Mothers of Children With Down Syndrome Reflect on Their Postnatal Support

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ABSTRACT. *Objective.* **Since 1964, researchers have been examining the ways in which physicians deliver a postnatal diagnosis of Down syndrome (DS). Almost all of the studies, however, have been limited to reflections or very small sample sizes. The objective of this study was to document, in the most robust comprehensive way, the reflections of mothers in the United States who received diagnoses of DS for their children.**

Methods. **An 11-page survey was mailed to 2945 persons on the membership lists of 5 DS parent organizations. The survey gathered both quantitative and qualitative data with yes/no questions, open-ended questions, and a series of statements asking the mothers to rate their level of agreement on a Likert scale of 1 to 7.**

Results. **Of the 1250 responses (42.4%), 985 were from mothers who received postnatal diagnoses of DS for their children. The majority of these mothers reported being frightened or anxious after learning the diagnosis, and very few rated the overall experience as a positive one. Mothers reported that their physicians talked little about the positive aspects of DS and rarely provided enough up-to-date printed materials or telephone numbers of other parents with children with DS. Improvement has been made with time, albeit slowly.**

Conclusion. **Mothers have called on physicians to improve the way in which postnatal diagnoses are delivered. Specific recommendations are offered.** ***Pediatrics* 2005;115:64–77;** ***Down syndrome, postnatal, diagnosis, medical support.***

ABBREVIATIONS. DS, Down syndrome; CVS, chorionic villus sampling; OB, obstetrician.

The majority of families who have children with Down syndrome (DS) do not learn of their children's diagnosis until after the children are born. Although prenatal testing now allows physicians to make a definite diagnosis as early as the eighth week of pregnancy, such measures are typically not offered to women until they are >35 years of age.[1] For younger mothers, the diagnosis of DS is almost always learned after the child is born, unless the woman specifically requests prenatal testing. For mothers in the advanced-maternal age category, postnatal diagnoses are made in circumstances in which the mother refuses definitive prenatal testing for religious or personal reasons.

Some women in the latter category might begin with prenatal screening but then choose not to continue with definitive procedures such as amniocentesis or chorionic villus sampling (CVS). Several reasons exist for their not doing so. First, screening tests supply the mother only with an odds ratio for her having a child with DS. Mothers might incorrectly understand the results as an all-or-nothing statistic and choose to discontinue additional prenatal testing on the basis of this interpretation. Second, with a 5% false-positive rate, only 69% of fetuses with DS are correctly detected with triple screening, 75% with quadruple screening, and 79% with the recent first-trimester screening method involving 2 maternal serum protein markers and ultrasonographic findings.[2–4] A minimum of nearly one fifth of mothers who have fetuses with DS are given odds ratios so low that they may not consider it reasonable to proceed with a definitive test such as amniocentesis or CVS, which each carry an approximately 0.25% to 0.30% chance of causing a spontaneous abortion.[5]

A total of ~1 of every 800 to 1000 live births involves an infant with DS, meaning that ~5000 parents receive the diagnosis for their child each year. A survey of 1126 mothers who have children with DS suggested that as many as 87.5% still receive the news postnatally.[6]

When a postnatal diagnosis is delivered to these thousands of new mothers each year, the announcement is, at minimum, surprising. In the past decade, new mothers have been expressing their reactions in a variety of popular literature works. "When we were told our child had DS, we immediately began to worry about his future, about his relationships with others, about his occupation as an adult, even about his potential for a prom date," recounts Cynthia Kidder.[7] "We were naive and uneducated and filled with fear." Marian Burke, mother of television celebrity Chris Burke, recalls bluntly, "It was the worst moment of my entire life."[8] Vicki Noble wrote that, when she was told by her physician that her son had DS, "I felt myself go numb, and I heard my voice from a distance asking, 'What does this mean?'"[9]

The pediatrician or neonatologist is most often the person to answer this question. Infants with DS are easily recognized after birth on the basis of physical characteristics (eg, short ears, depressed upper midface, palmar crease, and hypotonia), with confirmation with genetic karyotyping.[10] Conveying this

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news to parents, however, presents a formidable challenge to most physicians. Many clinicians admit that they have little, if any, training on how to deliver such information in a sensitive manner. "In general, what I was taught in medical school and in my training is that disability—no matter what its form—is a bad thing and to be avoided at all costs. Lectures or seminars on DS or other genetic syndromes were geared toward the description of the abnormalities . . . that children with congenital diseases may find their lives to be rich and valuable was hardly recognized, much less stressed," wrote perinatologist Steven Ralston.[11]

Since 1964, researchers have been examining the ways in which physicians deliver the postnatal diagnosis of DS.[12–33] Almost all of those studies, however, were limited to mere reflections or very small sample sizes. In only 3 studies to date were the assessments based on data from >100 mothers of children with DS. In 1976, Pueschel and Murphy[29] analyzed the responses of 414 mothers of children with DS to an 8-question survey; ~40% of respondents thought that they had been given inadequate, abrupt, or unsympathetic information by their physician when their child was diagnosed with DS. These mothers recommended that physicians use tactful language and that both parents, when available, be present to learn of the diagnosis. The mothers also stressed the importance of being informed as soon as a diagnosis has been made.

In 1983, Murdoch[28] analyzed the responses of 123 mothers of children with DS in Scotland to a 9-question survey; ~36% of respondents did not think that their physician did a good job of conveying the diagnosis. Most were told without their husband being present, and slightly more than one third of mothers reported that they were not given an opportunity to ask more about their child or express their feelings around the time of the diagnosis. In that survey, mothers were not asked for recommendations on how the process could be improved.

In 2004, Skotko and Canal studied quantitative and qualitative data for 467 mothers of children with DS in Spain who had responded to an 11-page survey.[6] Mothers reported feeling anxious, frightened, guilty, and angry after learning the diagnosis for their child. For the few mothers who felt optimistic about the birth, their responses were significantly correlated with the fact that the information from their doctors and the printed materials emphasized the positive aspects of DS. The majority of mothers strongly disagreed, however, with the idea that their physicians had supplied enough up-to-date information on DS or an adequate number of telephone numbers for parents who already had a child with the condition. The survey collected responses from 1972 to the present, but the longitudinal analysis yielded sobering findings; very little seemed to have changed, inasmuch as mothers' frustrations and dissatisfaction did not differ among the various age cohorts. For the process to be improved, the mothers recommended the following changes. (1) Health care professionals should clearly explain the results of prenatal testing. (2) Information, suspicions, and thoughts should be conveyed to the mothers immediately. (3) Physicians should deliver the diagnosis to both the mother and father, in a private setting. (4) When delivering the diagnosis, health care professionals should use sensitive and compassionate language. (5) Health care professionals should provide additional factual information immediately. (6) Health care professionals should provide parents with an up-to-date reference list of printed materials. (7) If needed and/or requested, a counselor should be available. (8) Health care professionals should not question a mother's decision to have her child. (9) Hospitals and birthing clinics should establish partnerships with local parent support groups.

The purpose of this study was to build on the work in Spain and to document, in the most comprehensive way, the reflections of mothers in the United States who received diagnoses of DS for their children. It could be argued that the last substantial study in the United States on this topic was in 1976,[29] and even those results were based on only 8 survey questions. Here, the results from 985 mothers in the United States with children with DS were analyzed; the mothers were asked to reflect on the experience of having a child with DS through an 11-page survey instrument. The central research question was as follows: how could medical support be improved for mothers who receive diagnoses of DS for their children? To answer this, additional questions were asked, as follows. How did your physician deliver the diagnosis? Were the verbal explanation adequate, the setting appropriate, the language sensitive, and the printed materials helpful? What was it like to receive the diagnosis?

Because data were also collected from mothers who had children with DS for the past 40 years, for the first time the following question could be answered: have mothers' perceptions differed over the years? If such perceptions offer a reflection on the evolution of our medical system, then this study also answers the following question: what, if anything, has improved in our hospitals?

