Decision-Making for Termination of Pregnancies With Fetal Anomalies: Analysis of 53,000 Pregnancies

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OBJECTIVE: To evaluate the degree to which prenatal knowledge of fetal anomalies and sociodemographic characteristics determined outcome of 53,000 pregnancies.

METHODS: Pregnancies were consecutively evaluated at a university hospital between 1984 and 1997. The severity of anomalies was graded by using an ordinal scale, in which 0 was no anomalies, 1 was no impact on quality of life, 2 was little impact but possibly requiring medical therapy, 3 was serious impact on quality of life even with optimal medical therapy, and 4 was incompatible with life.

RESULTS: The abortion rates for grades 1 and 3 anomalies increased from 0.9% to 72.5%, and 0.9% to 37.1% for central nervous system and non–central nervous system anomalies, respectively ($P < .001$). Multiple logistic regression showed that mothers without a high school education were more likely than those who completed high school to abort a normal pregnancy (odds ratio [OR] 1.62, 95% confidence interval [CI] 1.07, 2.45). In the 452 pregnancies in which there was one grade 3 anomaly, logistic regression also showed that the abortion rate decreased by 6% per year as maternal age decreased (OR 0.94, 95% CI 0.91, 0.97).

CONCLUSIONS: The severity of anomalies directly correlates with abortion rates, but at similar degrees of severity, central nervous system anomalies are more likely to lead to abortion. Maternal level of education inversely correlates with likelihood of termination of a normal pregnancy, whereas maternal age directly correlates with pregnancy termination when serious anomalies are present. Serious congenital anomalies may disproportionately affect children from families with the youngest mothers because these mothers are likely to continue these pregnancies. (Obstet Gynecol 2002;99:216–22. © 2002 by the American College of Obstetricians and Gynecologists.)

Technical advances and legislative changes have altered many aspects of reproductive behavior in the last quarter of the 20th century. In the United States and Canada, elective termination of pregnancy has been available for more than 25 years, and routine sonography has enabled physicians to identify numerous fetal anomalies relatively early in pregnancy. Although the results of sonography may be expected to affect the decision to terminate an individual pregnancy, there have been few systematic investigations of the multiple variables that influence the probability of therapeutic abortion when a fetal anomaly is identified in the mid-trimester of pregnancy. Pryde et al reported that the severity of sonographic anomalies identified in the central nervous system and other organs correlated with the decision to terminate a pregnancy.[1] In a study restricted to neural tube defects, Grevengood et al found that the spinal level of the defect influenced the decision to have a therapeutic abortion.[2] Neither of these studies estimated the contribution of sociodemographic factors in determining pregnancy outcome. More recently, Velie and Shaw showed that the likelihood of elective termination of pregnancy for neural tube defects was directly correlated with white race, educational level, and household income, although they could only identify pregnancy outcomes, not whether decisions to terminate had been based on results of sonography.[3]

In the course of a more limited study of pregnancy outcomes, we became interested in the relationship between prenatal discovery of a fetal anomaly and the decision to electively abort a pregnancy. We used a large existing prenatal diagnosis database to retrospectively investigate factors that influence outcome decisions when ultrasound evidence indicates a congenital anomaly. We decided to test three hypotheses. First, there is a correlation between the severity of individual fetal anomalies as estimated by genetic specialists and the frequency of therapeutic abortion in our database. Second, the likelihood of therapeutic abortion differs depending on the presence of central nervous system anomalies or anomalies of other organ systems. Finally, sociodemographic factors that influence the probability of therapeutic abortion can be isolated once an anomaly has been diagnosed by sonography.

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MATERIALS AND METHODS

The patient sample comprised pregnant women evaluated consecutively in the Division of Genetics and Ultrasound of the Department of Obstetrics and Gynecology at Washington University between November 1984 and December 1997. Patients were referred from the city of St. Louis, St. Louis County, and rural Missouri and Illinois. The indications for referral varied from primary care referrals for gestational age assignment to tertiary care referrals for suspected fetal anomaly. Our sample might, therefore, not be representative of typical pregnancies. The protocol was approved by our institutional human studies committee.

