

Postnatal Support for Mothers of Children With Down Syndrome

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Abstract

Delivering and receiving a postnatal diagnosis of Down syndrome is not an easy experience for most physicians or parents. In this study, 467 mothers of children with Down syndrome in Spain completed a survey about the postnatal support services they received immediately following the diagnosis of their child. Mothers reported feeling anxious, frightened, guilty, angry, and, in rare cases, suicidal. According to most mothers, physicians did not give adequate amounts of information about Down syndrome and rarely did they give enough printed materials or make referrals to parent support groups. Little seems to have changed since 1972. Mothers provided recommendations on how the Spanish medical system could be improved, with implications for other countries including the United States.

Down syndrome is a developmental disability commonly identified in newborns. Individuals with this condition can have long lives, full of noteworthy accomplishments and meaningful contributions to their communities (Kidder & Skotko, 2001). In Spain approximately 1 out of every 1,000 children are born with Down syndrome (Estudio Colaborativo Español de Malformaciones Congénitas, 1997; Organización Mundial de Salud, 2000), suggesting that more than 32,000 people with Down syndrome currently live there (Instituto Nacional De Estadística, 1999). The condition almost always results from a genetic nondisjunction, giving the child an extra copy of chromosome 21 in every cell. In a rare 4% of people with Down syndrome, the condition results from a translocation, typically between chromosomes 14 and 21; and in 1% of the cases, the cause is a genetic mosaicism, leaving some cells with a triple copy of chromosome 21 and others with the normal two (Cotran, Kumar, & Collins, 1999).

Multiple tests can be used to screen for a fetus with Down syndrome (Wald, Kennard, Hackshaw, & McGuire, 1997). The *triple screen* measures changes in the maternal serum concentrations of α -fetoprotein, unconjugated estriol, and human chorionic gonadotrophin and is commonly performed during the 15th to 21st weeks of pregnancy. With a 5% false positive rate, approximately 69% of fe-

tuses with Down syndrome are correctly detected with this screen (Wald et al., 1997). A *quadruple screen* adds a measurement of inhibin a and increases the detection rate to 75%, with a 5% false positive rate (Wald, Huttly, & Hackshaw, 2003). Ultrasounds are also used to screen for Down syndrome during the second trimester. The sensitivity of ultrasonographic markers remains controversial, however, and the number of fetuses with Down syndrome correctly identified using a thickened nuchal fold—one of the most prominent ultrasonographic markers—has varied between 7% to 75% in published studies (Smith-Bindman, Hosmer, Feldstein, Deeks, & Goldberg, 2001). A recent study of first-trimester screening involving ultrasonographic findings reported a detection rate as high as 78.7%, with a 5% false positive rate (Wapner et al., 2003).

For a definitive diagnosis to be made prenatally, however, a woman must elect to have chorionic villus sampling during the 8th or 11th week of pregnancy or amniocentesis during the 2nd and 3rd trimesters. Barring the exception of unusual laboratory mistakes, both tests offer a conclusive prenatal diagnosis for Down syndrome and because of this, some women turn directly to these tests without any prior results from screening measures. With chorionic villus sampling, chromosomal testing is done on chorionic tissue; with amniocentesis, genetic testing can be done directly on fetal cells sampled

from the amniotic fluid. Neither procedure is without risk, though. An amniocentesis carries a .25% to .30% chance of causing a spontaneous abortion (Powell, 2000), and the risks of chorionic villus sampling might be slightly higher. Because of these risks, the procedures are usually reserved for women over the age of 35 whose chances of having a child with Down syndrome are increased (Hook, Cross, & Schreinemachers, 1983).

Although these many prenatal options exist, however, results of a recent study suggest that as many as 87% of mothers in the United States receive the news after their child is born (Skotko, 2005a, 2005b). The postnatal diagnosis is made shortly after birth by physical characteristics (e.g., short ears, depressed upper mid-face, a palmar crease, and hypotonia) and confirmed by a genetic karyotype (Durlach & Oliver, 1991; Pueschel, 1990). Although the actual diagnosis is oftentimes a relatively easy one for most physicians, the process of relaying the information to mothers in a sensitive and respectful manner is not. It appears that most physicians admit that they have little, if any, training in delivering such information to mothers. Ralston (2000) noted:

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 Down syndrome 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. (p. 335)

Delivering a diagnosis can also be difficult for the health care professional because, according to Klein (1993):

It contrasts so dramatically with health care situations that the practitioner finds gratifying, e.g., successfully treating an acute medical crisis . . . When unable to 'fix' the problem, the clinician may erroneously believe that there is nothing that he or she, as a health care practitioner, can do to help the family or child. (p. 187)