METHODS

Sample

This study was part of larger, cross-cultural, epidemiologic research on prenatal and postnatal support for mothers with children with DS in Spain and the United States. For this study, surveys were distributed exclusively to mothers of children with DS (as opposed to other family members, such as fathers, grandparents, brothers, or sisters), to standardize the perspectives of our respondents and to record the sentiments of the person most intimately involved in the pregnancy.

Because there is no national database of families who have children with DS in the United States, surveys were distributed through 5 DS parent support groups. The groups were chosen because of their large membership sizes and their geographic distribution throughout the United States, ie, the Mile High Down Syndrome Association (Colorado), Triangle Down Syndrome Network (North Carolina), Massachusetts Down Syndrome Congress (Massachusetts), Down Syndrome Association of Los Angeles (California), and Down Syndrome Society of Rhode Island (Rhode Island). In total, surveys were mailed to 2945 persons on the groups' membership lists.

Survey Instrument

The 11-page survey (published as supporting information on the *Pediatrics* Web site) was developed partly on the basis of data published by Helm et al[34] and mothers' anecdotal stories described in popular literature works.[7–9] Before distribution, the survey was reviewed by a panel of experts in the disability field, including a pediatrician, a psychiatrist, a parent, a sister, a social medicine researcher, an international health care professional, and an educational specialist. The survey, translated into Spanish, was also pilot-tested with 6125 mothers in Spain. After review of the responses from that study group, modifications were made to the survey to minimize all sources of confusion in the survey questions.

A cover letter was written to explain the purpose of the project and to emphasize that participation in the project was completely voluntary. All materials were approved by the Committee on Human Studies at Harvard Medical School. Each mother in the sample received a packet that included the survey, the cover letter, and a self-addressed, stamped envelope. Four of the parent support groups chose to add their own cover letters to the packet, offering support for the project and encouraging their members to participate.

The survey gathered both quantitative and qualitative data with yes/no questions, open-ended questions, and a series of statement for which the mothers were asked to rate their level of agreement on a Likert scale of 1 to 7 (with 7 indicating strongly agree, 4 neutral, and 1 strongly disagree). The statements addressed topics such as triple screening, amniocentesis, printed material about DS, the decision to continue a pregnancy, prenatal care, and postnatal care. (Results for the prenatal questions will be reported elsewhere.) Questions about postnatal care included 7 statements about physician behavior when the mothers received their child's diagnosis of DS for the first time, 5 statements about the mothers' reactions after receiving the diagnosis, 5 statements about the printed materials the mothers received from their physicians immediately after the diagnosis, and 1 statement about the mothers' overall experience of having a child with DS. The survey also collected information on the gender and age of the child with DS. As optional measures, the mothers were asked to report their age at the time of the birth of the child with DS, their ethnicity, religious affiliation, highest level of education, total number of pregnancies, and the combined income of their household.

Data Collection

Research packets were mailed directly to the 5 parent support groups, which then distributed the survey materials directly to all of the members on their mailing lists. Whenever possible, the parent support groups tried to screen out companies, organizations, and other nonpersonal entities, so that the study's sample size would be limited to mothers as tightly as possible. The Mile High Down Syndrome Association mailed 600 packets, the Triangle Down Syndrome Network 200, the Massachusetts Down Syndrome Congress 800, the Down Syndrome Association of Los Angeles 1100, and the Down Syndrome Society of Rhode Island 245. Approximately 8 weeks after the first mailing, research packets were again sent to the support groups and were forwarded to all of the nonresponders. A new cover letter was included in the packet, reinviting the mothers to participate in our study.

At all times, confidentiality of the families was maintained. At no time were names and/or addresses received from the parent support groups. Contact information was received only when a parent voluntarily chose to respond to the survey. To protect more completely the confidentiality of the responses, the sheets with the contact information were separated from the rest of the survey and were stored in a locked file cabinet. After the responses were entered into a computer database, it was not possible to distinguish the identity of the respondents.

Data Analyses

Because the survey collected both quantitative and qualitative data, mixed methods were used to analyze the data. Throughout the study, the 2 types of analyses are reported under the same topic headings, with qualitative analyses and quantitative calculations supporting each other.

The first question was as follows: how did the mothers, as a group, respond to the Likert statements? To answer this inquiry, a mean and SD were calculated for each survey item and, where appropriate, grouped-means, one-way analysis of variance was used for subgroup analysis (eg, comparing the means for mothers who had received triple-screening results and those who had not). The next question was as follows: how did each mother's survey response relate to her other responses? For example, did the mothers who were frightened after learning the diagnosis for their child also report that their physicians emphasized the negative aspects of DS? For examination of these relationships, the correlations among all of the mothers' responses to our postnatal survey questions were calculated. The r values are reported, with significance at P values of .05, .01, and .001.

Did the mothers who had their children with DS in 1965 report different experiences than the mothers who had their children in 2003? To determine whether mothers' perceptions differed over time, linear regression analyses were performed with each Likert statement as the dependent variable and the child's age as the independent variable. The child's age was calculated by subtracting the date on which the survey was completed from the child's birth date. In cases in which where the mother did not complete one 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 β and R^2 values from the regressions are reported. To determine the significance of the predicted models, analysis of variance was performed; results reported here are the df, F, and P values for the Likert statements that achieved significance at the .05 level.

Could the mothers' reactions to the birth of their children with DS be predicted on the basis of the physicians' behaviors, the printed materials, or any of the mothers' background characteristics? To answer this question, mixed, stepwise, multivariate, regression analyses were performed for each of the maternal reactions (frightened, anxious, optimistic, overall positive experience, and suicidal). The independent variables included all of the other Likert scale responses regarding physician behavior and printed materials. The background characteristics entered into the regression analyses included income, educational level, mother's age at the time of the birth, child's age, and number of pregnancies for the mother. Variables were entered at the probability level of .05, and the standardized β and R^2 values from the regression analyses are reported here. To determine the significance of our predicted models, analysis of variance was performed; the df, F, and P values for the Likert statements that achieved significance at the .05 level are reported.

Three of our maternal background characteristics were categorical variables, namely, ethnicity, religious affiliation, and the state in which the mother received medical care during her pregnancy. To determine whether these variables could predict any of the Likert scale statement responses, grouped-means, one-way analysis of variance was performed. The R^2, df, F, and P values are reported. The means and SEs for the 5 parent support groups and the top 5 religious affiliations (Catholic, Christian unspecified, Protestant unspecified, Jewish, and none) are also reported.

After the quantitative data were analyzed, the qualitative data were studied to add details regarding the mothers' experiences. Responses were coded and themes were developed with the Constant Comparative Method of Qualitative Analysis first described by Glaser and Strauss.[35] For this analysis, the mothers' short-answer responses were coded on the basis of categories indicated by the quantitative data. Then the categories and abstracted themes were integrated from the mothers' responses. Finally, the themes were delimited and clarified to be concise, specific, and nonredundant. The 4 broad themes that emerged were prenatal screening, delivering the diagnosis, receiving the diagnosis, and support from other parents. The theme of delivering the diagnosis had many subcategories, ie, explaining DS, the timing of the news, the communicator, the setting, sensitive language, and printed materials.

RESULTS

Respondents

In total, 1250 responses (42.4%) were received, which represented 289 responses from Massachusetts (36.1%), 176 from Colorado (29.3%), 72 from Rhode Island (29.4%), 86 from North Carolina (43.0%), 352 from California (32.0%), 166 from other

states, and 109 who did not specify. Of these 1250 surveys, 43 were completed by fathers and were therefore excluded from our analyses. Another 81 surveys were returned with an indication that the respondent did not want to or could not complete the questionnaire. The majority of respondents in this category were grandparents, educators, physicians, brothers, sisters, or widows whose names were not screened from the initial survey distribution by the support groups.

Of the remaining 1126 surveys, 141 were completed by mothers who had received a prenatal diagnosis of DS on the basis of amniocentesis results. Because this study focused exclusively on maternal perceptions of postnatal diagnoses, these respondents were excluded from the current analyses. (The results for this cohort will be reported separately.) Of the remaining 985 respondents, 103 underwent triple screening with no confirmatory CVS or amniocentesis testing. The 882 other respondents had exclusively postnatal diagnoses, with no prenatal screening of any sort.

