-hearing individuals at a university completed questionnaires assessing attitudes toward genetic testing. **Results:** Eighty-five percent of hearing ($n = 133$) and 62% of deaf/hard-of-hearing ($n = 89$) individuals would allow genetic testing for deafness in their own newborn. **Conclusions:** These results indicate an acceptance of newborn genetic testing for deafness by individuals in the broader community, regardless of hearing status. ***Genet Med*** **2003:5(2):106–112.**

Key Words: *newborn hearing screening, genetic testing, deaf community, deaf,* GJB2

Approximately 50% of congenital deafness is due to genetic factors.[1,2] Recent identification of deafness-causing genes such as *GJB2*[3] has prompted suggestions of linking genetic testing to the early hearing detection and intervention (EHDI) process for newborns.[4] The benefits of genetic testing during the newborn period include more targeted medical management, such as sparing infants with two *GJB2* mutations from additional testing and clinical evaluation for syndromic deafness; offering prognostic information about the child; and providing accurate recurrence information to parents of a deaf child.[5] However, there are not enough data on the public's attitudes toward genetic testing for deafness in the newborn period to indicate whether or not there is support for such testing.

The implementation of newborn genetic screening for deafness will have an impact on both hearing and deaf/hard-of-hearing individuals as 90% to 95% of deaf/hard-of-hearing individuals are born to hearing parents.[1] However, genetic testing for deafness raises a series of ethical and social issues as deafness may be considered a cultural characteristic rather than a medical condition.[6,7] Like other cultures, members of the Deaf culture (capital D) share a common language (e.g., American Sign Language), history, social customs, and identity.[6–8] Many deaf individuals feel that deafness is not a disability[6,7] and therefore may perceive genetic counseling and testing for deafness as a threat to the Deaf culture or an intrusion on their family values or decisions.

Previous studies conducted in cultural or medical settings have yielded insight into the attitudes of deaf, hard-of-hearing, and hearing individuals with deaf family members toward diagnostic, carrier, and prenatal genetic testing for deafness.[9–14] Based on these studies, it appears that culturally Deaf individuals hold more negative attitudes toward genetic testing for deafness than nonculturally deaf individuals[9,10,13] or hearing individuals with a deaf family member.[10] As examples, culturally Deaf individuals were more likely than nonculturally deaf individuals to think that genetic testing for deafness would devalue deaf people,[9] do more harm than good,[9] and have a negative impact on the Deaf community.[13] Culturally Deaf participants were also more likely to be against prenatal testing for deafness compared with nonculturally deaf[9,13] and hearing individuals with a deaf relative.[10] Such testing might be perceived to threaten the continuation of the Deaf culture[10] or to be a criticism of their values. In contrast, a high level of interest in diagnostic, carrier, and prenatal genetic testing among hearing parents of deaf children has been documented.[11,14] For these parents, genetic testing was associated with a number of benefits, including identifying the cause of hearing loss, determining a recurrence chance, and preparation for future pregnancies.[11,14]

Previous studies suggest that attitudes of hearing and deaf/hard-of-hearing individuals (particularly culturally Deaf individuals) toward genetic testing for deafness are polarized and that widespread use of genetic testing for deafness may produce conflict. However, participants in previous studies were ascertained primarily through culturally or medically influenced settings (conferences for the deaf, hospital clinics). Thus these conclusions may not be representative of hearing and deaf/hard-of-hearing individuals ascertained from a broader community sample, raising two important implications. First, differences between hearing and deaf/hard-of-hearing individ-

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uals may not be as striking in the broader community, a finding that could have an important impact on genetic testing policy. Second, the generally positive attitudes of hearing parents with a deaf child toward diagnostic testing may not reflect the attitudes toward genetic testing in the newborn period of hearing individuals without a family history of deafness.

