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Abstract

The anticipated results of genetic research and the implications for genetic engineering have the potential to reduce the incidence of conditions such as cancer, but questions have been raised about the ethics of proceeding to conditions such as blindness, deafness or color-blindness. One area that has not been addressed is the preferences of deaf individuals for the hearing status of their children. The present study investigated the preference of deaf college students for the hearing status of children they might have in the future. The results indicated that the majority of respondents expressed no preference for hearing status of children. Of the approximately 25% who did state a preference, all but one would choose to have a deaf child. Implications of this finding are discussed.

There has been a growing interest in the progress of the Human Genome Project and related research designed to map the approximately 60,000 human genes. In the not-too-distant future there will be the possibility of altering the composition of human eggs and sperm prior to conception, thus changing the genetic composition of human beings. Breakthroughs already have been announced in identification of some recessive genes for deafness and more are soon to come

In the United States in the 1960s and 1970s hereditary deafness was identified as the cause of approximately half of the cases of severe to profound early childhood deafness, with meningitis, maternal rubella, mother child blood incompatibility, and prematurity accounting for a large proportion of the remainder (Hudgins, 1973; Reis, 1973; Vernon, 1968). In the ensuing years, there have been reductions in the numbers of young children who have become deaf through nonhereditary means, although the situation is subject to change, as in the increased numbers of children recently diagnosed as deaf through cytomegalovirus (CMV) infection (Moores, 2001; Schildroth,1994).

Hereditary deafness is a generic label for a variety of conditions. Konigsmark (1969) developed a system for categorizing hereditary deafness by type of transmission-dominant, recessive, and sex linked. There may be as many as 200 different types of genetic deafness. Perhaps 80% of the cases are recessive. Typically, each parent is hearing, but is a carrier of a recessive gene for deafness which is passed on to the child. In dominant deafness only one gene is required and is passed on by a deaf parent. Sex linked deafness, relatively uncommon, may be passed from a mother through an x chromosome to a son. This occurs in less than 2% of the cases (Brown, et al.,

1967). Clearly, then, most hereditary deafness involves inheritance from hearing parents.

There has been great interest in hereditary deafness in the United States for more than a century. As a result of his extensive genealogical research, Alexander Graham Bell concluded that the American system of education unknowingly led to an increase in the numbers of deaf children by bringing together deaf individuals who then married. In his "Memoir on the Formation of a Deaf Variety of the Human Race" Bell argued that residential schools for the deaf should be closed, deaf teachers should not be hired, organizations of the deaf should be ended, and the American Sign Language should not be used. In a later analysis of Bell's data, Fay (1898) concluded that the numbers of deaf children with deaf parents were small, that deaf people tended to marry other deaf people regardless of their education or use of sign language, and that the large majority of their children were hearing. Fay also noted that the marriage rates of deaf Americans were below those of the general population and they tended to have fewer children. Schein and Delk reported similar findings in 1974. These findings, clearly not supportive of Bell's ideas, were similar in that they reported that most genetically deaf children had hearing parents.

Still, the work of Bell and his concern with "disgenics" has had a continuing influence on the field of deafness, with many genetic researchers focused on eliminating or significantly reducing the number of deaf babies who are deaf because of genetic factors. As with Bell's original position, many people who are unfamiliar with or unsympathetic toward the view of deaf people as culturally and linguistically different as opposed to "deviant" or "disabled," seek to find a way to assist parents in eliminating deafness as a possibility for their future offspring.

Throughout the twentieth century only three to four percent of children in programs for deaf students in the United States and Canada have had deaf parents (Moores, 1996). There is anecdotal information on the preference of deaf parents, but little quantitative data. For example, Lane, Hoffmeister, and Bahan, (1996) stated that, although there is diversity, many members of the deaf world would prefer having a deaf child to a hearing child. Thompson, Thompson, and Murphy (1979), on the other hand, referred to the initial sadness of a deaf couple learning that they had a deaf child. These quite different perspectives of Lane, et al. and Thompson, et al. represent opinions and observations of the respective authors, and although they may be informed opinions, they are not the result of empirical research and do not quantify the extent to which their observations may be accurate. Neither Lane, Hoffmeister and Bahan (1996) nor Thompson, Thompson, and Murphy (1979) provided any data, so there is no information on the range of

preferences of deaf parents for their children, relative to hearing or deaf status.