Sonographic examinations were done using state-of-the-art equipment, including ATL Ultramark 4, 8, and 9 (Advanced Technology Laboratories, Bothell, WA), Acuson 128 XP (Acuson, Mountain View, CA), and GE 3200 (General Electric Medical Systems, Milwaukee, WI) systems. Examinations were performed by registered sonographers and sonologists who were obstetrician-geneticists or maternal-fetal medicine subspecialists. Invasive diagnostic procedures were performed by the same physician who interpreted the sonogram. Patients were given counseling at the time that an anomaly was identified and was performed by a physician in the Division of Genetics and Ultrasound with subspecialty training in genetics or maternal-fetal medicine. Three of the physicians in this group were present through the entire study period.

Postnatal outcome information was obtained in all cases of fetal anomaly and in 90% of routine cases in which no anomaly was suspected. The follow-up procedure for all obstetric cases was directed by a research nurse. For routine obstetric cases, the patient or the referring physician completed a questionnaire. In cases with anomalies, other confirmatory information was collected, such as results of pathologic studies, delivery records, or hospital discharge summaries. Most of the abortions for fetal anomalies were performed in our institution, simplifying this process, but outcome information was also obtained from the other abortion sites.

All anomalies diagnosed before the end of the 24th week of pregnancy were identified. The severity of each anomaly was ranked by a sonologist-geneticist, whose knowledge of severity had provided the basis for the genetic counseling. The ranking used an ordinal grading scale: 0 was no anomalies of a given type; 1 was an anomaly expected to have no impact on quality of life; 2 was an anomaly expected to have little or no impact on quality of life but which might require surgical or medical treatment; 3 was an anomaly with the potential for serious impact on quality of life, even with optimal medical or surgical treatment; and 4 was an anomaly incompatible with life. Some anomalies had to be given an indeterminate score because the database lacked details on some abnormal findings. For example, many anatomic cardiac anomalies are grouped together as a single diagnostic category, making it impossible to separate complicated structural defects from those more amenable to surgical repair. We divided the entire set of anomalies into those involving the central nervous system (CNS) and those involving other organ systems (non–CNS) (Table 1). Each fetus was assigned scores of

Table 1. Anomalies by Type and Grade of Severity

CNS Anomalies		
Severity grade	Specific anomaly	Cases, *n* (%)
1	Choroid plexus cysts	533 (0.99)
2	Ventriculomegaly	27 (0.05)
	Other	2 (0.002)
	Spina bifida/meningomyelocele	99 (0.18)
	Hydrocephalus, secondary	47 (0.09)
	Hydrocephalus, primary	29 (0.05)
3	Encephalocele	20 (0.04)
	Other	26 (0.05)
4	Anencephaly	92 (0.17)
	Other	19 (0.04)

Non-CNS Anomalies		
Severity grade	Specific anomaly	Cases, *n* (%)
1	Minimal renal pelvic dilation, bilateral	255 (0.48)
	Minimal renal pelvic dilation, unilateral	197 (0.37)
	Echogenic chordae tendinae	178 (0.33)
	Extrarenal pelvis, bilateral	44 (0.08)
	Extrarenal pelvis, unilateral	35 (0.07)
	Pericardial effusion	20 (0.04)
	Other	40 (0.07)
2	Hydronephrosis, bilateral	75 (0.14)
	Hydronephrosis, unilateral	56 (0.10)
	Clubfoot deformity	49 (0.09)
	Cardiac arrhythmia	45 (0.08)
	Cystic hygroma	40 (0.07)
	Multicystic kidney, unilateral	30 (0.06)
	Hydroureter	24 (0.04)
	Renal agenesis, unilateral	22 (0.04)
	Other	70 (0.13)
3	Gastroschisis	41 (0.08)
	Non-immune hydrops	40 (0.07)
	Omphalocele	33 (0.06)
	Other	151 (0.28)
4	Renal agenesis, bilateral	21 (0.04)
	Other	36 (0.07)

Individual anomalies that occurred in at least 20 subjects (about 0.04% of the total sample) are separately listed; the remaining anomalies are categorized as "other."
CNS = central nervous system.

