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Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers

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KEY WORDS
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Objective: This study was undertaken to ask mothers who had children with Down syndrome after receiving a prenatal diagnosis: How was the process and what, if anything, could be improved?

Study design: An 11-page survey was mailed to 2945 persons on the membership lists of 5 Down syndrome parent organizations. The survey gathered both quantitative and qualitative data from yes/no questions, open-ended questions, and a series of statements asking the mothers to rate their level of agreement on a 1-to-7 Likert scale. Qualitative data were analyzed using the Constant Comparative Method of Qualitative Analysis, and quantitative data were summarized using linear regressions, mixed stepwise multiple regressions, and grouped means, 1-way analysis of variance analyses.

Results: Of 1126 surveys received, 141 (12.5%) were from mothers who had received a prenatal diagnosis. Though satisfied with the care that they had received, the majority of respondents expressed frustration with the process. The most common suggestions were that the diagnosis be conveyed in person, that up-to-date printed materials on Down syndrome (DS) be provided, and that mothers be referred to local DS support groups.

Conclusion: Receiving a prenatal diagnosis of DS need not be a negative experience. By implementing suggestions proposed herein by the mothers, health care providers can even make the situation a positive one.

The risk of Down syndrome (DS) can now be assessed and a diagnosis confirmed in fetuses in the first trimester of pregnancy.[1] Delivering and receiving a prenatal diagnosis of DS, however, is not an easy experience for either the physician or the mother. Obstetricians often have little direct contact during their training with children who have developmental disabilities.[2] Physicians often distance themselves from their own personal beliefs in a commitment to provide balanced information for the new mother. A survey of 499 primary care physicians revealed that 63% reported that they "tried to be as unbiased as possible when delivering a prenatal diagnosis."[3] Thirteen percent reported that they "emphasize" the

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negative aspects of DS so that parents would favor a termination, 10% actively "urge" parents to terminate, and 10% indicated that they "emphasize" the positive aspects of DS so that parents favor continuation, and 4% actively "urge" parents to continue the pregnancy.

A study of 10 women who chose to continue the pregnancy after a prenatal diagnosis of DS reported that they "were not supported in arriving at their own fully informed decision because the providers were overtly or covertly advocating from their own point of view."[4] The study concluded that "negative terminology or accentuation of difficulties was found to be quite unhelpful and resulted in long-term resentment." The purpose of this current study is to reexamine this issue in a larger cohort with a more robust survey instrument. We asked mothers who had children with prenatally detected DS: How did your health care provider convey the information and what, if anything, could have been better?

Material and methods

Study members

This study was nested in larger cross-cultural epidemiologic research on prenatal and postnatal support for mothers who have children with DS in Spain and the United States.[5,6] Surveys were distributed exclusively to mothers of children with DS—other family members were not polled—to standardize the perspectives of our respondents and capture the specific sentiments of the mother. A national database of families who have children with DS does not exist. A survey of parents of children with DS was thus performed through organized parent support groups. Surveys were distributed to mothers through 5 DS parent support groups, chosen on the basis of the size and geographic distribution of their membership. Survey packets were sent to members of the Mile High Down Syndrome Association (Colorado), Triangle Down Syndrome Network (North Carolina), Massachusetts Down Syndrome Congress, Down Syndrome Association of Los Angeles (California), and the Down Syndrome Society of Rhode Island. Approximately 8 weeks after the first mailing, research packets were again sent to the support groups and reforwarded to all nonresponders.

Questionnaires

All materials were approved by the Committee on Human Studies at Harvard Medical School, and the confidentiality of participants was strictly maintained. The survey used for this current study is available as an Appendix,11 pages in length, on the online *Journal*. The survey was developed from published studies[4] and anecdotal data in the popular literature.[7-11] Before distribution, the survey was reviewed by a panel of experts in the disability field and was first distributed to 6125 mothers in Spain[5] to validate the questionnaire and sharpen the wording.

The questionnaire gathered both quantitative and qualitative data from yes/no questions, open-ended questions, and a series of statements asking mothers to rate their level of agreement on a 1-to-7 Likert scale with 7 being "strongly agree," 4 being "neutral," and 1 being "strongly disagree." Also gathered was information on the sex and age of the child with DS. As optional measures, mothers were asked to provide their own background characteristics, including ethnicity, religious affiliation, educational level, household income, and number of pregnancies.