The average age of the respondents ($N = 930$) was 43.7 years (SD: 12.2 years); some of the mothers did not provide responses to some of the survey items, and the numbers of respondents thus varied among the questions. The majority of mothers were white and Catholic and had graduated from a college or university (Table 1). Approximately 58% of the mothers had sons with DS, and 42% had daughters. The average reported household income was $99 260 (SD: $81 675; $N = 732$).

TABLE 1. Characteristics of Mothers Responding to the Survey ($N = 985$).

Background Variables	%
Race ($N = 961$)	
White	84.8
Hispanic or Latino	8.1
Asian	3.5
Black	2.2
American Indian or Alaska Native	0.1
Other	1.2
Religion ($N = 911$)	
Catholic	42.9
Christian (unspecified)	16.7
Protestant (unspecified)	6.9
None	5.0
Jewish	4.7
Methodist	3.7
Mormon	3.6
Baptist	3.5
Lutheran	2.6
Episcopalian	2.5
Unitarian	1.5
Presbyterian	1.5
Congregational	0.7
Buddhist	0.4
Other	3.4
Educational level ($N = 958$)	
Basic education not completed	0.3
Basic education	0.9
Graduated from high school	29.2
Graduated from university	48.5
Received masters degree	17.5
Received doctoral degree	3.4
Gender of child with DS ($N = 961$)	
Male	57.8
Female	42.2

When her child with DS was born, the average mother was 32.3 years of age (SD: 5.6; $N = 963$); ~29.0% of mothers were >35 years of age. As determined by the ages of their children with DS, the mothers were able to provide insights on postnatal care in the United States from 1964 to 2003, although the majority of respondents had children who had been diagnosed in the past 25 years (Fig 1).

Prenatal Screening

For the 103 mothers who had received triple-screening results but did not undergo amniocentesis or CVS testing, a natural research question followed. Was the experience of receiving a postnatal diagnosis different for those mothers, compared with the 882 mothers who did not undergo any prenatal testing? To answer this question, the means of the 2 groups were compared. Statistically significant differences were noted for several responses (Table 2). Mothers who underwent triple screening admitted knowing more about DS when their child was born than did mothers with no such prenatal testing. In addition, mothers who underwent triple screening felt more positive and were less anxious or frightened when their child was born. They also felt that their physician pitied them less and provided more printed materials that emphasized the positive aspects of DS. Mothers who underwent triple screening reported less-negative experiences when the child with DS was born than did their counterparts who underwent no such prenatal testing.

Most of the mothers who underwent triple screening, however, did not have the idea that they were at increased risk of having a child with DS. "The results came back fine," wrote one mother, "My obstetrician (OB) said 'Well, that is one less thing you have to worry about.' " Another mother reported, "My OB never explained that the α-fetoprotein test could have a false negative. I was unaware of this fact." For those who were given statistics, the meaning of those numbers was often unclear or unappreciated. "I didn't fully understand what it really meant," wrote one mother. "My number was 58. My husband said it would 'never happen that you'd be the 1 in 58.'"

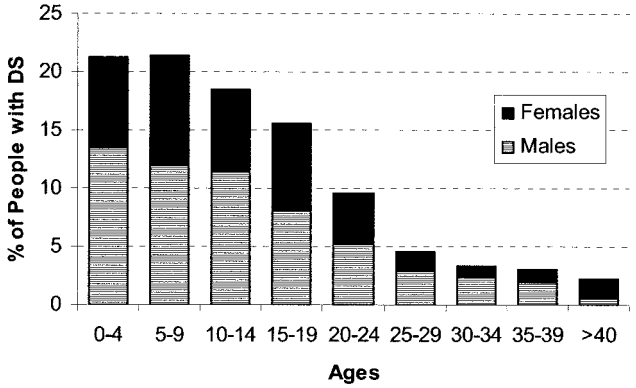

Fig 1. Distribution of ages of people with DS whose mothers responded to the survey. The majority of people with DS were <25 years of age (mean: 10.5 years; SD: 13.9 years; $N = 929$), but the mothers provided perspective on postnatal medical support from 1964 to 2003.

TABLE 2. Comparison of the Perceptions of Mothers Who Underwent Triple Screening and Those Who Did Not

Survey Questions	Mean Score (SD)*		*P* Value
	No Triple Screen (N = 882)	Triple Screen (N = 103)†	
When I learned that my child had DS			
I had no prior knowledge about this genetic condition	4.1 (2.4)	3.5 (2.2)	<.01
I felt positive	2.9 (1.9)	3.5 (2.0)	<.01
I had suicidal thoughts	1.6 (1.6)	1.5 (1.2)	.23
I felt anxious	5.8 (1.7)	5.1 (1.9)	<.001
I felt frightened	5.5 (2.0)	5.1 (2.1)	<.01
Physician behavior			
My physician provided me with enough telephone numbers of parents with a child with DS	2.4 (2.1)	2.3 (2.0)	.95
My physician provided me with enough up-to-date printed material on DS	2.4 (2.0)	2.7 (2.2)	.10
My physician pitied me	3.7 (2.2)	3.0 (2.0)	<.01
My physician emphasized the negative aspects of DS	3.7 (2.1)	3.3 (1.8)	.06
My physician told me about the negative aspects of DS	4.1 (2.1)	3.8 (1.9)	.18
My physician emphasized the positive aspects of DS	3.0 (2.0)	3.4 (2.1)	.09
My physician told me about the positive aspects of DS	3.0 (2.1)	3.4 (2.2)	.07
The printed materials that I received from my physician			
were easy to read and comprehend	4.0 (2.2)	4.0 (2.3)	.71
were helpful for understanding DS	3.7 (2.2)	3.9 (2.3)	.28
emphasized the positive aspects of DS	2.9 (2.0)	3.3 (2.2)	.04
emphasized the negative aspects of DS	3.1 (2.0)	2.9 (1.8)	.49
provided an equal mixture about the positive and negative aspects	3.0 (1.9)	3.1 (2.0)	.53
The birth of my child with DS was a positive experience	3.3 (3.2)	4.1 (2.1)	<.001

* Mothers were asked to rate their level of agreement with the statements on a Likert scale of 1 to 7 (with 1 indicating strongly disagree, 4 neutral, and 7 strongly agree).
† Mothers who underwent triple screening without amniocentesis or CVS testing.

Others thought that the results of triple screening were an all-or-nothing indication of DS, when actually the test merely provides an odds ratio for having a child with DS. "I had had the α-fetoprotein prenatal test, and it indicated nothing," recalled one mother.

Delivering the Diagnosis

Explaining DS

Because differences were noted between the mothers who underwent triple screening and those who did not, the subsequent analyses focused exclusively on the mothers who underwent no form of prenatal testing. The following results indicate the sentiments of mothers who had no reason to suspect that their children might have DS until they were born.

The majority of mothers thought that, when their physicians talked about DS, they neither talked about (mean rating: 3.0; SD: 2.1) nor emphasized (mean rating: 3.0; SD: 2.0) the positive aspects of the condition (Table 2). In contrast, approximately one half of the mothers mentioned that their physicians talked about (mean rating: 4.1; SD: 2.1) or emphasized (mean rating: 3.7; SD: 2.1) the negative aspects of DS.

Some mothers reported that their physician's explanations were insensitive or factually incorrect. A mother who had a child with DS in 2001 recalled that, when she received the diagnosis, "The doctor then asked if we understood that this meant that she would never live on her own or hold a job. This doctor was the 'expert.' " A mother who had a child in 1994 reported, "[The physician] told my husband that [my child] would be mentally retarded and never be able 'to make change for the bus.' " Others argued that the information that they received about DS was not relevant to their infant's health. "While it is important to explain the care needed to verify medical issues up front," wrote one mother, "it seems strange to force statistics about 'adult obesity' and 'teen behavioral problems' at birth."