Because policies regarding genetic testing for deafness should be influenced by as broad a population as possible, the present study assessed the attitudes of hearing, deaf, and hard-of-hearing people toward genetic testing for deafness, including newborn testing, in a more general setting, that is, in a nonmedically, culturally (Deaf or hearing) influenced setting. We believe that the present study sample of university students represents the broader community of hearing and deaf/hard-of-hearing individuals. This sample also represents the community of individuals who will come into contact with the EHDI process, i.e., a cohort of reproductive-age hearing individuals not ascertained for a family history of deafness and a cohort of reproductive-age deaf or hard-of-hearing individuals.

METHODS

The study sample was ascertained in the fall of 2001 from students enrolled at California State University Northridge (CSUN), located in the Los Angeles metropolitan area. CSUN is one of a few universities in the United States with a significant population of deaf and hard-of-hearing students (~250 enrolled per year), and it houses the National Center on Deafness (NCOD). Individuals were eligible to participate if they were at least 18 years old. Because of differences in the ratio of deaf or hard-of-hearing to hearing students in the classrooms, recruitment to complete an anonymous, self-administered questionnaire was conducted separately for each group. The hearing group was recruited from classes and student club meetings. Students who were deaf or hard-of-hearing were recruited during the registration period at NCOD. The study was approved by the University of California, Los Angeles Institutional Review Board and the CSUN Office of Research and Sponsored Projects.

The questionnaire contained items to assess demographics, knowledge, experience, and interest in genetics and genetic counseling, and attitudes toward genetic testing for deafness. Demographic items included age, ethnicity/race, hearing status (hearing, hard-of-hearing, deaf), degree (mild, severe, profound), and membership in the Deaf community (yes, no). Attitudes toward newborn and prenatal genetic testing, perceptions regarding the chance of having offspring who are deaf, preferences for offspring who were hearing or deaf, attitudes regarding the availability of genetic testing, and perceptions of the possible risks and benefits resulting from genetic testing for deafness were assessed. Many of the items were adapted from previous studies of attitudes toward genetic testing,[9,10,15] and several new items were created to assess attitudes toward newborn testing. Unlike previous studies, a brief description of what genetic counselors do (e.g., explain what genetic testing is, discuss the chances of having a [child with a] genetic condition, provide support) was included on the questionnaire. The questionnaire was pilot-tested and reviewed for clarity and sensitivity toward the Deaf community.

Attitudinal items were assessed with either a three-category response scale (yes, no, unsure) or a 5-point Likert response scale (strongly agree, agree, neutral, disagree, strongly disagree). Risk perception was assessed by asking participants to provide a number between 0% and 100% as their chance of having a deaf child. The responses of the deaf and hard-of-hearing participants were evaluated to determine whether attitudes toward genetic testing were associated with type of deafness or degree of deafness. Because stratification by these variables did not reveal significantly different response distributions, the responses of the deaf and hard-of-hearing participants were grouped together and compared with the responses of the hearing participants. Differences in perceived risk were assessed with a *t* test. Comparisons of categorical data across groups were performed with χ^2 test of independence, and comparisons within a group across items were performed using the McNemar test of correlated proportions. Group comparisons of Likert-scale items were performed with a two-sample Wilcoxon test. Analyses were performed with all five Likert-scale response categories, and with three response categories (strongly agree/agree, neutral, strongly disagree/disagree), with no difference in overall conclusions. Statistical analyses were performed with SAS version 8.2.[16]

RESULTS

Analyses are based on 222 of the 224 returned questionnaires. One questionnaire was excluded because most of the items were left blank, and one was excluded because the participant was less than 18 years old. Sample demographics are found in Table 1. Average age, ethnicity/race, and percentage of females in the sample are similar to those of the entire CSUN student population.[17]

Knowledge of and experience with genetic testing and genetic counseling

The majority of participants (80%) reported having little a priori knowledge about genetic testing, and 82% reported no personal experience with genetic testing. Of those who reported experience with genetic testing, the tests reported are not considered genetic tests. The vast majority (93%) never attended a genetic counseling session, and 50% had no knowledge of genetic counseling prior to reading the questionnaire. However, hearing participants were more likely to report prior knowledge of genetic counseling (46% vs. 29%, $P < 0.01$) and to indicate greater interest in attending a genetic counseling session before genetic testing for deafness than the deaf/hard-of-hearing participants (67% vs. 42%, $P < 0.0001$). The two groups also differed significantly in their perceptions of the chance to have a deaf child ($P < 0.0001$). On average, the hearing group reported that their chance of having a deaf child was 12.8% (median = 3), while the average value reported by the deaf/hard-of-hearing group was more than twice that at