Data analyses

As the survey collected both quantitative and qualitative data, a mixed methodology was used to analyze the data. The quantitative data were analyzed with SAS software (SAS Institute, Cary, NC), and the qualitative data were coded and abstracted with the use of the Constant Comparative Method of Qualitative Analysis.[12]

Means and SD were calculated for each survey item on the Likert Scale. A 1-way analysis of variance (ANOVA) was used to assess for potential differences among mothers: (1) those who had received a triple screen and amniocentesis; (2) those who had received an ultrasound and amniocentesis; (3) those who had received a triple screen, ultrasound, and amniocentesis; and (4) those who had only received an amniocentesis. Responses over time were addressed by a linear regression generated for each Likert statement, using the child's age as the independent variable. For instances where the mother did not complete 1 or both of these measures, the mother's calculated age at the time her child was born was subtracted from her current age. The standardized ßs and R^2 values from the regressions are reported. To determine the significance of the predicted models, an ANOVA analysis was generated. Reported here are the *df*, F, and *P* values for those Likert statements achieving significance at the .05 level.

Maternal reactions to the prenatal diagnosis according to the physician or other health care provider's behaviors, the printed materials, or any of the mothers' background characteristics were assessed by mixed stepwise multiple regressions generated for each of the maternal reactions (frightened, anxious, suicidal, optimistic). The independent variables included all of the other Likert scale responses on provider behavior and printed materials. Background characteristics entered into the regression included income, educational level, mother's age at birth, her child's age, and parity. Variables were entered at the probability of .05, and the standardized ßs and R^2 values from the regressions are reported here. ANOVAS were also run, and the *df*, F, and *P* values for those Likert

Table I Characteristics of mothers responding to the survey

Background variables	%
Race (n = 139)	
White	79.1
Hispanic or Latino	10.1
African American or black	5.8
Asian	2.9
American Indian or Alaska Native	1.4
Other	0.7
Religion (n = 135)*	
Catholic	42.2
Protestant	34.9
Mormon	4.4
Jewish	3.0
None	2.2
Other	12.7
Educational level (n = 139)	
High school degree or lower	28.8
College graduate	47.5
Postgraduate education	23.7

* Percentages do not total 100% due to rounding.

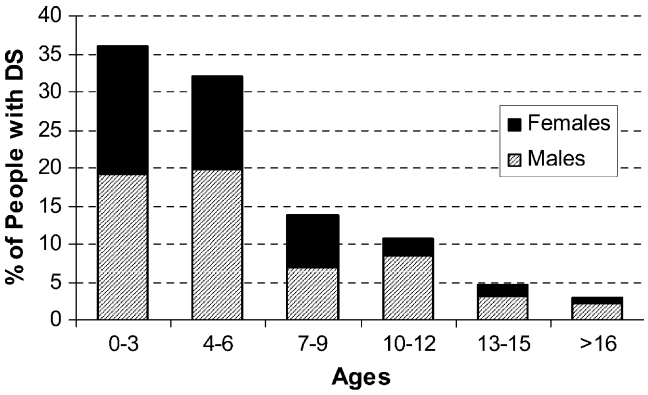

Figure Distribution of ages of people with DS whose mothers responded to the survey.

statements that achieved significant at the .05 variables are reported.

Five variables were categorical: maternal ethnicity, religious affiliation, state of residence during pregnancy, whether she received the results of amniocentesis in person, and whether she had received those results with her partner present. For these variables, a grouped means, 1-way ANOVA analysis was performed.

Results

A total of 2945 survey requests were sent, and 1250 responses (42.4%) were received, including 289 from Massachusetts (state response rate: 36.1%), 176 from Colorado (29.3%), 72 from Rhode Island (29.4%), 86 from North Carolina (43.0%), 352 from California (32.0%), and 166 from other states. Of these surveys, 43 were completed by fathers and were excluded. An additional 81 declined to complete the questionnaire; most of these responses were returned from people or groups on the mailing list, but not mothers of an infant with DS, eg, teachers, professional groups, and support organizations. Of the remaining 1126 surveys, 141 (12.5%) were submitted by mothers who had received a prenatal diagnosis of DS from an amniocentesis result (38 from Massachusetts [state response rate: 13.1%], 30 from Colorado [17.0%], 13 from Rhode Island [18.1%], 9 from North Carolina [10.5%], 40 from California [11.4%], and 11 from other).