Physician behaviors seemed to improve with time, albeit slowly. With the child's age as an independent predictor variable, linear regression analyses were performed for each of the Likert statements on physician behavior (Table 3). The more recent the birth, the more apt a mother was to report that her physician had talked about or emphasized the positive aspects of DS. These mothers also were less likely to indicate that their physicians had talked about or emphasized the negative aspects. Although the fit of these models was very weak (R^2 = 0.01-0.03), the standardized β values suggested that in 2003, compared with 1993, mothers reported 1.4-unit greater satisfaction that their physicians had told them about the positive aspects of DS and 1.8-unit greater satisfaction that their doctors had emphasized this information. Similarly, mothers in 2003 were 0.8 units less likely to report that their doctors had told them about the negative aspects of DS and 1.2 units less likely to report that their physicians had emphasized such details (Table 3).

Through the 1980s, many of the mothers were angered by their physicians' suggestion to place the child in an institutional setting. One mother wrote that in 1974 her OB "recommended institutionalizing the infant. In fact, he gave me a shot to dry up the milk and suggested that I never see the infant again (even in the hospital)." According to this mother, the OB said, "Just tell people he died and go on to have more children." Many of these mothers were angered by the incorrect portrayals of DS. "My physi-

TABLE 3. Mothers' Responses With Child's Age as an Independent Variable Predictor

Dependent Variable	β	R^2	*df*	*F*	*P* Value
The birth of my child with DS was a positive experience	−.15	0.02	789	16.7	<.001
Physician behaviors					
My physician told me about the positive aspects of DS	−.14	0.02	809	17.3	<.001
My physician told me about the negative aspects of DS	.08	0.01	806	4.99	<.05
My physician emphasized the positive aspects of DS	−.18	0.03	800	25.4	<.001
My physician emphasized the negative aspects of DS	.12	0.01	801	11.9	<.001
My physician provided me with enough telephone numbers of parents with a child with DS	−.09	0.01	809	5.9	<.05
My physician provided me with enough up-to-date printed materials on DS	−.16	0.02	804	21.5	<.001
My physician pitied me	.12	0.01	772	10.9	<.001
Printed materials					
The printed materials that I received from my physician emphasized the positive aspects of DS	−.21	0.04	705	32.4	<.001
The printed materials that I received from my physician provided an equal mixture about the positive and negative aspects of DS	−.19	0.04	671	26.1	<.001
The printed materials were helpful for understanding DS	−.24	0.05	679	40.3	<.001
The printed materials were easy to read and understand	−.24	0.06	677	42.6	<.001
Mothers' reactions					
When I learned that my child had DS, I was anxious	.12	0.01	804	12.7	<.001
When I learned that my child had DS, I felt positive	−.08	0.01	809	5.4	<.05
When I learned that my child had DS, I had no prior knowledge about this genetic condition	.10	0.01	808	8.3	<.01

cian told me that my child would never walk, talk, or function normally," wrote one mother who had her child in 1977.

In the late 1980s and 1990s, many mothers were offended by the suggestion that they offer their newborn child with DS for adoption. "The doctors said that she was going to give me a lot of problems and that she was going to be spending a lot of time in the hospital . . . she was going to be a vegetable or like a rag doll," reported a mother who had her child in 1985. A mother who had a child in 1999 wrote, "My worst experience was with my son's pediatrician. He kept on suggesting that giving up my son to adoption would be the best solution. For ~8 months I saw the doctor no less than 5 times, and he mentioned that every time."

Definitively positive comments did not seem to be included in mothers' responses until the late 1990s and early 2000s. "Although [the pediatrician] told us the infant had DS, she was very positive," wrote one mother who had a child with DS in 1999. "She said they were generally good infants and very loving."

Minor, but statistically significant, variations according to the location of postnatal care and the religious affiliation of the mother were noted. The mothers who had received postnatal care in Los Angeles, in comparison with mothers in Massachusetts, North Carolina, Rhode Island, or Colorado, reported that their physicians were less likely to talk about or emphasize the positive aspects of DS (Table 4). Furthermore, the mothers in Massachusetts were less likely to suggest that their physicians had emphasized the negative aspects, although their approval ratings were still below the neutral mark (Table 4). Mothers who identified themselves as Jewish ranked their physician's emphasis on the positive aspects of DS the highest among those of any religious affiliation (Table 5), although their opinion was still not agreeable.

The Timing of the News

Nearly all mothers from all different time periods wished that they had been informed earlier, as soon as their physician suspected the diagnosis. When

TABLE 4. Survey Responses With Significant Differences According to State

Variable	R^2	*df*	*F*	*P* Value	Mean Rating (SE)				
					Massachusetts	North Carolina	Rhode Island	Colorado	California
My physician told me about the positive aspects of DS	0.02	833	1.43	.05	3.3 (0.1)	3.2 (0.3)	3.4 (0.3)	3.1 (0.2)	2.7 (0.1)
My physician emphasized the positive aspects of DS	0.02	825	1.54	.02	3.4 (0.1)	3.2 (0.3)	3.5 (0.3)	3.0 (0.2)	2.7 (0.1)
My physician emphasized the negative aspects of DS	0.03	826	1.61	<.01	3.3 (0.1)	4.0 (0.3)	3.8 (0.3)	3.9 (0.2)	3.8 (0.1)
My physician provided me with enough telephone numbers	0.02	833	1.41	.05	2.6 (0.1)	2.8 (0.3)	2.8 (0.3)	2.3 (0.2)	2.0 (0.1)
The printed materials emphasized the positive aspects of DS	0.02	724	1.48	.04	3.1 (0.1)	3.4 (0.3)	3.8 (0.3)	2.9 (0.2)	2.4 (0.1)
The printed materials were helpful for understanding DS	0.03	696	1.6	.02	3.9 (0.2)	4.3 (0.3)	4.7 (0.4)	3.9 (0.2)	3.1 (0.1)

TABLE 5. Survey Responses With Significant Differences According to Religion

Variable	R^2	*df*	*F*	*P* Value	Mean Rating (SE)				
					Catholic	Christian Unspecified	Protestant Unspecified	None	Jewish
My physician emphasized the positive aspects of DS	0.02	782	1.55	<.05	3.2 (0.1)	2.6 (0.2)	2.8 (0.3)	3.1 (0.3)	3.6 (0.3)
When I learned that my child had DS, I was anxious	0.02	788	1.79	<.01	5.8 (0.1)	5.4 (0.1)	6.1 (0.2)	6.2 (0.3)	6.1 (0.3)

there was a delay in delivering the news, mothers seemed to notice. One mother who had a child with DS in 1968 wrote, "My pediatrician initially avoided meeting with me when I suspected that there was something wrong." One who had a child with DS in 1992 wrote, "He avoided me like I had the plague." Many of the mothers thought medical staff members were making excuses while delaying the announcement. "When [my child] was born, I don't think the staff knew what to do," wrote one mother who had her child in 1987. "They whisked the infant away to 'weigh' her because the 'scale broke.' My husband followed them around until they finally told him they thought the infant had a chromosomal disorder." Other mothers complained that their OBs and pediatricians tried to shift the responsibility of conveying the information. "I did not find out for 24 hours that they suspected my daughter had DS," reported one mother who had her child in 1997. "My OB stated that it was not his policy to give this type of information, but that of the pediatrician. I felt like I was the last to know."

A few mothers thought they found out too quickly. "I strongly feel that if a mother has no idea about her child having Down syndrome or any other disability, she should not be told seconds after delivery," said one mother who had her child in 2001. "This really scared me and was unnecessary since DS is not a life-threatening condition, seeing as he was perfectly healthy."

The Communicator

Mothers first received the news from a variety of health care professionals, including pediatricians, neonatologists, OBs, genetic counselors, nurses, and, in 2 cases, the lactation specialist and the candy-striper volunteer. Many of the mothers angrily reported that they overheard hospital staff members discussing their child's diagnosis of DS before they were informed directly.

