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Inconsistencies in genetic counseling and screening for consanguineous couples and their offspring: The need for practice guidelines

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Purpose: To determine current practices of genetic counseling and screening for consanguineous couples, their pregnancies and children, and to compare these practices to recommendations in the literature. **Methods:** A questionnaire was mailed to 1582 board certified genetic counselors and medical geneticists in the United States. **Results:** The return rate was 20% (n = 309). There was wide variation in the risk figures quoted to consanguineous couples to have offspring with birth defects and mental retardation (1% to 75% for incest between first-degree relatives, and 0.25% to 20% for first cousin unions). Suggested screening practices differed for consanguineous unions before conception, during pregnancy, following birth, and for children placed for adoption. Most respondents recommended screening based on ethnicity, yet disagreed as to which genetic disorders to include. **Conclusions:** To standardize genetic services, guidelines for screening the offspring of consanguineous unions are needed. A consensus should be reached as to the empirical risks for genetic disorders, birth defects, and mental retardation that may impair the offspring of consanguineous unions, with definition as to what these disorders are, and if the data applies to global populations. Guidelines should consider costs, the sensitivity and specificity of DNA and biochemical testing, and current practices of prenatal and newborn screening. Consideration should be given to screening based on ethnicity, particularly in populations where consanguineous unions are common, while remaining sensitive to cultural belief systems. Recommendations for screening healthy children from consanguineous unions to be placed for adoption pose ethical challenges. ***Genetics in Medicine*, 1999:1(6):286–292.**

Key Words: *consanguinity, genetic counseling, genetic screening, incest, practice guidelines, adoption*

Couples who are first cousins often seek preconceptional or prenatal genetic counseling services. The child of an incestuous union (defined as a sexual union between two first-degree relatives) may come to the attention of genetics professionals when there are plans to place the child in foster or adoptive care, or if an incestuous relationship is identified during pregnancy. There is limited information in the literature about how to advise and screen these couples, their pregnancies, and their offspring. Our study was designed to determine current practices, among genetic professionals in the United States, for providing risk figures and genetic screening for offspring of consanguineous unions.

Offspring of consanguineous couples are at risk to have inherited autosomal recessive mutations from a common ancestor. It is likely that the risks for multifactorial disorders are also increased. There have been few studies documenting the actual risks to the offspring of these unions. The risks quoted for birth defects and mental retardation are often based on studies of populations where consanguineous unions are common.[1–8] Although marriages between close relatives are discouraged (and even illegal) in most population groups in Europe and North America,[5] consanguineous unions account for 20% to 60% of all marriages in many parts of the world.[3,4,6] For example, in some cultures, particularly in Asia and Africa, marriages between an uncle and niece (second-degree relatives), or between cousins, are preferred. Uncle–niece marriages, and unions between a man and his mother's brother's daughter, are encouraged in the primarily Hindu states of South India. Among some Muslim groups, uncle–niece unions are avoided, whereas cousin marriages between a man and his father's brother's daughter are popular.[6,7] Only a few studies have been done to assess risks to offspring from incestuous relationships[9–13]

Most human genetics texts have a few short paragraphs discussing consanguinity, but they supply little practical information regarding genetic counseling issues for these families. In general, first cousins are given a risk for significant disease, birth defects, and mental retardation of "two times the background risk." In three standard human genetics textbooks, the baseline risk for severe anomalies at birth is listed between 2%

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and 3.5%, compared to a 3% to 7% risk to the offspring of first cousins.[5,14,15] Children of an incestuous mating (i.e., offspring from a parent-child or sibling-sibling union) are listed as having risks between 32% and 44%. What is considered a significant problem is not clear.

Our study was designed to determine current practices of genetic counseling and screening for various degrees of consanguinity. We addressed the following questions: (1) What risk figures for congenital problems and mental retardation are genetic service providers quoting to consanguineous clients, as compared to those from nonconsanguineous unions? (2) What genetic services are being offered to consanguineous couples and their offspring in a preconceptional, prenatal, and pediatric genetic counseling setting? Are the practices different if the child is being placed for adoption? How do these practices compare to recommendations in the literature? (3) How does ethnicity influence these screening practices?