Such information is especially important at present, given recent advances in genetics and molecular biology, specifically work on the Human Genome Project of the National Institutes of Health, which is involved in mapping the approximately 60,000 human genes. There is the potential in the near future of altering the composition of human sperm and eggs before conception. Significant breakthroughs have already been achieved in the area of hereditary hearing loss (Amos, 1994; Couke, Van Camp, & Djoyodihajo, 1994; Steele, 1998). Steele concluded that time is running out on progressive hereditary hearing loss and that a molecular understanding and intervention strategy may be closer than we think. At present "success" is being reported on the more easily identifiable causes of the at least 200 types of hereditary hearing loss, but more major breakthroughs are inevitable. Though some applaud these rapid advancements, others are concerned that future generations of deaf people will be threatened by these genetic manipulation techniques.

Rifkin (1998) has raised several ethical and practical concerns regarding the implications of genetic engineering. He asked if cancer can be eliminated by altering the genetic codes of individuals, should or would we proceed to less serious "disorders" such as color blindness, dyslexia, obesity, or short stature? He cited a study in which 43% of Americans would approve using gene therapy to improve children's physical characteristics. Rifkin raised the dilemma of where the line should be drawn and who should have the authority to make the decision.

Moores (1998) argued that before long prospective parents will be able to sit down with genetic counselors who will provide them with information that we can only imagine at present. There will be enormous legal and ethical questions. One issue that will be addressed is that of deaf parents and their preferences for the hearing status of their children. If hearing parents are permitted to alter genetic codes to produce hearing children if that is their preference, then deaf parents should be able to have access to the same genetic engineering techniques to produce a child that matches their preference in this area. The present study was designed to begin defining the preferences of selected samples of deaf people, to examine objectively their preferences for deaf or hearing children. This study investigates the preferences of a sample of deaf college students for the hearing or deaf status of future children.

Method

Participants

Participants were 53 deaf female and 53 deaf male undergraduate students at Gallaudet University, the world's only institution of higher education with an entire undergraduate population of deaf students. Average age for the female students was 20.9, with an age range from 17 to 29 years. Average age for male students was 23.0, with an age range from 18 to 37 years. As may be seen from Table 1, background characteristics of the male and female respondents were quite similar. Approximately 60% of the sample graduated from residential high schools for deaf students. Somewhat more than half were the only deaf family member. Approximately 20% lived in families with no hearing members and a similar number in which other family members were both deaf and hearing. Seventy-one percent of the participants had learned to sign by age four years and 25% used a hearing aid "most of the time" or "always." Only one subject reported having any children, a 22 year old woman with a two year old hearing son.

Student Survey

A student survey was developed by the authors to obtain background information on the subjects regarding school attendance, family information, communication patterns, possible plans for children, and gender and hearing status preferences, if any, for future children. Surveys were color coded for gender -- blue for males and pink for females.

Procedure

Participants were approached individually in the snack bar area of the university, a common meeting area for students, by the third author, a native signing deaf graduate of the university, with a B.A. in Psychology and an M.A. in Education. Each person was asked to fill out a short questionnaire about his or her background and preferences for any children they might have in the future. All students who were approached agreed to participate and completed the questionnaire and were informed about the nature of the study and the availability of the results. The study was approved by Gallaudet University's Institutional Review Board (IRB) and participants were so informed. Responses were coded and entered by two research assistants and checked by one of the investigators.