Table 1
Sample demographics

	Group	
	Hearing	Deaf/HOH
n	133	60/29
Average age (SD)	27.9 (8.9)	24.2 (6.4)
(Hearing: $n = 132$; Deaf/HOH: $n = 88$)		
% female	69	63
(Hearing: $n = 133$; Deaf/HOH: $n = 89$)		
Ethnicity/race (%)		
(Hearing: $n = 129$; Deaf/HOH: $n = 87$)		
Caucasian	48.8	47.1
Hispanic	27.1	12.6
Asian	8.5	20.7
African American	6.9	9.2
Other	8.5	10.3
% identify with Deaf community	5	81
(Hearing: $n = 131$; Deaf/HOH: $n = 88$)		
% with relative born deaf or HOH	9	24
(Hearing: $n = 131$; Deaf/HOH: $n = 87$)		
% parents	23	10
(Hearing: $n = 129$; Deaf/HOH: $n = 87$)		

HOH, hard-of-hearing.

30.5% (median = 30). Although neither group was particularly familiar with genetic testing or genetic counseling, there was an implicit understanding that personal history of deafness increases the chance of having a deaf child.

Attitudes toward newborn and prenatal genetic testing for deafness

Participants were asked whether they would have their *own* newborn tested if a genetic test were available (Fig. 1). Although the distribution of responses differed between the two groups ($P = 0.0004$), the majority in both groups (85% of the hearing group and 62% of the deaf/hard-of-hearing group) indicated that they would test their own newborn for deafness using a genetic test.

When asked about testing all newborns (Table 2), 53% of the hearing group agreed that *all* newborns should have genetic testing for deafness, while 35% of the deaf/hard-of-hearing group agreed and 56% were neutral about this statement ($P = 0.02$). A similar pattern of responses was found when participants were asked about testing all newborns for deafness with a

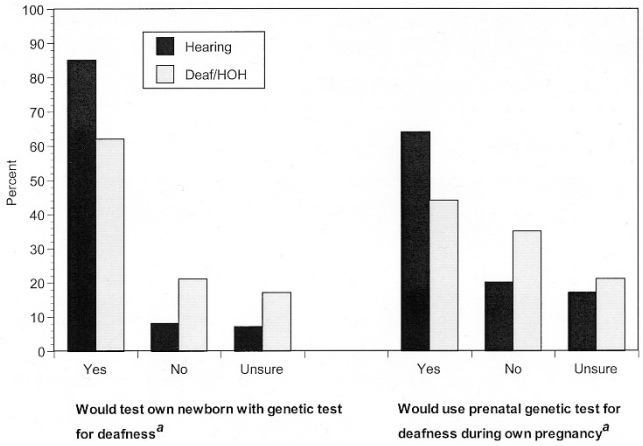

Fig. 1 Personal interest in newborn and prenatal genetic testing for deafness. [a]Response distribution differed between hearing and deaf/hard-of-hearing groups ($P < 0.05$). HOH, hard-of-hearing.

nongenetic test (Table 2). The majority of both groups (>75%) felt that genetic testing for deafness should be available to anybody interested (Table 2), although a greater proportion of the hearing group indicated agreement with this statement ($P = 0.001$).

Participants were also asked whether they would be interested in prenatal genetic testing for deafness (Fig. 1). The distribution of responses between the two groups differed ($P = 0.009$), with 64% of the hearing group reporting that they would have prenatal genetic testing compared with 44% of the deaf/hard-of-hearing group. Twenty-one percent of the deaf/hard-of-hearing group offered a neutral response to this item. The proportion of each group interested in prenatal genetic testing was considerably smaller than the proportions indicating interest in newborn genetic testing (hearing group: 85% for newborn vs. 64% for prenatal, $P < 0.001$; deaf/hard-of-hearing group: 62% for newborn vs. 44% for prenatal, $P < 0.001$).