SUBJECTS AND METHODS

We sent a four-page questionnaire in June 1996 to 1582 medical geneticists and genetic counselors certified, as of 1993, by the American Board of Medical Genetics. We asked demographic questions including: degrees held in human/medical genetics, site of training, primary work setting, geographic location of work setting, specialty area in human/medical genetics, and years of practice.

To determine whether our survey group had experience in genetic counseling for consanguinity, we asked how often genetic counseling services were provided for varying degrees of relatedness in a preconceptional and prenatal setting. We also queried how often, if at all, the respondent had been asked to screen a child from a first cousin or incestuous relationship who was being placed for adoption.

Initial survey questions asked what risk figures were quoted to a Caucasian couple (with a negative family history) as a baseline for having a child with problems detected at birth, compared to consanguineous couples, given various degrees of relatedness.

The body of the questionnaire consisted of open-ended questions related to screening practices, given varying degrees of parental consanguinity, in a preconceptional, prenatal, and pediatric setting. In each survey question, the following background assumptions were given: there were unlimited financial resources at the disposal of the genetics professional; the couple was Caucasian; the family history was negative; and the couple's age was under 35. We also asked a question to assess whether screening practices for a healthy child being placed for adoption would be different if the child was the product of a first cousin or incestuous relationship versus a nonrelated couple. A final open-ended question asked about screening practices for consanguinity given various ancestral or ethnic origins (i.e., Ashkenazi Jewish, Chinese/Southeast Asian, Japanese, Italian, African American, Indian/Pakistani, other).

A copy of the survey is available upon request.

RESULTS

Sample demographics

Of the 1582 questionnaires mailed, 309 were returned, giving a response rate of 20%. Respondents were not compensated for their participation. There was a similar return rate from genetic counselors (52%) and medical geneticists (47%), with 1% of respondents identifying as "other." The respondents represented a wide geographic area, comparable to the geographic distribution of the members of the National Society of Genetic Counselors (NSGC) at the time of the survey.[16]

The respondents had varied backgrounds of clinical training and areas of subspecialty in human/medical genetics. More than 66 professional training sites for medical geneticists and 25 training sites for genetic counselors were reported. Only 5.5% of the respondents said they had no direct patient contact. Twenty-two percent of those surveyed worked exclusively in prenatal diagnosis, while 39% focused their primary practice on prenatal and other areas of genetic counseling (adult and/or specialty disease counseling). Twenty-two percent of respondents were involved in pediatric genetic counseling. More than 91% of those surveyed stated they had at least 6 years of experience in the field, with 30% having 15 or more years of clinical practice.

Sixty-five percent of the respondents stated they provided genetic services for consanguinity between 1 and 5 times annually. Approximately 18% of respondents replied they were asked to assess a child from a first cousin union being placed for adoption at least 1 to 5 times annually. More than 24% of those responding stated they had been consulted 1 to 5 times yearly about a child from an incestuous union being placed for adoption.

Risk figures

As a general background risk to have a child with problems detected at birth, 96% of the survey respondents quoted occurrence risk figures within the range of 2% to 5% (Fig. 1) with the range of responses varying from 0.25% to 20%. Considering

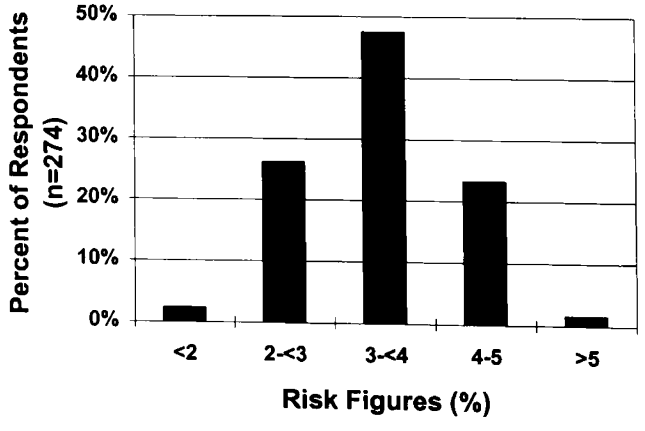

Fig. 1 Quoted risk figures for a child of nonconsanguineous Caucasian parents to have problems detected at birth. For risk figures given as a range, the average value was calculated for this analysis (i.e., 2.5% for 2–3% or 4% for 3–5%).