Since 1964, researchers from various countries have been studying the manner in which physicians deliver a diagnosis of Down syndrome (Berg, Gilderdale, & Way, 1969; Carr, 1970; Cooley, 1993; Cunningham, Morgan, & McGucken, 1984; Cunningham & Sloper, 1977; Drillien & Wilkinson, 1964; Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1985; Gath, 1985; Gath & Gumley, 1984; Gayton & Walker, 1974; Hedov, Wikblad, & Annerén, 2002; Klein, 1993; Krahn, Hallum, & Kime, 1993; Lucas & Lucas, 1980; MacDonald, Carson, Palmer,

& Slay, 1982; Murdoch, 1983; Pueschel & Murphy, 1976; Quine & Rutter, 1994; Springer & Steele, 1980; Stone, 1973). These studies, however, have been limited by small sample sizes and brief survey questions. Particularly during the past decade, research has been noticeably sparse.

In 1993, in a study of 12 American parents who had a child with Down syndrome, Krahn et al. concluded that multiple components were necessary to strengthen the initial parent–physician dialogue: (a) Down syndrome should be explained clearly and with detail, including positive characteristics of the child; (b) specific information should be included on specialty referrals, services, and support; (c) the diagnosis should be delivered by a professional who is familiar with the parents; (d) communication should be entwined with compassion and caring; (e) the conversation should be at a pace that parents can follow; (f) the diagnosis should be delivered in the presence of both parents, whenever possible; (g) parents should be notified as soon as a problem is suspected; and (h) the baby should be held by the parents or health care professional during the conversation (Krahn et al., 1993).

In a 1994 survey completed by 166 parents from England who had children with “severe mental and physical disabilities” (56 of whom had children with Down syndrome), approximately 58% of them were dissatisfied with their physician’s delivery of their child’s diagnosis (Quine & Rutter, 1994). Satisfaction levels were associated with three components: (a) parents being informed as soon as health care professionals know that something is wrong with their child, (b) the person delivering the diagnosis having a sympathetic approach, and (c) as much information as possible about Down syndrome being provided to the parents.

In a 1995 study conducted by Garwick, Patterson, Forrest, and Blum, 18 families from the United States who had a child with Down syndrome reported that shock was the predominant initial reaction after receiving their child’s diagnosis. These families confirmed negative reactions to (a) receiving a diagnosis by telephone, (b) hearing about their child’s diagnosis in the presence of hospital roommates, or (c) being given outdated or inadequate information from the hospitals.

Most recently in 2002, in a survey of 86 families from Sweden who had a child with Down syndrome, Hedov et al. found that 56% of them felt that they were not supported after receiving a postnatal diagnosis. Approximately 70% of these par-

ents felt the information that they had received was insufficient and focused too much on the negative health aspects associated with Down syndrome.

Where research has been scant, anecdotal descriptions have been robust. In the past decade, parents have offered their raw reflections in a variety of forms of popular prose:

After several days of crying, and soul searching, and reading what little information was available at the time (most of which was depressing and frightening), [we] made the difficult decision to disregard the professional advice and bring [our son] home. (Kinglsey, 1994, p. 3)

When told by a physician that her newborn had Down syndrome, Nobel (1992) said, "I felt myself go numb, and I heard my voice from a distance asking, 'What does this mean?'" (p. 41). Kidder (2001) recounted that,

When we were told our child had Down syndrome, 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. We were naïve and uneducated and filled with fear. (p. 162)

The mother of television star Chris Burke, bluntly stated, "It was the worst moment of my entire life" (Burke & McDaniel, 2001, p. 30).

Support groups are often established for parents to enable them to discuss their feelings with others in the same situation. The Down syndrome movement in Spain has, in many ways, evolved similarly to that in the United States. The first Down syndrome parent organization in Spain was formed in 1976, and new parent support groups grew rapidly during the late 1970s and 1980s. As momentum was established, these support groups began to include advocacy components in their mission statements; and in 1991, the movement was centralized when a national Down Syndrome Association was established—Federación Española del Síndrome de Down (FESID). The association, which was legally recognized as a nonprofit, nongovernmental organization in 1996, has since established a national action plan for the Down syndrome movement in Spain.

To date, no researchers have yet to document the reflections of mothers in Spain who received a postnatal diagnosis of Down syndrome for their child. In addition, no study has been large enough to provide substantial data for effective change in any country. Here, we report results from the most comprehensive survey to date of such mothers' reflections. Approximately 500 mothers who had children with Down syndrome were asked to share

memories from their child's birth. Our central research question was, How could medical support be improved for mothers who receive diagnoses of Down syndrome for their child? To answer this question, we asked, What were mothers' perceptions of physician behaviors at the time of diagnosis? What was it like waiting for a diagnosis and receiving notification that their child had Down syndrome? How did the physicians deliver the news? How did the setting, printed materials, and support groups affect the mothers' emotions at the time?