1 to 4 corresponding to its most severe CNS and non-CNS anomalies.

For this study, "therapeutic abortion" was defined as an abortion performed for fetal anomalies or maternal medical conditions, and "spontaneous abortion" was defined as a pregnancy loss that occurred without medical or surgical intervention before 20 weeks of gestation. An infant born after 20 weeks without signs of life was considered a stillbirth. Because the decision to abort one fetus from a given pregnancy was usually not independent of the decision to abort a second fetus from that pregnancy, a single fetus was randomly selected from each pregnancy when more than one fetus was present. This preserved the independence requirement of all data analyses and excluded the possibility of bias due to counting the abortion of multiple fetuses from the same mother as multiple abortions.

χ^2 tests were used to evaluate the association between the abortion rate and all discrete measures. Student *t*-tests provided the same information when continuous variables were evaluated. The Wilcoxon rank-sum test was used when continuous variables were skewed and when ordered categorical variables, such as the number of living children, were being evaluated. Stepwise logistic regression was used to determine a best set of independent predictors of the decision to have an abortion. Because of sparse data at some levels of severity, and because a good fit of the logistic model requires a linear relationship between the logarithm of the odds of an abortion and all ordered predictor variables, we collapsed and recoded our measures of maximum CNS and maximum non-CNS anomalies before performing logistic regression analysis. The logistic model was used to compute 95% confidence levels and odds ratios. The Hosmer–Lemshow goodness-of-fit test was used to ensure the fit of the logistic models. All data were analyzed by using SAS software (SAS Institute, Cary, NC); when appropriate, results are expressed as mean(±standard deviation [SD]).

RESULTS

Data on fetal anomalies were available from 57,058 pregnancies, including 1397 involving multiple fetuses (1317 twins, 73 triplets, and 7 quadruplets or greater). Because spontaneous abortions frequently occur during the early months of pregnancy when there is still time to decide to have a therapeutic abortion, and because data on the time at which spontaneous abortions occurred were not available, all 2508 fetuses that aborted spontaneously were excluded. In addition, 11 pregnancies were excluded because the outcome of the pregnancy was unknown, and 22 were excluded due to fetal death in utero. Of the remaining 54,517 fetuses, 832 were excluded because of the presence of at least one anomaly of unknown severity and 55 were excluded because of the presence of a chromosome abnormality of unknown severity. Thus, the data set on which these results are based includes 53,630 fetuses from separate pregnancies. This group included 894 CNS anomalies and 1502 non-CNS anomalies (Table 1). Extensive demographic information was available about parents, previous pregnancies, and the outcome of the current pregnancy (Table 2). Because complete demographic information was not available on every pregnancy, some of our totals do not add up to 53,630.

We analyzed CNS and non-CNS anomalies to account for individual fetuses having more than one anomaly and found that the distribution of severity for both types of anomaly was broadly distributed over all levels, providing the variability necessary for adequate assessment of the association between the severity of an anomaly and the decision to abort (Table 3).

We observed significant correlations between therapeutic abortion and various demographic variables. Abortion rates were inversely associated with educational level; it was 2.26% in mothers who had not completed high school ($n = 3451$) compared with a 1.51% abortion rate in mothers who graduated from college ($n = 17{,}846$, $P < .001$). Similarly, the abortion rate decreased from 2.26% for fathers who were non–high school graduates ($n = 2744$) to 1.63% for those who were college graduates ($n = 17{,}047$, $P = .022$).

Grade 1 anomalies were not associated with the decision to have an abortion, but a great association was observed between abortion rates and the severity of other CNS anomalies, non-CNS anomalies, and chromosomal abnormalities ($P < .001$ in each case) (Table 4). Because these results strongly suggest that CNS anomalies of a given severity provide much greater incentive for abortion than do non-CNS anomalies of the same severity, we looked in detail at 98 fetuses with "isolated" grade 3 CNS anomalies (no non-CNS anomaly or chromosomal abnormality) and 167 fetuses with "isolated" level 3 non-CNS anomalies. Abortion rates were 73.5% for the isolated CNS anomalies and 37.3% for the isolated non-CNS anomalies ($P < .001$). These values, which are almost identical to those found for grade 3 CNS and non-CNS anomalies associated with additional less severe anomalies (Table 4), further support the hypothesis that CNS anomalies are a powerful incentive to terminate pregnancy.