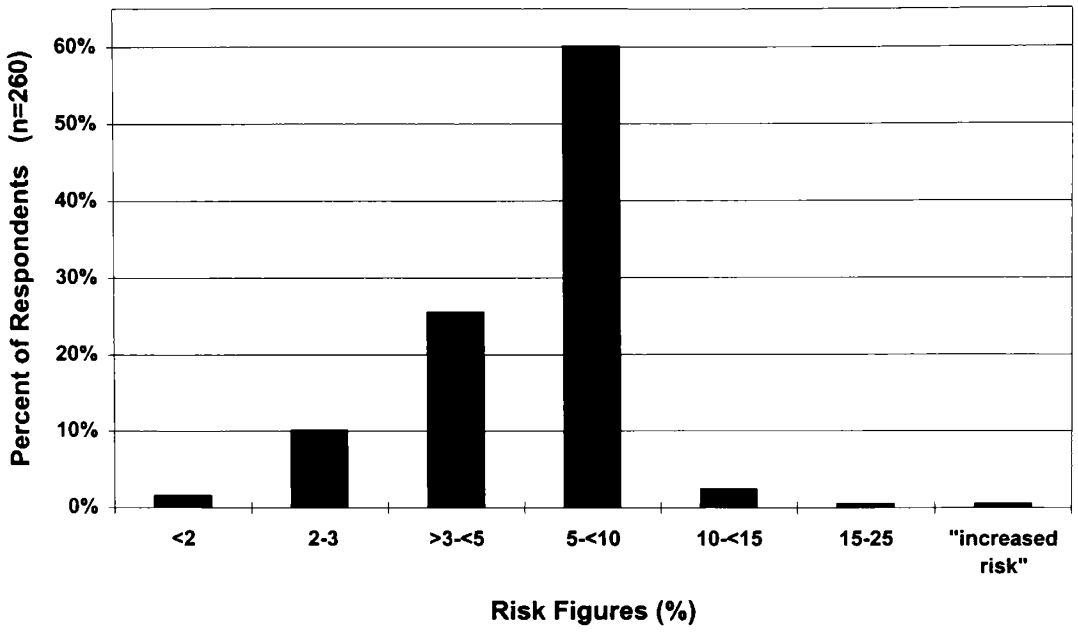

Fig. 2 Quoted risk figures for a child of third-degree relatives (i.e., first cousins) to have problems detected at birth. For risk figures given as a range, the average value was calculated for this analysis.

the offspring of third-degree relatives (i.e., first cousins), the risk figures quoted for birth defects ranged from 0.1% to 30% (Fig. 2). For incest between first-degree relatives, the survey population quoted occurrence risks for problems at birth between 1% and 75% (Fig. 3).

Preconceptional screening

Because it is unlikely that an incestuous couple would seek genetic counseling before a pregnancy, we focused on screening practices for first cousins. Table 1 summarizes the responses (n = 243) to the question, "Given unlimited financial resources, what screening would you offer, before conception, to a Caucasian couple (under age 35) with an apparently negative family history, related as third-degree relatives (i.e., first cousins)?" More than 38 separate combinations of suggestions for screening were given. Other suggestions for screening the couple not given in Table 1 included physical examination and routine karyotype of the couple, and carrier testing for fragile X syndrome, alpha-1-antitrypsin, phenylketonuria (PKU), hemochromatosis, Gaucher disease, medium-chain acyl-CoA dehydrogenase deficiency (MCAD), spinal muscular atrophy, and congenital adrenal hyperplasia.

Prenatal screening

Table 2 provides a summary of the responses to the question, "Given unlimited financial resources, what screening, if any, would you offer in a pregnancy to a Caucasian woman with a negative family history, who is related to her partner as follows: incest, first cousins, not related." More than 87 prenatal screening combinations were suggested for screening the pregnancy of an incestuous couple, 74 combinations for the fetus of first cousins, and 45 for the fetus of a nonrelated couple.