The Setting

Many of the mothers expressed anger that they were informed about the diagnosis without their partner present. "The physician on duty . . . gave me the diagnosis—very cold and matter-of-fact—without my husband present," recalled one mother who had her child with DS in 1981. "When I told her I had to call my husband, she criticized me for possibly endangering his drive to the hospital to be with me." Mothers also argued that it was unfair for them to have to relate the diagnosis to their partners, especially when they often had little understanding of DS themselves. The reverse was also true. "What frustrated us was a doctor should have talked to us, both of us, in my room instead of my husband hearing it from the nurse and then having to tell me," wrote a mother who had a child in 1999.

Several of the mothers also reported, with bitterness, that their doctor conveyed the diagnosis with other people. "The pediatric nurse practitioner came to my room and announced that the infant had DS," wrote one mother who had her child in 1982. "This was done in front of other family members and visitors as well as my roommate and her guests. My mother-in-law was crying and took my older daughter into the hall. My daughter assumed the infant had died since everyone was upset." A mother who had her infant in 1994 wrote, "A doctor . . . told us our daughter had DS in the nursery while my daughter, mother, and several other people were watching. He said, 'We think your daughter has DS, but now she can have facial surgery.' " Because of the same sentiments, many mothers found it difficult to share a room with another new mother, especially as the roommate celebrated her "perfect" newborn. Mothers who had their own rooms appreciated the privacy to express their emotions, as needed.

The Language

Some mothers suggested that their physicians pitied them while delivering the diagnosis of DS (mean rating: 3.7; SD: 2.2) (Table 2). These mothers were more apt to feel frightened ($r = 0.15$) or anxious ($r = 0.18$) and were less likely to think that the birth of their child was a positive experience ($r = -0.31$) (Table 6). This seems to have improved with time, albeit in a minor way. According to the linear regression analysis, mothers in 2003, in comparison with those in 1993, were 1.2 units less likely to report that their physicians pitied them ($R^2 = 0.01$) (Table 3).

Many mothers were upset that some health care professionals intimated that the birth of a child with DS was a regrettable happening. "Right after [my child] was born, the doctor flat out told my husband that this could have been prevented or discontinued at an earlier stage of the pregnancy," wrote one mother who had a child with DS in 2000. A mother who had a child in 1993 recalled, "I had a resident in the recovery room when I learned that my daughter had DS. When I started to cry, I overheard him say, 'What did she expect? She refused prenatal testing.' I looked him in the eye and told him that it would not have made a difference. I then asked him to leave and for the rest of my hospitalization not to come near my daughter or myself." Another mother reported, from her experience in 1997, "The attending neonatologist, rather than extending some form of

TABLE 6. Correlations Among Mothers' Responses to Survey Questions ($N = 882$)

	r Value																	
	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R
A																		
B	0.35*																	
C	−0.06	0.09																
D	0.33*	0.88*	0.09															
E	−0.15*	−0.11*	0.79*	−0.12*														
F	0.22*	0.40*	0.05	0.45*	−0.04													
G	0.30*	0.40*	0.09	0.46*	0.00	0.62*												
H	0.25*	0.43*	0.05	0.48*	−0.02	0.54*	0.77*											
I	−0.03	0.02	0.46*	0.03	0.48*	0.07	0.13*	0.13*										
J	0.21†	0.34*	0.18*	0.39*	0.13†	0.41*	0.61*	0.71*	0.36*									
K	0.23‡	0.36*	0.12†	0.40*	0.04	0.48*	0.67*	0.74*	0.23*	0.71*								
L	0.23*	0.33*	0.15*	0.35*	0.09	0.46*	0.63*	0.70*	0.29*	0.64*	0.87*							
M	−0.29*	−0.38*	0.17*	−0.39*	0.26*	−0.22*	−0.31*	−0.30*	0.10†	−0.24*	−0.23*	−0.17*						
N	−0.31*	−0.03	0.10‡	−0.02	0.09‡	−0.07	−0.03	−0.05	0.11‡	−0.01	−0.07†	−0.08†	0.15*					
O	−0.24*	−0.01	0.11*	0.00	0.12*	−0.03	−0.06	−0.03	0.10†	0.01	−0.04	−0.02	0.18*	0.61*				
P	−0.17*	−0.07‡	0.06	−0.07†	0.14*	−0.05	−0.01	0.03	0.05	0.02	−0.02	−0.02	0.16*	0.19*	0.09†			
Q	0.44*	0.14*	−0.02	0.15*	−0.05	0.03	0.14*	0.10‡	−0.01	0.08†	0.09†	0.11†	−0.09‡	−0.43*	−0.34*	−0.25*		
R	−0.10†	−0.10*	0.07†	−0.11*	0.08*	−0.17*	−0.14*	−0.16*	0.05	−0.09†	−0.16*	−0.15*	0.10†	0.19*	0.09*	0.08	−0.04	

The statements were as follows: A: The birth of my child with DS was a positive experience; B: My physician told me about the positive aspects of DS; C: My physician told me about the negative aspects of DS; D: My physician emphasized the positive aspects of DS; E: My physician emphasized the negative aspects of DS; F: My physician provided me with enough telephone numbers of parents who have a child with DS; G: My physician provided me with enough up-to-date printed material on DS; H: The printed material that I received emphasized the positive aspects of DS; I: The printed material that I received emphasized the negative aspects of DS; J: The printed materials that I received from my physician provided an equal mixture about the positive and negative aspects of DS; K: The printed materials were helpful for understanding DS; L: The printed materials were easy to read and understand; M: My physician pitied me; N: When I had my child with DS, I was frightened; O: When I had my child with DS, I was anxious; P: When I had my child with DS, I experienced suicidal thoughts; Q: When I had my child with DS, I felt positive; R: When I learned that my child has DS, I had no prior knowledge about this genetic condition.

* $P < .001$.

† $P < .05$.

‡ $P < .01$.

compassion, lambasted us for our ignorance in not doing prior testing and for bringing this burden to society—noting the economical, educational, and social hardships he would bring." Regarding a postnatal visit, a mother who had a child in 1992 wrote, "[My doctor] stressed 'next time' the need for amniocentesis so that I could 'choose to terminate.' "

In nearly all survey responses, mothers recalled words or phrases uttered by health care professionals that were particularly grating. One mother who had a child with DS in 1999 was hurt when her physician kept "referring to children with DS as 'these kids' or 'Down's kids' as if they are all the same." A mother who had a child in 1985 wrote, "One of the most significant things all doctors and hospital personnel can do is to always refer to the baby as a 'baby first.' He/she is NOT a 'Downs' or a 'Down syndrome infant.' He/she is a baby who happens to have DS." No label, however, seemed to be as biting as the "M word" (Mongoloid). Many mothers who had children with DS in the 1960s, 1970s, and 1980s reported the use of this word by their physicians. As the survey responses demonstrated, however, the epithet has not been eliminated from the medical vocabulary. A mother who had a child in 1998 reported that her physician used the word when describing her newborn for the first time.

Other accounts were described as cruel. "In 1962, a resident . . . took a little soft stuffed doll that I was holding in my hand and said, 'See this? This is the same as your daughter—nothing. Just a syndrome, that's all she is,' " reported one mother. Another mother reported that, in 1966, she was told "that it would not be fair to [her] other children if [she] took [her son] home." Another mother objected to the label "FLK," which was commonly used among physicians and residents to designate a "funny-looking kid." "There is nothing funny about DS, and nothing funny-looking about my child," reported this mother, who heard a physician use this label to describe her newborn in 1997.

Mothers were grateful when their physicians had some prior experience working or living with children with disabilities. "My physician has a child with cerebral palsy," wrote a mother who had a child with DS in 1992. "I saw how much he loved his child and heard of his family's struggle to help their child. His caring about me and my family meant a lot to me." Mothers also appreciated when a physician pointed out the joy in their child. "My pediatrician came into my room after seeing my daughter and he said, 'She's beautiful.' That meant so much to me," wrote a mother who had her child in 2001.