Preference for a deaf or a hearing child

Participants were asked whether they would prefer a deaf child, a hearing child, or if it did not matter, and a significant difference was found between the two groups ($P < 0.0001$). The vast majority of the hearing group (73%) indicated that they would prefer to have a hearing child. None of the hearing participants stated that they would prefer to have a deaf child. In contrast, the vast majority of the deaf/hard-of-hearing group (81%) stated that it did not matter whether they had a deaf child or a hearing child. Seven percent of this latter group indicated that they would prefer a deaf child.

Possible risks of genetic testing for deafness

There were significant differences between the two groups about whether genetic testing would devalue ($P < 0.0001$) or eliminate ($P < 0.0001$) deaf people (Table 2). The vast majority of the hearing group (>70%) disagreed that genetic testing would result in these outcomes. In contrast, the majority of the deaf/hard-of-hearing group (51%) was neutral about whether

Table 2
Distribution of attitudes toward genetic testing for deafness by hearing status

Question	Group	Agree (%)	Neutral (%)	Disagree (%)
All newborns should have their hearing tested using a genetic test[a]	Hearing ($n = 132$)	53.0	38.7	8.3
	Deaf/HOH ($n = 89$)	34.8	56.2	9.0
All newborns should have their hearing tested using a test that does not involve genetics[a]	Hearing ($n = 132$)	50.7	41.7	7.6
	Deaf/HOH ($n = 88$)	35.2	52.3	12.5
Genetic testing for deafness should be available to anybody interested[a]	Hearing ($n = 132$)	91.7	5.3	3.0
	Deaf/HOH ($n = 89$)	75.3	21.3	3.4
A genetic test for deafness would devalue deaf people[a]	Hearing ($n = 133$)	8.3	21.0	70.7
	Deaf/HOH ($n = 88$)	20.5	51.1	28.4
Genetic testing for deafness would result in the elimination of deaf people from the population[a]	Hearing ($n = 131$)	12.2	14.5	73.3
	Deaf/HOH ($n = 88$)	29.5	36.4	34.1
A positive result in a genetic test for deafness could lead to discrimination in health insurance	Hearing ($n = 132$)	50.7	16.7	32.6
	Deaf/HOH ($n = 87$)	52.9	27.6	19.5
A positive result in a genetic test for deafness could lead to discrimination in employment	Hearing ($n = 132$)	44.7	14.4	40.9
	Deaf/HOH ($n = 87$)	43.0	30.2	26.8
A positive result in a genetic test for deafness could lead to discrimination in personal relationships	Hearing ($n = 132$)	26.5	21.2	52.3
	Deaf/HOH ($n = 86$)	25.6	40.7	33.7
A positive result in a genetic test for deafness could lead to discrimination in education[a]	Hearing ($n = 132$)	28.8	17.4	53.8
	Deaf/HOH ($n = 86$)	38.4	30.2	31.4
Genetic testing for deafness would affect family relationships	Hearing ($n = 132$)	29.5	25.8	44.7
	Deaf/HOH ($n = 88$)	29.5	40.9	29.6

—Continued

Table 2
Continued

Question	Group	Agree (%)	Neutral (%)	Disagree (%)
Genetic testing for deafness may detect if a person can pass on genes associated with deafness to their children[a]	Hearing ($n = 133$)	80.4	12.8	6.8
	Deaf/HOH ($n = 88$)	46.6	46.6	6.8
Genetic testing for deafness would allow people to make decisions about having children[a]	Hearing ($n = 133$)	75.9	16.5	7.5
	Deaf/HOH ($n = 88$)	45.5	38.6	15.9
Genetic testing for deafness would help people understand why deafness occurs[a]	Hearing ($n = 133$)	78.2	12.8	9.0
	Deaf/HOH ($n = 88$)	61.4	28.4	10.2
Genetic testing for deafness could benefit society	Hearing ($n = 132$)	53.8	34.1	12.1
	Deaf/HOH ($n = 89$)	41.6	41.6	16.8
Genetic testing for deafness could benefit my family	Hearing ($n = 132$)	31.8	43.9	24.3
	Deaf/HOH ($n = 89$)	39.3	41.6	19.1
Genetic testing for deafness could benefit me	Hearing ($n = 131$)	29.0	38.9	32.1
	Deaf/HOH ($n = 89$)	42.7	37.1	20.2