Because we were collecting data from mothers who had children with Down syndrome over the past 30 years, we also asked: Were mothers' perceptions different depending upon when they had received their postnatal diagnosis (i.e., had the medical system changed, in the eyes of the mothers)? The anecdotal literature led us to question whether certain background characteristics, such as age, race, religion, education, and total pregnancies of a woman, could predict a maternal response to receiving a diagnosis of Down syndrome for her child.

Method

Sample

This study was nested in a larger cross-cultural epidemiological study on prenatal and postnatal support for mothers who had children with Down syndrome in Spain and the United States. We chose Spain for multiple reasons: (a) the evolution of the disability movement in Spain has mirrored, in many ways, that of the United States; (b) Spain has a national Down syndrome parent organization, allowing for access to a large sample size; and (c) the Institute on Community Integration in Salamanca specializes in disability research and could provide technical support for a widespread survey distribution.

We chose to distribute our surveys exclusively to mothers of children with Down syndrome, rather than other family members, such as fathers, grandparents, brothers, or sisters, in order to standardize the perspectives of our respondents and capture the sentiments of the person most intimately involved in the pregnancy. Mothers of children with Down syndrome were identified from the membership lists of (a) the Down syndrome parent support groups associated with FEISD, (b) the Fundación Síndrome de Down de Cantabria, and (c) the Fundación Síndrome de Down de Madrid. In total, surveys

were mailed to 6,125 mothers, representing approximately 19% of the mothers in Spain who have a child with Down syndrome.

Survey Instrument

The 11-page survey was partially developed on data published by Helm, Miranda, and Chedd (1998a, 1998b) and was reviewed by a panel of experts in the disability field, including a pediatrician, psychiatrist, parent, sister, social medicine researcher, international health professional, and educational specialist. We also wrote a cover letter to explain the purpose of the project and to emphasize that participation was purely voluntary. Both the survey and cover letter were translated into Spanish and reviewed for both translation and cultural appropriateness by the second author. After all materials were approved by the Committee on Human Studies at Harvard Medical School, each mother in our sample received a packet including a survey, cover letter, and self-addressed stamped envelope.

Through use of this survey, we gathered both quantitative and qualitative data from yes/no questions, open-ended questions, and a series of statements (e.g., “My physician emphasized the positive aspects of children with Down syndrome”) as the mothers to rate their level of agreement on a 1 to 7 Likert scale, with 7 being *strongly agree*; 4, *neutral*; and 1, *strongly disagree*. The statements covered such topics as triple screening, amniocentesis, printed material about Down syndrome, the decision to continue the pregnancy, prenatal care, and postnatal care. (Results from the prenatal questions are reported elsewhere.) Questions about postnatal care included 6 statements about physician behavior when the mothers received their child’s diagnosis for the first time, 5 statements about mothers’ reactions upon receiving the diagnosis, and 6 statements about printed material that mothers received from their physicians immediately following the diagnosis.

Data Collection

Research packets were mailed to FEISD, the Fundación Síndrome de Down de Cantabria, and the Fundación Síndrome de Down de Madrid. The FEISD sent out 5,000 research packets to its 62 local parent organizations. These Down syndrome parent organizations distributed the packets to all of their members, often by hand at group meetings. The Fundación Síndrome de Down de Cantabria and the Fundación Síndrome de Down de Madrid

mailed 125 and 1,000 research packets, respectively, to all of their members.

The confidentiality of the families was maintained at all times; names or addresses were not used. Only when a parent voluntarily chose to respond to the survey did we receive his or her contact information. To further protect the confidentiality of the responses, the sheet with the contact information was separated from the rest of the survey and stored in a locked file cabinet. After the responses were inputted in a computer database, it was impossible to distinguish the identity of the respondents.

Data Analyses

Because we collected both quantitative and qualitative data using the survey, a mixed methodology was used to analyze the data. Throughout this study, we report both analyses under shared topic headings so that qualitative analyses could support quantitative calculations and vice versa.

We first analyzed the quantitative data and reported the mean, standard deviation (*SD*), and number of respondents for each survey question. We also wanted to know, Did mothers’ perceptions of physician behaviors differ over time? To answer this question, we generated a linear regression for each physician–behavior question, using the child’s age as the independent variable. We reported the standardized β s and R^2 values from the regressions. To determine the significance of our predicted models, we also ran an ANOVA on the predictor (using the .05 level of significance).