Printed Materials

Mothers strongly disagreed with the idea that their physicians had provided them with a satisfactory amount of up-to-date printed materials around the time of the diagnosis (mean rating: 2.4; SD: 2.0) (Table 2). A mother who had her child with DS in 1996 wrote, "After having my infant with DS, I didn't get any information about DS. We didn't get any printed material until she was transported to another hospital for heart/breathing problems. All printed infor-

mation . . . was given to us by a social worker in the second hospital. It would have been better to get more information sooner from our OB and pediatrician." When material was received, it was often dated. "Nurses at the hospital gave me information that was from the 1970s," recalled a mother who had her child in 1988. Another mother recalled her experience in 1995, "After our son was born, our pediatrician gave us his only copy of a 1960s books regarding DS. It referred to m_____, horrible! The pediatrician was so proud to give us *his* book and made very clear that it was his only book and he wanted it back." Still another mother reported that the material she received in 1991 started with, "So you've decided to keep your DS infant?"

Although the materials that mothers did receive were easy to read and comprehend (mean rating: 4.0; SD: 2.2) and somewhat helpful for understanding DS (mean rating: 3.7; SD: 2.2), the printed information did not provide an equal mixture of information on the positive and negative aspects of DS (mean rating: 3.0; SD: 1.9) (Table 2). The materials did not, according to the mothers, emphasize the positive aspects of DS (mean rating: 2.9; SD: 2.0), but the materials did not necessarily emphasize the negative aspects (mean rating: 3.1; SD: 2.0) (Table 2). The mothers from Massachusetts, North Carolina, and Rhode Island tended to find their printed materials more helpful for understanding DS and more positive in tone than did those from Colorado or California (Table 4).

The linear regression analyses with the child's age as the independent variable revealed that all of the mothers' opinions about the printed materials changed with time, with the exception of the emphasis on the negative aspects. Although the fit of the models was very weak ($R^2 = 0.04–0.06$), the standardized β values suggested that in 2003, compared with 1993, mothers were 2.1 units more likely to indicate that the printed materials emphasized the positive aspects and 1.9 units more likely to suggest that the materials provided an equal mixture of information on the positive and negative aspects of DS. For the mothers in 2003, the materials were also 2.4 units more helpful and easier to understand. The physicians in 2003 were 1.6 units more likely to provide enough up-to-date materials on DS (Table 3). Even with this increase, however, the mothers' opinion regarding whether they had received enough information still rarely passed the neutral mark of 4 (Table 2).

Receiving the Diagnosis

Approximately one half of the mothers had some knowledge of DS before receiving the diagnosis, whereas the other one half did not (mean rating: 4.1; SD: 2.4) (Table 2). Very few mothers felt positive after learning the diagnosis (mean rating: 2.9; SD: 1.9). For those who did, their feelings of optimism could be significantly predicted by instances in which the physician mentioned the positive aspects of DS and provided a sufficient amount of up-to-date materials. This positive feeling could also be predicted by 2 maternal background characteristics, ie, the mother's educational level and the combined household income. The multivariate regression model was as follows: positive feelings = 4.0 + 0.12 physician talking about positive aspects + 0.07 physician providing up-to-date printed materials − 0.33 educational level − 0.000003 income ($R^2 = 0.06$, $F[0.05;4;609] = 10.5$, $P < .001$). This means that, when all other variables are held constant and the neutral level of 4 is used as a starting point, a mother would report 0.12 units higher if her physician talked about the positive aspects of DS. She would be predicted to report 0.07 units higher if the doctor provided enough up-to-date materials. For each additional educational degree, the mother would be predicted to report 0.33 units lower; for every $10 000 increase in household income, she would report 0.03 units lower.

The majority of mothers felt either frightened (mean rating: 5.5; SD: 2.0) or anxious (mean rating: 5.8; SD: 1.7) (Table 2). In the free response section of the survey, mothers also admitted feeling "shocked," "angry," "devastated," "overwhelmed," "depressed," "stunned," and "helpless." "Giving birth to a child with DS was very traumatic," wrote a mother of her experience in 1997. "I had no forewarning, so I had a lot to take in." Another mother recalled from 1996, "I was so scared. The birth was also dramatic. I felt mental and physical shock." For mothers who felt frightened, their responses could be statistically predicted by their physician's emphasis on the negative aspects of DS and the number of other pregnancies. The multivariate regression model was as follows: frightened = 4.89 + 0.11 physician emphasizing negative aspects − 0.12 pregnancies + 0.11 educational level ($R^2 = 0.02$, $F[0.05;3;797] = 6.5$, $P < .001$). This means that, when other variables are held constant and a fear level of 4.89 is used as a starting point, every 1-unit increase in the mother's perceptions of her physician emphasizing the negative aspects of DS would result in a 0.11-unit increase in her level of fright. In contrast, for every additional pregnancy that the mother had, her level would be expected to decrease by 0.12 units. Also, for each additional educational degree, the mother would be predicted to increase her level of fear by 0.11 units. For mothers who felt anxiety, their levels could be predicted by the same factors. The multivariate regression model was as follows: anxiety = 4.30 + 0.10 physician emphasizing negative aspects + 0.23 educational level + 0.000002 income ($R^2 = 0.03$, $F[0.05;3;607] = 7.25$, $P < .001$). With all other variables being held constant and an anxiety level of 4.30 being used as a starting point, for every 1-unit increase in a mother's reporting that her physician emphasized negative aspects, her anxiety level would be predicted to be 0.10 units higher. A higher educational level would increase the anxiety level by 0.23 units; for every $10 000 increase in household income, the anxiety level would increase by 0.02 units. Almost no mothers reported suicidal ideations after receiving the diagnosis (mean rating: 1.6; SD: 1.6; Table 2). The few mothers who did also responded that their physicians had pitied them ($r = 0.16$, $P < .001$) or emphasized the negative aspects of DS ($r = 0.14$, $P < .001$) (Table 6). Of all of the religious affiliations, mothers

who identified themselves as Protestant, Jewish, or atheist reported the highest levels of anxiety associated with the diagnosis for their child (Table 5).

The linear regression analyses with the child's age as the independent variable suggested that all of the maternal reactions except fright and suicidality changed with time (Table 3). Although the fit of the models was weak ($R^2 = 0.01$), the standardized β values revealed that in 1993, compared with 2003, mothers were 1.2 units more anxious, 0.8 units less positive, and 1.0 units more unknowledgeable about DS.

Support From Other Parents

Mothers strongly disagreed with the idea that their physicians had provided them with enough telephone numbers of parents who already had a child with DS (mean rating: 2.4; SD: 2.1) (Table 2). This seems to have improved slightly with time (Table 3), although the maternal response rate in more recent years still rarely passed the neutral mark of 4 (Table 2). When a connection was made with a support group, the mothers were sincerely grateful. One mother wrote of her experience in 1986, "After [my son] was born, it was very clear that I was going through the stages of grief. The support group was the most positive thing that happened, along with supportive family and friends." A mother who had her child with DS in 2001 outlined, "Hooking up with other families who have children with DS has helped our family in a variety of ways: emotional support, problem solving, networking, educational support, fun times, sibling support, and receiving services."

Overall Experience

In summary, mothers expressed mixed opinions about whether the birth of their child with DS was a positive experience. Although the majority tended to disagree, some mothers rated reserved agreement (mean rating: 3.3; SD: 3.2; Table 2). The satisfaction levels seemed to improve with time (Table 3). According to the linear regression model, mothers who had children with DS in 2003 would be predicted to report that their birthing experience was 1.5 units more positive than that of mothers who had children in 1993 and 3.0 units more positive than that of mothers who had children in 1983.