Screening children of consanguineous unions

Table 3 is a tabulation of the survey responses to open-ended questions related to screening a child from a consanguineous union versus a healthy child from a nonconsanguineous union, and if screening practices would be different if the child were to be placed for adoption. For a child from an incestuous union, 124 different combinations of screening were suggested (134 if the child were placed for adoption), and 84 combinations were listed for screening a child from a first cousin union. Other suggestions for testing the child not listed in Table 3 included alpha 1-antitrypsin, MCAD, Duchenne muscular dystrophy (DMD), glucose-6-phosphate dehydrogenase (G6PD), lactate and pyruvate levels, thyroid and cholesterol testing, and an ultrasound of the head.

Ethnic screening

The final question was an open-ended query as to how the preceding screening practices would change, given varying ancestral/ethnic origins. For someone of Ashkenazi Jewish ancestry, 12 diseases were mentioned in screening. These included Tay-Sachs disease (TSD), Gaucher disease, CF, Canavan disease, breast cancer, Niemann-Pick disease, Factor XI deficiency, Fanconi syndrome, spinal muscular atrophy, familial dysautonomia, Krabbe disease, and hemoglobinopathies. All of the 232 respondents would screen Jewish consultands for TSD, 45% for Gaucher disease, 34% for CF, and 30% for Canavan disease. Although 33.6% of respondents recommended TSD screening alone, the remainder of the survey population

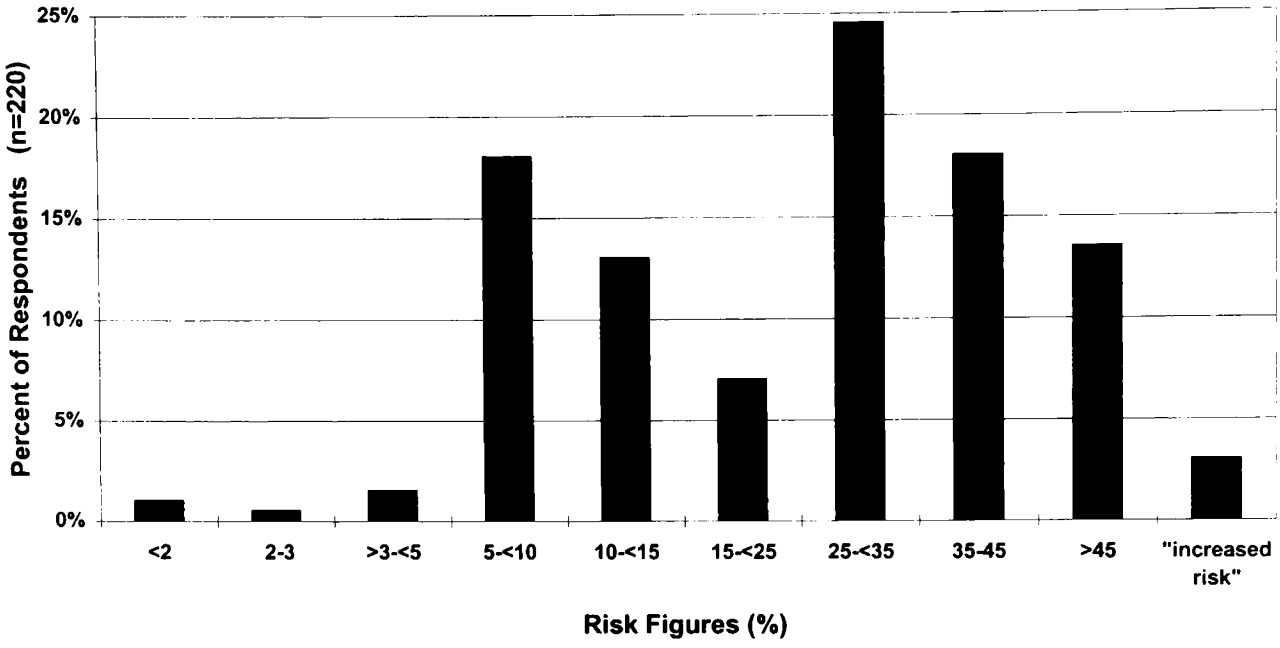

Fig. 3 Quoted risk figures for a child of first-degree relatives (i.e., siblings or parent-child) to have problems detected at birth. For risk figures given as a range, the average value was calculated for this analysis.