Table 1. Frequencies for Characteristics of Sample

	Female	Male	Total
Number	53	53	106
Age Range	17-29	18-39	17-39
High School Graduation			
Residential	30	30	60
Day School/Day Class	21	20	41
Composition of Immediate Family (Not Including Respondent)			
All Hearing	26	29	55
Both Hearing and Deaf	10	12	22
All Deaf	11	10	21
Age Learned to Sign			
Birth to Four Years	38	34	72
Five Years and Older	14	15	29
Hearing Aid Usage			
Never	27	31	58
Sometimes	10	11	21
Most of the Time	6	3	9
Always	10	7	17

Note: Not all participants responded to all questions

Results

As shown in Table 2, responses of males and females were similar. In terms of preference, 78 of 105 (74%) respondents stated that the hearing status of future children did not matter to them. For those who did express a preference, 26 wanted a deaf child or children and only one (1) wanted a hearing child.

Discussion

A clear majority of the sample, approximately 75%, reported that the hearing status of any future children did not make a difference to them. The responses were consistent for both male and female students across gender. It is interesting to note that only one person expressed a preference for

hearing children. However, the fact that 25% of the respondents expressed a preference for deaf children should receive major attention.

Table 2. Preferences of Respondents

Want Children	Female	Male	Total
Yes	52	51	103
No	0	1	1
Hearing Status Preferred			
Does Not Matter	38	40	78
Deaf	14	12	26
Hearing	0	1	1

When the students filled in the questionnaire they were not provided with any information about the progress of the Human Genome Project. Presumably, they responded under the assumption that they could not alter their own genetic code and thus possibly influence the hearing status of children yet to be conceived, and under the assumption they were likely to be in the group of 90% or more of deaf adults who will have hearing children. It is possible that many of the respondents were expressing a willingness to accept any baby, regardless of hearing status, but that more would have expressed a preference if they thought they could have an influence on the outcome. Because 26 of 27 of the students who expressed a preference would select a deaf child, constituting 25% of the entire sample, this figure may reflect a minimum. Even this percentage is significant and has important implications. It is possible that a significant number of deaf people would choose to have a deaf child if they could, in terms of scientific realities, make this selection. It would also be interesting to observe and record the reactions of members of the hearing population if deaf parents made such a choice. The general hearing population has little or no exposure to deaf individuals or to the deaf culture. They may not be aware of the ethical and moral issues involving the question of genetic engineering and might have no difficulty in supporting the right of hearing parents to alter their genetic codes to prevent the conception and birth of deaf infants. Most, certainly, are unaware of the fact that there are deaf people who might prefer to have deaf children. It is problematic whether the general population and the scientific community itself would be supportive of the concept of extending to prospective deaf parents the same rights that they would to hearing parents. This is one of the many moral issues that will be upon parents-to-be and professionals in the near future.

Limitations of the Study

The study was conducted at Gallaudet University with a sample of deaf undergraduate students, who may not be representative of the young adult deaf population of the United states as a whole. Since the Deaf President Now movement in 1988, culminating in the selection of the first deaf president in the history of the university, Gallaudet has been a center for deaf awareness and deaf empowerment. More so than in most other environments, deafness is perceived as a normal condition within a social context and not as a handicap or disability. More than 20% of the Gallaudet undergraduate student body, and of this sample, have deaf parents, as compared to 4% of the general deaf population. In fact, 45% of the sample have deaf parents and/or siblings. Their acceptance and embrace of deafness may be stronger than in other groups of young deaf adults. There may be great variation in other subgroups of the deaf population. For example, only about 20% of deaf children now attend residential schools. It is not clear that the 80% in non-residential placements, with less exposure to deaf adults, would grow up to have the same preferences for the hearing status of their children. At the end of the nineteenth century Fay (1898) reported that deaf people, regardless of educational background or mode of communication, tended to marry other deaf people and to have hearing children. A century later, it is not clear if the marriage patterns of deaf adults are similar to the past, and given the possibility of choice, at least for some, in the near future, whether deaf parents will produce predominantly hearing offspring. Much more information is needed.

Additional analyses of the data are being conducted to assess the relationship among selected characteristics of subjects and their stated preferences for deaf or hearing children. These will be reported in a follow-up report.

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