[a]Response distribution differed between hearing and deaf/hard-of-hearing groups ($P < 0.05$). HOH, hard-of-hearing.

or not genetic testing would result in a devaluation of deaf people; and there was no consensus among the deaf/hard-of-hearing participants about whether or not such testing would eliminate deaf people from the population.

There was very little evidence that the two groups differed in perceptions about possible forms of discrimination as a result of genetic testing for deafness. The majority of both groups (>50%) agreed that genetic testing for deafness could result in discrimination in health insurance, but there was no consensus about whether or not it could lead to discrimination in employment (Table 2). About a quarter of each group agreed with the statement that genetic testing for deafness could result in discrimination in personal relationships (Table 2). Similar results were found when the participants were asked whether genetic test results would affect family relationships (Table 2). However, the two groups differed when asked about education discrimination ($P = 0.006$). While the majority of the hearing group (54%) disagreed that genetic testing could result in discrimination in education, there was no consensus among the deaf/hard-of-hearing group (Table 2).

Possible benefits of genetic testing for deafness

A greater proportion of hearing respondents, compared with the deaf/hard-of-hearing group, agreed with the statement that genetic testing might detect whether a person can pass on genes associated with deafness ($P < 0.0001$) (Table 2). Hearing respondents also were more likely than deaf/hard-of-hearing respondents to agree with the statement that genetic testing would allow people to make decisions about having children ($P < 0.0001$) (Table 2). In both cases, the responses of the deaf/hard-of-hearing group were split between agree and neutral on each of these two items. The two groups also differed about whether genetic testing would help people understand why deafness occurs ($P = 0.01$). Although >60% of both groups agreed, 28% of the deaf/hard-of-hearing group expressed a neutral opinion about this statement (Table 2). There was no difference between the two groups' responses to statements that genetic testing would benefit society, their own family, or the participants themselves, nor was there clear consensus about whether genetic testing for deafness would foster these outcomes (Table 2).

DISCUSSION

With the recent identification of genes associated with hearing loss, genetic testing and evaluation will serve as important adjuncts to the EHDI process. However, it is important to assess the attitudes of those who would be affected by genetic evaluation, i.e., the broader community of hearing and deaf/hard-of-hearing individuals. We conducted a study in a university setting that is the first to explicitly address attitudes toward *newborn* genetic testing for deafness, in a sample primarily composed of two groups of reproductive age: hearing individuals not ascertained for a family history of deafness and individuals who were deaf or hard-of-hearing. We found that the majority of hearing and deaf/hard-of-hearing individuals endorsed genetic testing of their own newborn for deafness and thought that genetic testing should be available to anyone who is interested. More than 50% of hearing individuals and approximately 40% of deaf/hard-of-hearing individuals supported the idea that *all* newborns should undergo genetic testing for deafness. This positive attitude within the broader community of young adults provides contrast to previous studies conducted in culturally or medically influenced settings, where a predominantly negative attitude toward genetic testing for deafness has been documented among culturally Deaf individuals.[9,10,13]

There also was greater interest in newborn genetic testing than prenatal genetic testing regardless of hearing status. This result suggests that genetic information about hearing status has more instrumental value in the newborn period than it does in the prenatal period. Parents of deaf children have reported that pediatric genetic testing would help to determine the etiology of their child's condition, the recurrence chance, and the appropriate medical management of their child,[11,14] thereby producing an array of cognitive, emotional, and behavioral benefits. Genetic testing during the newborn period would offer these benefits as well, and it may account for the higher level of interest in a newborn test.