Table 1
Percentage of respondents recommending preconceptional screening of first cousin couples

Screening	% of Respondents
No testing/depends on ethnicity/ depends on family history	34%
Cystic fibrosis testing	35%
Cystic fibrosis and other screening[a]	51%
Hemoglobinopathy screening	4.5%
Tay-Sachs carrier testing	4%

[a]Other screening: Fragile X syndrome, parental chromosomes, spinal muscular atrophy, hemochromatosis, Gaucher disease, medium–chain acyl–CoA dehydrogenase deficiency, congenital adrenal hyperplasia, alpha–1–antitrypsin, phenylketonuria, physical examination.

Table 2
Percentage of respondents recommending prenatal screening of consanguineous unions

Screening	Incest (n = 254)	First cousins (n = 253)	Not related (n = 244)
No Testing/DOE[a]/DOFH[b]	7%	11%	12%
Ultrasound	64%	60%	41%
Maternal serum triple screen	48%	51%	53%
Amniocentesis (karyotype)	3%	2%	<1%
Cystic fibrosis testing	51%	45%	14%
Fetal echocardiogram	6%	4%	0
"Amniotic fluid metabolic screen"	3%	3%	0

[a]DOE, depends on ethnicity.
[b]DOFH, depends on family history.

recommended some combination of an "Ashkenazi Jewish screening panel," with 39 separate combinations of panels being suggested. The most popular choices for panels were Gaucher disease/TSD(13.4%), Canavan disease/Gaucher disease/TSD (9.9%), and CF/Gaucher disease/TSD (7.3%).

Although ethnic screening for hemoglobinopathies was suggested by all of the respondents for individuals of Chinese/Korean, Japanese, Italian, African American, and Indian/Pakistani ancestry, the modality of screening differed (i.e., hemoglobin electrophoresis, DNA analysis, or MCV). Screening for G6PD was recommended by 16/233 (6.9%) of respondents for individuals of African American ancestry, 8/221 (3.6%) of respondents for individuals of Italian ancestry, and 6/147 (4%) of respondents for individuals of Indian/Pakistani ancestry. Cystic fibrosis screening for individuals of Italian ancestry was suggested by 6/221 (2.7%) of those responding. Additional suggestions for screening people of Indian/Pakistani ancestry included neural tube defects and ichthyosis. Thirty-one of the survey respondents suggested specifically screening for Tay-Sachs disease in individuals of French Canadian ancestry. Other suggested screening in this population included tyrosinemia and hypercholesterolemia.

For isolated population groups, suggestions for screening included: urine organic acids, maple syrup urine disease and glutaric acidemia type I in the Amish population; screening for kidney disease and cholesterol problems in the Finnish population; hemoglobinopathy screening in the Arabic, Portuguese, and Hispanic populations; screening for familial Mediterranean Fever in the Armenian population; and screening for neural tube defects in the Irish/Welsh population.

Table 3
Percentage of respondents recommending screening of children based on degree of parental consanguinity and adoption status

Screening	Incest (n = 244)	Incest–child adopted out (n = 237)	First cousins (n = 237)	First cousins–child adopted out (n = 219)	Child adopted out–parents not related (n = 209)
No testing/DOE[a]/DOFH[b]	15%	30%	28%	41%	53%
Physical exam only	20%	7%	24%	9%	8%
Genetic/dysmorphology evaluation	12%	17%	5%	7%	6%
Developmental assessment	19%	18%	10%	12%	5%
Ophthalmologic exam	6%	7%	3%	5%	2%
Hearing testing	11%	18%	8%	14%	5%
Renal/abdominal ultrasound	3%	3%	1%	3%	1%
Skeletal x-ray	2%	1%	<1%	0	0
Echocardiogram	1%	3%	1%	2%	<1%
Metabolic screening (plasma or urine)	23%	23%	15%	16%	3%
Cystic fibrosis testing	20%	36%	16%	30%	8%
Chromosome analysis	3%	3%	0	2%	3%

[a]DOE, depends on ethnicity.
[b]DOFH, depends on family history.