What physician behaviors, printed materials, or maternal background characteristics could best predict whether a mother would regard the birth of her child with DS as a positive experience? The mixed, stepwise, multivariate, regression analyses revealed that all of the following variables played a role: physician's effort to talk about the positive aspects, physician's emphasis on the negative aspects, and amount of up-to-date printed materials provided. The regression model was as follows: positive experience = 2.3 + 0.27 physician talking about positive aspects − 0.10 physician emphasize negative aspects + 0.18 physician providing up-to-date printed materials ($R^2 = 0.15$, $F[0.05;3;803] = 49.9$, $P < .001$). This means that, when all other variables are held constant and a dissatisfaction level of 2.3 is used as a starting point, every 1-unit increase in the mothers' perceptions of her physician talking about the positive elements of DS would increase her feeling that the birth was an overall positive experience by 0.27 units. In contrast, for every 1-unit increase in the physician emphasizing the negative aspects, the subjective positive experience would decrease by 0.10 units. Up-to-date materials would increase the experience level by 0.18 units.

DISCUSSION

Overall Results

Despite the recent popularity of prenatal testing, physicians are still called on to convey postnatal diagnoses of DS in a sensitive supportive manner. Of the >1000 mothers who responded to the survey, 87% of them learned of their child's diagnosis after delivery. The population most likely to receive such postnatal diagnoses appears to be younger mothers. Only 29% of survey respondents were >35 years of age when they had their child, which suggests that older women, in comparison with their younger counterparts, are having fewer children and/or are more frequently terminating their pregnancies after definitive prenatal testing.

Approximately 10% of mothers who received postnatal DS diagnoses underwent some form of prenatal screening, most commonly triple screening. Their reasons for not continuing with definitive testing were that the odds ratio results of the triple screening were difficult to appreciate or the ratios were too low to warrant additional testing (analogous to false-negative results). This suggests that many of these mothers might have chosen to terminate their pregnancies if they had undergone amniocentesis or CVS testing.

Mothers rarely reported that the birth of their child with DS was a positive experience. Most reported feeling frightened and/or anxious after learning of the diagnosis. According to the mixed, stepwise, multivariate, regression analyses, primigravid mothers who were highly educated and wealthy worried most regarding the diagnosis of DS. Perhaps these mothers were more likely to live in social circles in which a disability would be viewed as unfortunate or unpopular. In addition or as an alternative, these women might have had more demanding jobs, which caused them to worry about how they would find time to raise a child with a disability. Multigravid mothers seemed better equipped to absorb a diagnosis of DS. For these women, the fears and mystery associated with raising children might have been resolved after a previous pregnancy. In addition or as an alternative, these mothers might have already come to believe, through their other children, that all children are born with an inherent richness, including those with DS, and that no child is perfect. Mothers were also more likely to be frightened and anxious if they perceived that their physicians emphasized the negative aspects of DS. Intriguingly, women who were Jewish, unspecified Protestants, or atheists were more likely to be frightened or anxious than were Catholics or unspecified Christians. This

suggests that religion might have an impact on how a mother is able to cope with the new diagnosis.

A few women did report having positive thoughts after receiving the diagnosis from their physicians, and slightly more reported that, when everything was considered together, the overall experience at the time of the birth was a positive one. The mixed, stepwise, multivariate, regression analyses revealed that many physician behaviors could predict whether a mother would find positivism in the diagnosis. Mothers were most optimistic when their physicians talked about the positive aspects of DS and provided them with up-to-date printed materials. The statistical model suggested that, if mothers strongly agreed that their physicians did both, then their optimism level would rank 5.3 on a Likert scale of 1 to 7.

The statistical models also suggested that 3 factors could predict whether a mother would view her overall experience of giving birth to an infant with DS as a positive one. Physicians who talked about the positive aspects of DS and provided up-to-date materials seemed to contribute the most toward a mother finding the birth a joyous one. If a mother strongly agreed that her physician did both, then her satisfaction level would be predicted to be 5.5 on a Likert scale of 1 to 7. A physician who emphasized the negative aspects of DS would decrease her ability to find happiness in the situation. If a mother strongly agreed that her physician did so, then she would be predicted to have a satisfaction level of 1.6.

In both the quantitative and qualitative data, mothers suggested that physicians were inadequate in explaining DS. Very few health care professionals talked about the positive aspects of DS, gave up-to-date information, or provided enough telephone numbers for parent support groups. The linear regression analyses suggested that this is changing, albeit slowly. In nearly all of the Likert statements, mothers from the current period ranked their physicians' behaviors less negatively than did mothers from earlier periods. For most variables, though, the change has progressed from strong disagreement to disagreement.

Some physicians might ask whether some amount of dissatisfaction is inevitable with the disclosure of an unexpected diagnosis such as DS. Previous research suggests not. Cunningham et al[15] surveyed the perceptions of 2 cohorts of mothers with children with DS in England, ie, those who received diagnoses with the normal protocols already practiced by their physicians and those who received diagnoses through a model service in which mothers were informed (1) by a physician, (2) as soon as possible, except in cases of maternal ill health, (3) with the husband present, (4) in a private place, (5) with the infant present, (6) with as much time as needed for questions, (7) with the indication that a specialist would talk to the parents again as soon as they wanted, (8) with provision of a private place for the parents directly after the conversation, and (9) with the indication that a follow-up interview with the pediatrician would be arranged ~24 hours later. In the model service cohort ($N = 9$), 100% of the mothers reported that they were satisfied with the delivery of the diagnosis for their child; in the control group ($N = 25$), only 20% of mothers expressed similar satisfaction. The conclusion seems obvious, ie, when parental suggestions are implemented, satisfaction levels improve.

Recommendations for Health Care Professionals

In both their free-response and quantitative answers in this study, the mothers made the following suggestions regarding how the diagnosis of DS could be delivered in a thoughtful sensitive manner. First, the person to deliver the news should be a physician. When the announcement is made that an infant has DS, the mother will invariably have questions and/or concerns. Mothers in this study thought that a physician was the most appropriate person to provide answers. They also emphasized that it takes a committed team to make the experience of having a child with DS a positive one. One mother reported that, "the anesthesiologist went to the waiting room and told our parents everything was fine, though our daughter had DS and a low Apgar [score] due to her cardiac defect." Another mother wrote that, "the nurse in the recovery room said, 'This is a mother's worst nightmare.' " Still another mother mentioned that, "a social worker came in and explained to me that having a child with DS was like having a death in the family." Every person who comes into contact with a new mother can make an impression. Ensuring that each person is sensitive and knowledgeable prevents that impression from being a negative one.

Second, OBs need to coordinate their messages with neonatologists and pediatricians. Many different physicians can be in a position to make a postnatal diagnosis of DS. Depending on the hospital and the circumstances, the diagnosis could be made by the OB, the neonatologist, or the family's established pediatrician. Mothers recommended that all hospitals have a plan in place so that all relevant physicians know how best to coordinate their messages. One mother wrote, "I think too many health care providers don't want to be the one to break the news and most don't handle it well . . . [My OB] didn't want to alarm us until [my son] was seen by the pediatrician and said nothing. Twelve hours later we saw the pediatrician and got the news. Finding out earlier wouldn't have changed anything, but it felt like a pass-the-buck-type situation." Another mother reported a similar sentiment, "The way the OB handled the suspicions of my daughter's DS immediately after her birth was extremely unprofessional and simply insensitive. It was almost as if she was scared of me and my daughter and was trying to 'run away' and pawn me off on other physicians. It made me feel very sad and disappointed. I think if she had been more forthright and open (and matter-of-fact) it would have made the 'news' of her DS much more positive and easier to digest."

Third, the news should be delivered once the mother is settled and as soon as a physician suspects the diagnosis. Some mothers were angry that they were told immediately after delivery, particularly while episiotomies were being sutured. Other moth-

ers were upset that their physicians delayed sharing their suspicions before DS was confirmed with genetic karyotyping. In these cases, the mothers could sense that "something was different" and often detected changes in medical staff behavior while confirmatory testing was being performed. "The nurse who assisted my OB with the birth took [my daughter] and kept her for hours," wrote one mother. "When we kept calling to have her returned, we were given excuse after excuse why they couldn't return her." A physician should not wait until the diagnosis is confirmed; mothers prefer to be aware of the physician's thought process, no matter how difficult the news might be. The general consensus is that mothers would like to be informed as soon as the physician suspects that the child might have DS but not before the mother has had a chance to recover from the experience of giving birth. (The exception to this recommendation would be a situation in which the child requires immediate intensive care. In such a case, the mother should be informed promptly.)