We found that more hearing than deaf/hard-of-hearing individuals would use prenatal genetic testing, a result that is consistent with previous research. Because the hearing status of a child does not matter to the majority of deaf/hard-of-hearing individuals,[9,10,13] the emotional and preparatory benefits associated with prenatal information[10,13,14] may not play as prominent a role as it does for hearing individuals, who generally state that they prefer a hearing child.

The 64% of hearing individuals in the current study who would use prenatal diagnosis falls into the 49% to 87% range noted previously for hearing parents of a deaf child. This result suggests that hearing individuals may be interested in prenatal diagnosis for deafness regardless of their family history. In contrast, the 44% of deaf/hard-of-hearing individuals who would use prenatal diagnosis was higher than the 16% to approximately 35% found in earlier studies.[9,10,13] Thus the attitudes of deaf/hard-of-hearing individuals toward prenatal diagnosis are variable and likely to be a function of a variety of factors, including strength of cultural identity[13] or educational background since this sample was drawn from a university setting.

More than half of the hearing and deaf/hard-of-hearing individuals felt that genetic testing for deafness would provide useful information, including explanation of deafness and information about the chance of recurrence. However, responses of the deaf/hard-of-hearing group were more heterogeneous compared with those of the hearing group. These results may explain the differential interest in genetic testing for deafness, as hearing individuals are more likely to associate the test results with useful information. However, they also suggest that hearing individuals may be somewhat naïve about the etiological heterogeneity of deafness and the limitations of genetic testing for deafness.[11]

The possibility of discrimination as a result of genetic testing has been of concern for some time,[15,18] and genetic testing for deafness generates similar concerns about insurance and employment discrimination regardless of hearing status. However, deaf/hard-of-hearing individuals are more likely to be concerned than hearing individuals about additional implications of widespread genetic testing, such as the elimination and devaluation of deaf people and education discrimination. Although 20% of deaf/hard-of-hearing individuals in the current study felt that genetic testing might devalue deaf people, it is less than the 50% of culturally Deaf individuals who previously stated that genetic testing would devalue deaf individuals.[9] Thus our study demonstrates that there is considerable variability in the attitudes of deaf individuals regarding possible adverse outcomes of genetic testing.

Nearly two-thirds of the hearing group expressed interest in attending a genetic counseling session before proceeding with genetic testing for deafness. Thus incorporating genetic counseling into the EHDI process will likely be welcomed, if not expected, by the predominant group of clients—hearing parents of a newborn. A smaller percentage of the deaf/hard-of-hearing group (42%) expressed interest in genetic counseling prior to genetic testing for deafness. In contrast to previous findings on a college campus of predominantly deaf individuals,[8] our results suggest some hesitance by the deaf/hard-of-hearing individuals in this study to seek genetic counseling services. This may be due, in part, to a lack of familiarity with the role of genetic counselors because participants were ascertained outside of a medical setting.

Finally, it is intriguing to note the similarity between attitudes toward using a genetic test and attitudes toward using a nongenetic test to identify deafness in the newborn period. This result suggests that a gene-based newborn hearing test does not evoke a uniquely different reaction from that evoked by a nongenetic hearing test among hearing and deaf/hard-of-individuals. Instead, it appears that the broader hearing and deaf/hard-of-hearing population are responding to the concept of newborn identification of hearing loss instead of the mechanism for doing so.

The current study has several limitations, and additional research on attitudes toward newborn genetic testing for deafness is warranted. Limitations include influences of a univer-

sity setting and the uniqueness of the CSUN setting where both hearing and deaf/hard-of-hearing students are grouped together. However, the stance taken by most individuals in this study suggests that the addition of genetic testing into the EHDI process has the potential to be accepted by many members of the broader community. Comprehensive genetic counseling and testing strategies that are culturally sensitive, address concerns, and promote beneficial outcomes should be developed for the EHDI process.

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