The average age of the mothers at the time of the prenatal diagnosis was 35.4 (SD = 5.8, n = 139), with 75 (53.2%) being older than 35 years. Some of the mothers omitted responses to some of the survey items, so the number of respondents varied per question. The majority of respondents were white, Catholic or Protestant, and college educated (Table I). Approximately 60% of the mothers had boys with DS, and the average reported household income was $92,553 (SD = $62,348, n = 115). Parent support groups did not collect demographic data on their members for comparison. As determined by the age of the children, mothers were able to provide perspective on prenatal care in the United States from 1981 to 2003 (Figure).

Of the mothers who had an amniocentesis, 85 (60.3%) first had a multiple serum marker test at a mean gestational age of 16.3 weeks (SD = 3.4, n = 72). The majority of the respondents were scared and anxious after receiving the results of the triple screen (Table II) and indicated that their obstetricians had neither explained DS before nor after the test. About half of the mothers already knew something about DS before the triple screen, but nearly all of them thought their obstetricians had failed to provide enough up-to-date printed material on DS. These variables remained consistent over time.

The respondents had amniocentesis performed at a mean gestational age of 19.4 weeks (SD = 5.5, n = 138), 31 (22%) because of questionable ultrasonographic findings, 51 (36%) because of multiple marker test results, 34 (24%) because of ultrasonographic and multiple marker test findings, and 25 (18%) because of advanced maternal age only. One-way ANOVA analyses did not show any statistical differences among the responses for these 4 groups. In regard to the amniocentesis, 26.8% of them had received the results in person, and 71.0% had learned of the diagnosis without their partners present. The majority reported feeling anxious and scared. About half felt rushed or pressured into making a decision about continuing the pregnancy (Table II). Mixed multiple stepwise regressions revealed that the level of a mother's fear could be predicted by her feeling pressured: *Scared* = 5.75 + 0.13 *Pressured*

Table II Mothers' reflections on their prenatal support

	Mean	(SD)	N
Triple screen			
Before the triple screen procedure, I already had a good idea about what DS was.	4.0	2.3	85
Before receiving test results from my triple screen, my physician explained to me what DS was.	2.3	1.7	85
After receiving test results, my physician explained to me what DS was.	3.7	2.3	83
After receiving the results, I felt encouraged by my physician to terminate my pregnancy.	3.1	2.3	82
After receiving the results, I felt encouraged by my physician to continue my pregnancy.	3.5	1.9	82
After receiving test results, I felt scared.	6.0	1.6	81
After receiving test results, I felt anxious.	5.8	1.8	80
After receiving test results, I experienced suicidal thoughts.	1.5	1.2	81
After receiving test results, I felt positive.	3.1	1.9	81
After receiving test results, I felt my physician gave me enough up-to-date printed material on DS.	2.4	2.0	79
Amniocentesis (mothers' reflections)			
After receiving the results, I felt positive.	3.0	1.8	141
After receiving the results, I experienced suicidal thoughts.	1.5	1.4	140
After receiving the results, I felt anxious.	6.1	1.5	140
After receiving the results, I felt scared.	6.3	1.3	141
After receiving the results, I felt rushed or pressured into making a decision about the continuation of my pregnancy.	4.0	2.6	137
I am glad that my physician gave his/her opinion about what he/she would do in my situation.	2.9	1.7	111
Before the amniocentesis, I already had a good idea about what DS was.	4.2	2.2	141
I wanted to have an amniocentesis done.	5.2	2.0	141
Amniocentesis (physician behaviors)			
I felt encouraged by my physician to have an amniocentesis.	6.0	1.3	139
I felt pressured by my physician to have an amniocentesis.	3.6	2.1	140
My physician explained the results to me in a manner that I could understand.	5.7	1.6	140
After receiving test results, my physician encouraged me to terminate my pregnancy.	3.0	2.2	139
After receiving test results, my physician encouraged me to continue my pregnancy.	3.6	2.0	140
After receiving the test results, my physician told me about the positive aspects of DS.	3.3	2.1	141
After receiving the test results, my physician emphasized the positive aspects of DS.	3.2	1.9	138
After receiving the test results, my physician told me about the negative aspects of DS.	3.8	2.0	140
After receiving the test results, my physician emphasized the negative aspects of DS.	3.3	2.1	137
After receiving test results, my physician gave me his/her opinion about what he/she would do in my situation.	2.6	2.0	136
My physician pitied me.	3.0	2.1	137
After receiving test results, my physician provided me with enough phone numbers of parents who have a child with DS.	2.4	2.0	139
After receiving test results, my physician gave me enough up-to-date printed material on DS.	2.7	2.1	139
Printed materials			
The printed materials that I received provided an equal mix about the positive and negative aspects of DS.	4.4	2.0	98
The printed materials that I received emphasized the negative aspects of DS.	3.2	1.9	97
The printed materials that I received emphasized the positive aspects of DS.	4.6	1.9	98
The printed materials were helpful in understanding DS.	5.5	1.7	97
The printed materials encouraged me to continue my pregnancy.	4.1	2.0	94
The printed materials encouraged me to terminate my pregnancy.	2.5	1.7	92
I liked the printed materials that I received.	4.7	1.9	95
The printed materials were easy to read and understand.	5.5	1.6	95
Prenatal testing overall			
My physician was supportive of my decision to continue my pregnancy.	5.0	2.0	140
My physician tried to change my decision about continuing my pregnancy.	2.5	2.0	138
The prenatal medical support that I received following my decision to continue my pregnancy was exceptionally good.	5.3	2.0	139
After I decided to continue my pregnancy, it was a struggle to find adequate prenatal care.	1.7	1.5	139
After I decided to continue my pregnancy, my physician began giving me parenting tips on how best to raise a child with DS.	2.2	1.7	137