A stepwise logistic regression analysis was also done to evaluate the independent significance of variables that were significant univariate predictors of therapeutic

Table 2. Demographic Characteristics of Parents, Previous Pregnancies, and Outcome of Current Pregnancy

Variable	Data
Outcome of pregnancy (%)	
Abortion	1.5
Live birth	97.0
Neonatal death	0.6
Stillbirth	0.9
Age of mother (y)	30.7 ± 6
Age of father (y)	32.3 ± 7
Mother's level of education (%)	
Not high school graduate	8.2
High school graduate	17.8
Some college	31.5
College graduate	42.5
Father's level of education (%)	
Not high school graduate	7.2
High school graduate	20.0
Some college	28.1
College graduate	44.7
Mother's race (%)	
White	77.8
Black	16.2
Other	6.0
Father's race (%)	
White	75.6
Black	17.1
Other	7.3
Parents of mixed race (%)	9.9
Number of children (%)	
0	51.9
1	27.4
2	13.6
3	4.6
≥4	2.5
At least one previous stillbirth (%)	1.8
At least one previous neonatal death (%)	1.5
At least one previous death of a child (%)	0.1
Chromosomal abnormality (%)	0.3
Down syndrome (%)	0.2
Previous spontaneous abortions	
0	78.9
1	15.6
2	3.7
≥3	1.8
Previous therapeutic abortions	
0	84.7
1	12.0
2	2.5
≥3	0.8
At least one previous event (%)*	33.8
No. of previous events*	0.53 ± 0.9

Data with the plus/minus sign are means (±standard deviation).

*Events include previous stillbirths, neonatal deaths, deaths of children, spontaneous abortions, and therapeutic abortions.

abortion (Table 5). Results showed that the most powerful independent predictors of abortion were CNS anomalies, non-CNS anomalies, and chromosomal abnormalities.

Table 3. Fetal Anomalies by Type and Severity

	CNS	Non-CNS
Severity of anomaly		
Grade 1	1.0 ($n = 533$)	1.3 ($n = 718$)
Grade 2	<0.1 ($n = 27$)	0.7 ($n = 363$)
Grade 3	0.3 ($n = 163$)	0.5 ($n = 246$)
Grade 4	0.2 ($n = 110$)	0.1 ($n = 56$)
At least one anomaly of any severity	1.5 ($n = 821$)	2.2 ($n = 1248$)
Mean (± SD) total number of anomalies*	0.02 ± 0.1 (0,3)	0.03 ± 0.2 (0,7)

Entries are the percent of cases in which at least one anomaly of the given type and severity was present.

CNS = central nervous system; SD = standard deviation.

* Numbers in parentheses are the minimum and maximum number of anomalies of each type in any one fetus.

Further analyses focused on the predictive impact of the mother's educational level, which was excluded from the logistic regression owing to missing data even though univariate analysis showed that lower educational levels were associated with increased abortion rates. To assess the role of education independent of the effect of anomalies, we analyzed the 46,855 pregnancies with no anomalies or chromosomal abnormalities. The covariate adjusted odds ratio [OR] of an abortion was 1.62 (95% confidence interval [CI] 1.07, 2.45; $P = .022$) for non–high school graduates versus high school graduates, indicating that women without high school education were more likely than their more educated counterparts to have an abortion.

To evaluate the effect of maternal education on the decision to have an abortion when a severe anomaly was present, we analyzed the 452 pregnancies with at least one grade 3 CNS anomaly, non-CNS anomaly, or chromosomal abnormality. We excluded grade 4 anomalies because the extreme severity of these anomalies produced an abortion rate so high that educational level had no effect. In women with fetal grade 3 anomalies, a strong positive correlation between educational level and the decision to abort was observed; abortion rates increased from 30.6% to 53.9% as education level increased from less than high school to college graduate ($P = .036$, χ^2 test). When we performed multivariate analysis to control for age, the association between education and abortion rate became nonsignificant ($P = .341$). The small sample and inclusion of many younger women lacking a high school education may account for this lack of significance. However, the 6% per year reduction in abortion rate with decreasing maternal age in the grade 3 group was significant (OR = 0.94, 95% CI 0.91, 0.97, $P < .001$).