Fourth, whenever possible, the physician should make the announcement with both parents present, in a private setting. If both parents are in the hospital, then the physician should bring both of them into a private room to explain DS. If the father of the child is not readily available (eg, has left the hospital), then the physician should explain the news to the mother and offer to review everything once the father has returned to the hospital. There are almost no circumstances, short of the mother being unconscious, in which the father should be informed before the mother. Physicians should inform the parents in a setting without visitors and roommates. If there are guests in the mother's birthing suite, then the physician could kindly ask them to leave the room while he or she speaks with the parents.

Fifth, when delivering the news about DS, the physician should first congratulate the parents on the birth of their child and should not forget to talk about the positive aspects of DS. Physicians should not begin their conversation by saying, "I'm sorry." Many mothers emphasized that the birth of a child with DS is not a tragedy and should not be introduced as one. Instead, a physician might begin by saying, "Congratulations on the birth of a beautiful infant." Parents requested that physicians hold the infant and refer to the child by name, if one has been chosen. When explaining the specifics of DS, the physician should carefully present an informed but balanced picture. "While obviously the downside must be explained, the upside should as well," wrote one mother who had a child in 1994. "When our second son (without DS) was born, no one told us that he 'wasn't going to go to Harvard,' yet the statistical likelihood he will is nil. Yet parents of children [with DS] are told their sons and daughters will not drive (but many young adults with DS do), won't go to college (again not true), will have serious medical problems (not all do), and 'won't make change for the bus' (just you wait and see)." Many mothers mentioned that the best words used by their physician during this initial explanation were, "Love your child like any other child."

Sixth, health care professionals should keep their personal opinions to themselves. Mothers requested that health care professionals offer sound medical advice based on the most up-to-date information. Unless specifically requested by a mother, they should not share their personal opinions on DS. One mother wrote, "the ultrasound tech who checked for DS markers . . . shared with us she had aborted her child with DS." Another mother reported, "My covering OB who made rounds on me on day 2 of hospitalization made a judgmental comment about my decision not to have prenatal testing. Her attitude came across clearly that this birth could have been prevented." Most mothers stated that health care professionals are privileged to give medical information but not personal opinions.

Seventh, mothers should be provided with up-to-date printed materials. Mothers requested that, when the diagnosis of DS is shared, they be given current literature on DS that includes positive imagery. Many mothers found the book *Babies With Down Syndrome: A New Parent's Guide* to be very informative and helpful.[36] Other books with positive approaches, appropriate for new parents, include *Common Threads: Celebrating Life With Down Syndrome*,[7] *Life as We Know It: A Father, a Family, and an Exceptional Child*,[37] *Count Us In: Growing Up With Down Syndrome*,[38] and *A Parent's Guide to Down Syndrome: Toward a Brighter Future*.[39] If hospitals are financially unable to provide these resources, then they should provide a handout listing the most current literature on DS. One such list can be found on the National Down Syndrome Congress Web site (www.ndsccenter.org/resources/print.asp). Mothers also requested that they be provided with a checklist of relevant health information for their newborns with DS. This information can be downloaded easily for parents from the National Down Syndrome Society Web site (www.ndss.org). Both of the national DS organizations provide new-parent packages (available for free download at: www.ndsccenter.org/resources/newparentpack.asp and www.ndss.org/content.cfm?fuseaction=CommFFP.New). Physicians could easily download this information for parents.

Eighth, parents should be provided access to other families who have children with DS. After DS has been explained, a physician should offer to provide contact information for a local support group, if the mother is interested. Mothers repeatedly stated in their survey responses that their local parent support groups were of invaluable help, especially during the first years of their child's life. A directory of local DS support groups can be found through the National Down Syndrome Society (www.ndss.org).

Ninth, after the initial diagnosis or suspicion is shared with parents, they should be offered a private hospital room. Mothers responded to the news with a variety of different emotions. They requested that they be given a private space where they can freely express those feelings, if so desired.

Tenth, all physicians should be cognizant of the realities and possibilities of growing up with DS

today. One mother wrote, "My OB told us that the only example he had for us was 'Corky' from television, and 'remember how great he was on that show?' " Mothers considered it the responsibility of physicians to stay informed of the educational and social potentials of children with DS. Staying abreast of the medical and scientific literature is not sufficient. For an update on the most recent achievements of children with DS, health care professionals can read *Common Threads: Celebrating Life With Down Syndrome*,[7] *Down Syndrome: Visions for the 21st Century*,[40] or *Down Syndrome: A Promising Future, Together*.[41]

Future Research

This study is the largest and most comprehensive analysis of mothers' reflections after receiving a postnatal diagnosis of DS. It is by no means a definitive analysis, however, and more research remains to be performed. First, fathers' perspectives could certainly be studied in a similar manner. Are their feelings and needs different from those of the mothers? Second, physicians' reflections should be quantified and, if possible, correlated with the perceptions of the patients. How do OBs, neonatologists, and pediatricians view their skills, in comparison with how their patients see them? Third, in our age of increasing global dialogue, similar studies should be performed in other countries. To date, research in England, Scotland, Ireland, Spain, Sweden, and Australia has suggested that women are strongly dissatisfied with the care they receive after a postnatal diagnosis of DS.[12,13,15,16,20,21,23,26,28,30,32] Are their sentiments shared by mothers in other countries?

Limitations of the Current Study

As with all retrospective studies, our research is subject to recall bias. The mothers answered this survey with an average of 11 years of hindsight, and it is possible that their answers were based, in part, on information and resources they would like to have received, now that they have learned much about DS. Because of the clarity with which mothers described their birthing experiences (especially mothers who had children with DS in the 1940s, 1950s, and 1960s), however, it seems that receiving the diagnosis of DS might represent a true flashbulb memory, ie, accurate, complete, and immune to forgetfulness.[42–45] A previous longitudinal study supports this theory.[46] In England, 21 mothers who had children with DS were interviewed before their children were 2 years of age and again, with identical questions, 21 years later. Mothers were asked how they felt when they received the diagnosis of DS, how the diagnosis was made, and what could have been improved about their support services. Among the 10 questions asked, 82% of the replies were essentially the same after the 21-year interval. We did not assess the mothers' reflections immediately after the births of their children with DS; however, it is reasonable to assume that their opinions have not changed much from their original feelings.

The study is also subject to selection bias. Only mothers who were members of a DS support group were sampled. It is possible that only mothers who had the most difficult experiences coping with the births of their children with DS would enroll in a DS support group and only those who had particularly stressful birthing experiences would choose to respond to our survey. Experience with DS support groups suggests that this is not the case. Unfortunately, there is no national database of families who have children with DS; the most robust way of surveying mothers was through the support groups. With such an approach, however, the study was limited to the socioeconomic and ethnic diversity of those groups, which include primarily middle- to upper-class white families. The current study does not adequately reflect the sentiments of mothers of other ethnicities or lower socioeconomic brackets. Until the DS support groups diversify their membership, these populations will be difficult to study in a robust comprehensive way.

Implications

The results of this study, coupled with the previous research on mothers in Spain, make mothers' dissatisfaction with their postnatal care clear. Hospitals and physicians could dismiss the results of previous studies as being unfounded or not applicable to their circumstances. However, now 985 mothers in the United States and 467 mothers in Spain have called for change. They have specifically outlined ways in which medical systems could be improved; it is now incumbent on health care professionals to provide the compassion and sensitivity that all patients deserve.

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BREATHING MOVEMENT AND LUNG DEVELOPMENT

"Normal lung development is associated with a progressive increase of apoptosis constantly counteracting proliferation. Intermittent fetal breathing movements are essential for proper lung development and may act as a potential key regulator of apoptosis. Because prematurely born infants with immature lungs need continuous mechanical ventilation for their survival, the fine balance between growth and apoptosis may be compromised."

Del Riccio V, van Tuyl M, Post M. Apoptosis in lung development and neonatal lung injury. *Pediatr Res*. 2004;55:183–189

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