Mothers were asked to rate their level of agreement with the statements on a 1-to-7 Likert scale with 1 being "strongly disagree," 4 being "neutral," and 7 being "strongly agree."

Table III Top factors that influenced mothers to continue their pregnancies

	Mean	(SD)	N
My "inner voice"	6.2	(1.6)	134
My religion	5.8	(1.9)	135
My husband's/partner's opinion	5.6	(2.1)	135
Material that I found on my own	4.3	(2.3)	134
Talking to another parent who had a child with DS	4.3	(2.4)	135
Positive images and stories about persons with DS in printed materials	4.1	(2.2)	136

Mothers were asked to rate their level of agreement with the statements on a 1-to-7 Likert scale with 1 being "strongly disagree," 4 being "neutral," and 7 being "strongly agree."

(R^2 = 0.06, F[0.05; 1, 135] = 10.0, $P < .01$). With all other variables held constant, mothers who felt "strongly pressured or rushed into making a decision" would be expected to rate their fear level at 6.66 on a 1-to-7 Likert scale.

For the few mothers who felt positive about the experience, satisfaction was associated with providers who explained the results in an understandable manner that included discussion of the positive aspects of DS and with a maternal educational level: *Positive* = 2.51 + 0.19 *Understand DS* + 0.29 *Positive aspects* – 0.36 *Educational* degree (R^2 = 0.15, F[0.05; 3, 134] = 8.80, $P < .001$). When all other variables are held constant, a college-educated mother who strongly agreed that her obstetrician explained DS and talked about the positive aspects would be expected to have a satisfaction level of 4.43, slightly better than neutral. About half of the mothers had a "good idea" about DS before the amniocentesis, and nearly all mothers strongly disagreed that physicians should give their personal opinions about what they would do in a similar situation (Table II). These variables remained consistent over time.

The majority of mothers felt encouraged, although not pressured, by their physician to have an amniocentesis (Table II). Obstetricians did seem to explain the results in a manner that could be understood; however, they did not appear to explain DS adequately, either by mentioning the positive or negative aspects of the syndrome. Mothers who had children 10 to 20 years ago were more likely to report that their physicians had talked about the negative aspects: *Negative aspects* = 3.38 + 0.08 *Child's age* (R^2 = 0.02, F[0.05; 1, 128] = 4.02, $P < .05$), indicating that mothers who received a prenatal diagnosis in 1983 would be expected to report a level of 4.98, agreeing that their obstetricians talked about the negative sides to DS. According to the mothers, obstetricians did not supply enough up-to-date printed materials or phone numbers of other parents who have children with DS (Table II). These variables remained consistent over time.

Respondents were asked to use the 1-to-7 Likert scale to assess 19 factors that might have played a role in their decision to continue their pregnancy (such as, religion, partner's opinion, meeting a person with DS, reading about someone with DS). Six of these items averaged over the neutral mark of "4" (Table III). A mother's conscience was the primary influence for continuation, with a mother's religion and her partner's opinion ranking second and third, respectively.