Table 4. Abortion Rate, by Maximum Severity of Non-CNS Anomalies, CNS Anomalies, and Chromosomal Abnormalities

Type of anomaly	No anomaly *n*/*N* (%)*	Maximum severity of anomaly				*P*
		1	2	3	4	
Non-CNS	624/52,382 (1.19)	6/649 (0.92)	43/303 (14.2)	89/240 (37.1)	40/56 (71.4)	<.001
CNS	576/52,809 (1.09)	5/532 (0.94)	6/19 (31.6)	116/160 (72.5)	99/110 (90.0)	<.001
Chromosomal abnormalities	708/53,461 (1.36)	0/5 (0.00)	4/17 (23.1)	52/112 (46.4)	17/35 (51.4)	<.001

CNS = central nervous system.

* Numerators are the number of abortions lacking the specified group of anomalies at any level; denominators are the total number of pregnancies that lacked the anomaly.

DISCUSSION

Our data collected over 13 years document the influence of sonographic findings and sociodemographic characteristics on pregnancy outcome and provide the most comprehensive information on this topic to date. Our main motivation for reviewing sonographic data was not to determine rates of therapeutic abortion for fetal anomalies, but rather to identify factors that were associated with the decision to terminate a pregnancy. We gathered data on 53,630 pregnancies affected by 2394 fetal anomalies, of which 894 involved the CNS and 1502 involved other organ systems. As other investigators have reported, severity of anomaly influences the likelihood of pregnancy termination. In 1992, Pryde et al reported that rates of therapeutic abortion were 66%, 12%, and 0% in various nonchromosomal CNS and non-CNS anomalies classified as "severe," "uncertain," and "mild," respectively.[1] These results are similar to ours, despite the difficulty of quantitatively comparing different rating scales and patient sample. A minor difference is that the study by Pryde et al lacked abortions in the "mild" category. In a study restricted to neural tube defects diagnosed by the end of the 24th week of gestation,[2] pregnancy termination for spina bifida was more likely when the defect was above the ninth thoracic vertebrae; in all, 21 of 27 pregnancies (78%) were aborted, a rate close to that among cases with grade 3 and 4 CNS anomalies in our study. Several studies have uniformly reported high rates of abortion for the most common and serious fetal anomalies.[4] The agreement between our rates of pregnancy termination for different anomalies and other published rates suggests that our database is representative of women in other developed countries.

Table 5. Independent Predictors of the Decision to Have an Abortion

Variable	Odds ratio (95% CI)	*P*
Intercept		<.001
Maximum CNS anomaly Grade ≥2*	327 (144, 259)	<.001
Maximum non-CNS anomaly		
Grade 2 vs grade ≤ 1	18.8 (15.6, 22.6)	
Grade 3 vs grade ≤ 1	58.7 (45.4, 75.8)	<.001
Grade 4 vs grade ≤ 1	126 (92.8, 170.5)	
Chromosome abnormality Grade ≥2*	87.4 (61.2, 124.9)	<.001
At least one living child	1.43 (1.19, 1.71)	<.001
Mother's race†	1.75 (1.30, 2.35)	<.001
History of ≥ 1 event‡	1.40 (1.17, 1.67)	<.001

Results are based on a stepwise logistic regression analysis with maximum CNS and non-CNS anomaly values recoded to ensure a good model fit. All variables entered into the initial model remained significant after multivariate adjustment for covariates.

CI = confidence interval; CNS = central nervous system.

* Dichotomized as grade ≥2 versus <2 in this analysis because that dichotomy produced the best fit for the logistic model. This was not necessary for non-CNS anomalies.

† "Other" (eg, Asian or Hispanic) versus black or white.

‡ Previous still births, neonatal deaths, deaths of children, spontaneous abortions and therapeutic abortions.