DISCUSSION

Our survey population is an experienced cohort of clinical genetics professionals, from a variety of specialties and clinical training programs, representing a range of geographic areas within the United States. Our study is the first to assess the current practices of providing genetic services for consanguinity. Our results indicate that there is limited consensus among these professionals as to what a genetic evaluation for consanguinity (preconceptional, prenatal, or pediatric) should entail.

Making decisions about genetic testing requires accurate risk estimates. Our survey results show that there is variation in the risks being quoted for problems detected at birth in the offspring of first cousins and incestuous unions. Although most (73.3%) of those surveyed used a 2% to 3.5% baseline risk for congenital anomalies (the range quoted in common genetic textbooks), to a nonrelated Caucasian couple with a negative family history, the range of responses varied between 0.25% and 20% (Fig. 1). With regard to first cousins, more than 85% of those surveyed quoted risks for birth defects between 4% and 10%, similar to the risks cited in genetic textbooks. In cases of incest between first-degree relatives, the survey population quoted an occurrence risk for congenital malformations/birth defects between 1% and 75%. Less than half of the respondents quoted risk figures in the 25% to 45% range that is cited in genetic textbooks.[5,14,15]

Although phrases such as "congenital anomalies," "problems at birth," and "birth defects" are commonly used in baseline risk quotations in genetic counseling, what exactly do these terms encompass? Risks for common diseases with complex inheritance usually are not included. What is the range of severity of mental retardation included in these figures? The studies estimating risks to the offspring of first- and second-degree relatives for congenital malformations/birth defects have been done in geographic populations where consanguinity is common. Can such data be applied to any consanguineous couple from any socioeconomic or ethnic group? Likewise, the risks for incest have been based on a limited number of studies.

For preconceptional screening (Table 1), 34% of the survey respondents would not offer any testing to consanguineous couples beyond screening based on ethnicity and family medical history. Thirty-five percent of respondents would offer CF carrier testing, and 51% would offer CF testing with other screening. Approximately 5% of those surveyed would routinely screen for hemoglobinopathy carrier status, and 4% for TSD, regardless of ethnicity.

Slightly fewer respondents would offer no additional testing in a pregnancy of a nonrelated couple as compared with a pregnancy of first cousins, 3.5% versus 13% (Table 2). Ultrasound screening was more likely to be used for the pregnancy of a consanguineous or incestuous union (more than 60%), versus 41% who would provide routine ultrasound screening to a nonconsanguineous couple. Nearly half of our respondents would offer CF testing in a pregnancy of an incestuous or first-cousin relationship, compared to 14% in a "routine" pregnancy. A maternal serum triple marker screen (alpha fetoprotein, human chorionic gonadotropin, and unconjugated estriol) would be offered by a similar proportion of our respondents in all three categories. Although chromosome anomalies do not occur more frequently in the offspring of consanguineous unions, 2 to 3% of those surveyed would offer fetal karyotyping. Six percent of our respondents would offer a

fetal echocardiogram in the pregnancy of an incestuous couple, and 4% in a pregnancy of first cousins. Three percent of our survey population suggested a metabolic screen on amniotic fluid.

One component of our survey was to assess current clinical practices for screening a child from an incestuous union, and compare these results to the recommendations that were published by Hall,[17] and Baird and McGillivray[12] almost 20 years ago. Their recommendations (summarized in Table 4) included extensive physical and developmental assessments as well as specific genetic testing. Our survey responses indicate that few clinicians follow these screening guidelines (Table 3). For example, although an ophthalmologic exam and hearing screening is recommended in the published guidelines, few of the professionals we surveyed would offer either of these tests. In place of the intravenous pyelogram (IVP) in the published guidelines, 3% of our survey respondents would screen the child of an incestuous union with abdominal ultrasound. Few of our respondents would offer skeletal surveys. One percent of those surveyed would offer an echocardiogram to screen the child of a consanguineous union, as compared to the 4 to 6% of respondents that would offer fetal echocardiography (Table 2). Although 85% of respondents would offer some type of screening for a child from an incestuous union, the type of evaluation varied.

There was little difference between the type of evaluation offered to a child from a first cousin union whether or not the child was to be placed for adoption (Table 3). For most areas of testing, the respondents suggested less testing for a child from an incestuous union being placed for adoption than if the child remained with the biological parent(s). In the survey's comment section, several of the respondents stated that they were opposed to genetic screening of a healthy child being placed for adoption because the child might face discrimination.