The mothers who received printed materials from their obstetrician reported that the literature was easy to read and helpful in understanding DS (Table II). A majority of the respondents thought the materials emphasized the positive aspects of DS, and about half thought the materials had encouraged them to continue their pregnancy. Overall, most mothers "liked the printed materials" that they had received. These variables remained consistent over time. Mothers agreed that their obstetricians had been supportive of their decision to continue their pregnancy (Table II). This, however, was not always the case: *Supportive physician* = 5.60 – 0.11 *Child's age* (R^2 = 0.04, F[0.05; 1, 128] = 6.90, $P < .01$). From this model, mothers receiving a prenatal diagnosis of DS in 2003 would be predicted to report a satisfaction level of 5.6, whereas those in 1983 would be expected to have a dissatisfaction level of 3.4. Very few thought that their physician had tried to change their decision about continuing the pregnancy, but this, too, has evolved: *Change decision* = 1.93 + 0.11 *Child's age* (R^2 = 0.05, F[0.05; 1, 126] = 8.11, $P < .01$). This means that the mothers receiving a prenatal diagnosis in 1983 would be predicted to indicate an agreement level of 4.13, suggesting that their obstetricians did try to influence decisions, at least partially. Few reported that it was difficult to find adequate prenatal support, and most agreed that their prenatal support was good. Most respondents reported that their birthing experience was positive (mean = 5.2, SD = 1.9, n = 137). In contrast, by previous report, mothers who learned about the diagnosis of DS after their child was born labeled their experience as negative (mean = 3.4, SD = 3.1, n = 929).[6]

Respondents recommended that physicians do the following to improve the process:

1. Results of the triple screen should be clearly explained as a risk assessment, not a "positive" or "negative" result. Many mothers understood the triple screen to be an all-or-nothing diagnostic test, even after their obstetrician had given them the results. The weak sensitivity and positive predictive value of the test should be explained in terms that each mother can understand. In addition, mothers requested that DS be first explained after the screening test rather than waiting for the results of an amniocentesis or chorionic villus sampling (CVS) to begin a discussion.

2. Results of the amniocentesis or CVS should, whenever possible, be delivered in person, with both parents present. Mothers who had learned of the diagnosis by telephone reported intense resentment for their obstetricians and/or genetic counselors. Ideally, physicians should ask that all persons receiving definitive prenatal testing return in person to hear the results. If a personal visit is not possible, physicians should offer each couple the option of returning or receiving the results over the telephone. If the latter, physicians should note that women who have children with DS wish they had learned the results in person, with their partner present. If the diagnosis is delivered on the telephone, the physician should arrange for a follow-up in person visit as soon as possible.
3. Sensitive language should be used when delivering a diagnosis of DS. Mothers requested that physicians not begin by saying, "I'm sorry," or "Unfortunately, I have some bad news to share." In addition, several mothers, including some who had children as recent as 1997, reported their obstetricians had used the word "mongoloid" in describing DS, a term that is reprehensible in today's society and should not be used by today's physicians.
4. If obstetricians rely on genetic counselors or other specialists to explain DS, sensitive, accurate, and consistent messages must be conveyed. In 1999, 1 mother reported that her genetic counselors "told my husband and I that our child may not be able to complete school, will have limited cognitive abilities, and may remain a child, emotionally and mentally for life. Her information didn't include any possibilities of the lowest to highest range of functioning at all." Another mother wrote, "[the genetic counselor] showed a really pitiful video first of people with DS who were very low tone and lethargic-looking and then proceeded to tell us (in 1999) that our child would never be able to read, write, or count change."
5. Discuss all reasons for prenatal diagnosis including reassurance, advance awareness before delivery of the diagnosis of DS, adoption, as well as pregnancy termination. Many of the mothers who responded to this survey never planned to terminate the pregnancy and were upset when their physicians provided detailed descriptions of pregnancy terminations without knowing whether they would like those options discussed.
6. Up-to-date information on DS should be available. Respondents requested clinical information on the health concerns for infants with DS and "success stories" that demonstrated the potential and possibilities for children with DS. The Healthcare Guidelines for infants and toddlers with DS can be downloaded from the National Down Syndrome Society's Web site (http://www.ndss.org). For success stories, mothers recommended *Common Threads: Celebrating Life with Down Syndrome*.[7] Many mothers also appreciated receiving the book *Babies with Down Syndrome: A New Parent's Guide*[13] and *A Parent's Guide to Down Syndrome: Toward a Brighter Future*[14]; others found the message in *Choosing Naia: A Family's Journey*[11] relevant. A list of current and relevant resources can be found through the National Down Syndrome Congress's Web site at http://www.ndsccenter.org/resources/print.asp.
7. Contact with local DS support groups should be offered, if desired. Respondents appreciated providers who gave them the contact information for local DS support groups. One mother reported that after talking to other parents, "I felt 100% better and positive about having my daughter." Another mentioned, "I regret that I didn't get involved with any support groups in the beginning. I thought everyone would sit around and cry on each other's shoulders, and I wasn't ready for a pity party. I only wish that physicians, nurses, and hospitals were better informed about the wonderful opportunities that are out there to help parents." The National Down Syndrome Society maintains a directory of all DS support groups at the Web site, http://www.ndss.org/content.cfm?fuseaction=InfoResSrchFrm.