An important aim of our study was to determine whether anomalies that affect the CNS differentially influence the rate of pregnancy termination. Although it is difficult to directly compare our grade 3 and 4 CNS and non-CNS anomalies, our data strongly support the hypothesis that involvement of the CNS greatly increases the likelihood of abortion. In fact, the probability of termination for grade 3 CNS anomalies was higher than for grade 4 non-CNS and chromosomal abnormalities. This suggests that at some level, most parents recognized that CNS defects would compromise the quality of life of their child so greatly that they could not continue the pregnancy. This observation may also mean that physicians and counselors communicated the grave implications of CNS anomalies differently.

We also demonstrated that maternal age directly correlates with the decision to terminate a pregnancy after a serious (grade 3) anomaly has been identified before the end of the 24th week of gestation. Because nearly all women whose fetuses had a grade 4 anomaly chose to abort their pregnancies, we could not evaluate the association between abortion rate and age in this group.

We can offer several hypotheses for this last finding. First, the information about the severity of the various

anomalies may have been transmitted in such a way that the full implications were misinterpreted by younger and, therefore, less educated women. If the potential for surgical correction of hydrocephalus or neural tube defects was mentioned, the younger parents might have missed the message that these anomalies are still associated with substantial long-term morbidity and a low probability of a normal childhood.[5] Second, older parents with more education may have higher general expectations for their children and greater awareness that chronic medical or neurologic problems, even if they are not life-threatening, will adversely affect quality of life. Third, physicians may communicate differently with older, better educated couples and unintentionally provide them with different information. Finally, younger patients with lower levels of education may be skeptical of medical information. They may tend to take a "wait and see" attitude at times when a definitive choice has to be made, or they may require additional time or attention to fully understand the implications of an ultrasonographic anomaly.

Our study had several limitations. We could not use data on 891 fetuses with anomalies of unknown severity, including many with congenital heart disease. Although it would have been helpful to include these fetuses in the analysis, surgical therapy for congenital heart disease changed so rapidly over the study period that we would not have been able to accurately grade these anomalies even if their nature had been better defined. Therapy and outcomes for the other anomalies that we tracked did not appreciably change over the study period.

We also do not have information about religion in our database. At the time when this intake questionnaire was created, we believed that this question was too intrusive and intentionally omitted it. Although we now would like to have this information, it is not clear whether or how religion would affect our results, since abortion rates for some severe fetal anomalies are high even in several predominently Catholic nations in Europe.[4] Although we cannot be certain that our results are generalizable to other parts of the country or to other developed nations, our referral base includes data from diverse social, geographic (urban, suburban, and rural), and economic strata in our region and may reasonably reflect the U.S. population at the close of the 20th century.

We doubt that differences in access to abortion influenced our observations. The observation that almost all women carrying a fetus with a grade 4 anomaly chose to abort supports the idea that women had fairly equal access to pregnancy termination.

It is important to emphasize that continuation of a pregnancy with a serious anomaly does not indicate a flawed choice by parents. We are, however, concerned that youth and concomitantly, lack of education, were indicators of pregnancy outcomes in this group of patients. As far as lack of information contributes to this observation, alternate methods of providing patient education must be considered so that the decisions made about therapeutic abortion are truly informed. Physicians and genetic counselors need not be judgmental or directive in their recommendations; rather, they must provide accurate, comprehensible information about the long-term consequences of severe anomalies that are now readily diagnosed prenatally.

In conclusion, the severity of individual fetal anomalies was correlated with the frequency of therapeutic abortion in our database. The likelihood of therapeutic abortion differs depending on the presence of CNS anomalies or anomalies of other organ systems. Finally, sociodemographic factors that influence the probability of therapeutic abortion can be partially isolated. Our observations have wider implications related to the demographic characteristics of birth defects in childhood. Although the diagnostic yield of routine screening sonography is low in uncomplicated pregnancies, epidemiologic information from several developed nations indicates that routine sonography has played a role in reducing the frequency of various birth defects, including those affecting the CNS.[3,6–14] If low sociodemographic status reduces access to prenatal sonography and young maternal age diminishes the likelihood of therapeutic abortion after identification of serious fetal anomalies, birth defects will disproportionately affect the children of parents who may be least capable of caring for their special needs.[3]

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