There are some limitations in our study. With a return rate of 20%, our respondents may not reflect the actual clinical practices of the majority of genetic counselors and medical geneticists. Since our survey asked knowledge-based questions, professionals who have not provided services for consanguinity, or those who were unsure of the "correct" answers, are less likely to have responded. Our survey was lengthy (six pages), and not all of the respondents answered each question. We asked our questions in the artificial situation of having unlimited financial resources for genetic testing. Thus, our respondents' remarks may differ from the services they actually offer their clients. Also, we were unable to query as to the reasoning behind why each respondent would offer a particular genetic screening modality.

Our survey results indicate that medical geneticists and genetic counselors do not have uniform practices for providing genetic counseling and screening for consanguinity. Guidelines are needed to address the goals for the evaluation of offspring of consanguineous unions. Such guidelines should take into account the availability of DNA and biochemical testing for various genetic conditions, as well as current practices for routine newborn screening and prenatal testing. Guidelines should consider the goals of screening, for example, is the purpose of screening to detect *any* possible future genetic disorder during that individual's life, or is it to maximize the outcome for a healthy child in the first few years of life? In the latter case, screening for treatable metabolic disorders in the newborn period would be useful while screening for founder breast cancer mutations (depending on the child's ethnicity) would be unacceptable. The magnitude of the risk as well as the physical and psychological burden of disease, as perceived by the counselee and counselor, will have an impact on the threshold for genetic screening.

The issue of screening goals becomes particularly troublesome when considering genetic screening of a child from a consanguineous union who is placed for adoption (a situation for which 25% of our respondents reported being consultants in the case of incest, and 18% for first cousins, at least 1 to 5 times annually). Do the prospective adoptive parents have the right to request all potentially obtainable genetic information about this child before adoption? Hall[17] and Baird and McGillivray[12] suggested waiting one year before placing a child from an incestuous union in a permanent home. Is this waiting period appropriate given the potential psychological consequences to the child? Should parentage testing be required to assure that the child is indeed the product of incest? Whose interests are paramount–the child's or the adoptive parents? Should an apparently healthy child from a consanguineous union be screened for a selected number of potentially untreatable or late onset diseases when that child might be discriminated against in the future? Dr. Dorothy Wertz cautions that, "Testing for untreatable adult-onset disorders prior to adoption makes the child into a commodity undergoing quality control."[18]

Table 4
Published recommendations for screening children of incest[a]

- Physical examination and developmental assessment every 3 months until age 3 years
- Formal psychometric testing at 1 year
- Urine metabolic screening
- Plasma amino acids
- Urine organic acids
- Complete blood count
- Sweat chloride (at 3 months of age if Caucasian)
- Thyroxin estimations
- Ophthalmologic screening
- Hearing test
- Intravenous pyelogram
- Skeletal survey
- Karyotype if mental retardation or multiple congenital anomalies are present

[a]Compiled from Hall JG (1978) Am J Dis Child 132: 1045; and Baird and McGillivray (1982) J Pediatr 101(5):854–857.

Many of our survey participants commented that some of their consanguineous clients describe feelings of shame and embarrassment regarding their relationships, and fears of having "deformed babies." Genetic professionals can provide reassurance to these couples but it is important that we all provide similar information. Guidelines should consider sensitivity to cultural issues, particularly in ethnic groups where marriage to a relative is acceptable and even encouraged, or in small cultural groups which are traditionally inbred (such as the Amish).[19] Screening should be offered to provide reassurance and to maximize the outcome for a healthy child without offering testing in a directive or coercive manner. The consultand's desire to be tested or not to be tested must be respected.

The development of protocols for genetic evaluation in the context of consanguinity can help to assure that these couples and their offspring receive optimal health care. One anonymous survey respondent nicely summarized the variables to consider in developing guidelines in the following statement:

"I suggest that the rationale for screening/testing in the setting of consanguinity must look to costs, desire for information and population frequencies of disorders–just as it does when there are no consanguinity considerations. The degree of consanguinity would then be a variable in that setting, and often not the most important one."

Acknowledgments

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