Comment

Only 12.5% of respondents, all mothers of a child with DS, had received a diagnosis prenatally. It is estimated that 1 of every 800 to 1000 live births is to an infant with DS,[15] suggesting that around 5000 new persons with DS are born each year. This means that approximately 625 newborn infants with DS will have been diagnosed prenatally each year. This intimates that (1) the majority of women who have fetuses with DS still find out about the diagnosis postnatally, or (2) a large number of women who receive prenatal diagnoses of DS choose to terminate their pregnancies, or (3) a combination of both circumstances.

This study indicates that women who choose to continue their pregnancy after a prenatal diagnosis of DS do so primarily because of religious or personal reasons. The majority of these mothers approached the amniocentesis or CVS either confident that they would continue the pregnancy, no matter what the results indicate, or undecided, needing to gather more information if the results indicated the fetus had DS. Rarely, did a mother in this study indicate that she was adamant about terminating, only to have her opinion changed after receiving more information from her obstetrician or other sources. Some of the women, however, did feel

rushed into making a decision about the continuation of their pregnancies. This might have stemmed, in part, from the late timing of their amniocenteses.

Mothers who received prenatal care within the last 5 years seemed especially satisfied with the care that they received. In addition, these mothers were generally happier over the birth of their infant with DS than their counterparts who had received the diagnosis postnatally. This difference might stem from the fact that mothers who received a prenatal diagnosis tended to resolve any grief before their child was born. As no therapeutic intervention yet exists to cure DS or ameliorate some of its manifestations in utero, prenatal screening and diagnosing have almost exclusively existed to allow women the option of terminating their pregnancies. Knowing this, health care providers have historically operated under the assumption that if a woman consents to prenatal screening or diagnosing, she must believe that having a child with DS would be an undesired outcome and wish to terminate her pregnancy if such a diagnosis were made prenatally. The results of this study indicate that this is not true for all women. Consequently, health care providers should appreciate that many women consent to prenatal testing with ambivalence or no intent whatsoever to terminate.

As with all retrospective studies, this research is subject to recall bias. Our respondents answered the survey with approximately 4.4 years of hindsight. Their answers could have been based, in part, on information and resources that they would have preferred to receive now that they have become quite knowledgeable about DS. From the clarity in which mothers described their experiences, this does not seem to be the case, suggesting that receiving a prenatal diagnosis of DS is a true flashbulb memory—accurate, complete, and immune to forgetfulness.[16] A previous longitudinal study has also shown that mothers who have 21-year-old children with DS could describe the births of their children with nearly 82% accuracy from their initial accounts.[17] The current study is also subject to selection bias. Only mothers who were members of a DS support group were sampled. As there is no national database of families who have children with DS, the most comprehensive way to sample these mothers is through the support groups. However, our study is limited by the socioeconomic and ethnic composition of these groups, primarily middle- to upper-class college-educated white mothers. The current study does not adequately capture the sentiments of mothers from other ethnic or socioeconomic groups. Also, this study purposefully focused on mothers who chose to continue their pregnancies. Future research should investigate the sentiments of those mothers who chose to terminate fetuses with DS.

Despite the limitations of this report, the message from the 141 mothers surveyed is a constructive one. Delivering a prenatal diagnosis still remains a challenge for even the most experienced physicians, but the process should no longer be viewed as a gloomy affair. In fact, with the appropriate sensitivity and explanation, obstetricians can make the births of children with DS celebratory experiences for mothers who choose to continue their pregnancies after receiving prenatal diagnoses.

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Supplementary data

Supplementary data associated with this article can be found, in the online version, at www.ajog.org.