Another question we asked was: Could any of the mothers’ background characteristics predict their levels of satisfaction with their medical support? To answer this question, we generated mixed stepwise multiple regressions, with the independent variables being child’s age (a variable of how long ago the mother had her child), mother’s age at the time of her child’s birth, number of pregnancies, yearly income, and level of education. Variables were entered at a probability of .05, and we reported the standardized β s and R^2 values from the regressions. Again, to determine the significance of our predicted models, we also ran an ANOVA on the predictors. We also wanted to know whether there were certain maternal feelings and reactions associated with others. For example, did the mothers who experienced fear upon the birth of their child also have doctors who emphasized the negative aspects of Down syndrome? To answer these ques-

tions, we generated correlations between all the survey questions and the r values, indicating significance at the .05, .01, and .001 levels.

We further asked: Could the physician behaviors predict the emotional responses of the mothers? For example, did the mothers who felt frightened upon learning the diagnosis of their child have physicians who emphasized the negative aspects of Down syndrome? We explored these associations by generating mixed stepwise multiple regressions, using the maternal emotions (frightened, anxious, suicidal, optimistic) as the dependent variables and all of the physician behavior questions as the independent ones. Variables were entered at a probability of .05, and we reported the standardized β s and R^2 values from the regressions. To determine the significance of our predicted models, we also ran an ANOVA on the predictors.

After the quantitative data were analyzed, we studied the qualitative data to add dimension to the mothers' experiences. We coded responses and developed themes using the constant comparative method of qualitative analysis first described by Glaser and Strauss (1967). For this analysis, we initially coded the mothers' short-answer responses based on categories that emerged from the quantitative data. We then integrated the categories and abstracted themes from the mothers' responses. Finally, our themes were delimited and clarified so as to be concise, specific, and not redundant. Three broad themes emerged: waiting for the diagnosis, receiving the diagnosis, and delivering the diagnosis. The following subcategories emerged under the third theme: verbal explanation, the setting, the language, support from other parents, and printed materials. Comments from mothers that are most representative of these themes are provided below.

Results

Respondents

We received 501 responses (8.2%), which represented mothers from 51 (69%) different Down syndrome support groups throughout Spain. Of the 501 surveys received, 29 were completed by fathers and excluded from our analyses. An additional 5 surveys were also withheld because they were completed by mothers who had a prenatal diagnosis of Down syndrome based on amniocentesis results. Of the remaining 467 responses, 45 (10%) were from mothers who had triple screen analyses without further prenatal testing. Because these mothers did not

receive a definitive diagnosis of Down syndrome until after their child was born, they were included in our dataset. The remaining 90% of our survey participants had no prenatal testing done prior to the birth of their child with Down syndrome.

The average age of the 428 respondents was 43.7 years ($SD = 9.25$); some of the mothers omitted responses to some of the survey items, so the number of respondents varied per question. The majority of the mothers were white, Catholic, and had completed their high school education (Table 1). About 52% had sons with Down syndrome and 48% had daughters. The survey included an optional question about family income, but not enough mothers provided a response to generate a reliable statistic.

Approximately 39% of mothers were over the age of 35 when they had their child with Down syndrome, higher than the 19% national average last reported in 1999 (Organización Mundial de la Salud). The average maternal age at birth for our respondents was 33.7 ($SD = 6.61$, $N = 456$) and, as determined by the age of their children with

Table 1 Characteristics of Mothers Responding to the Survey ($N = 467$)

Background variable	Percentage
Race ($n = 455$)	
White	99
Other	1
Religion ($n = 406$)	
Catholic	88
Christian	6
None	6
Educational level ($n = 449$)	
Did not complete basic education ^a	4
Basic education	24
Graduated from high school	30
Graduated from university	32
Received masters degree	3
Received doctorate degree	3
Other	4
Gender of child with Down syndrome ($n = 447$)	
Male	52
Female	48

^aLess than 8 years of education.

Down syndrome, the mothers provided perspective on postnatal medical support in Spain from 1972–2002, although the majority of our sample (about 75%) had children who were diagnosed in the past 15 years (Figure 1).

Prenatal Screening

The 45 mothers who responded to our survey and had a triple screen did not report being frightened, anxious, or suicidal after receiving the triple screen results. In fact, many reported feeling very optimistic, likely due to the fact that almost all of these respondents received negative triple screen results, indicating that their fetus did not have Down syndrome. “The test was favorable in that the doctors communicated to me that there were no problems with the pregnancy and everything was stupendous,” wrote one mother. After learning that their child was born with Down syndrome, however, many of these mothers felt betrayed by the test and their physicians. Said one mother who had received a negative result, “The incident . . . gave us much pain because the doctor placed his convictions in front of ours and did not continue to give us the option of deciding if we wanted to have the [amniocentesis].” Another was more blunt, “If I had known that my child would not come out well, he probably would not have been born.” Others expressed shock. “I did not believe that this child was mine because my gynecologist told me that my baby was a girl and that everything was

normal,” said one mother. “My gynecologist assured me that the result of my test or analysis of alpha-fetoprotein was good—that is to say, it was improbable that I had a child with problems such that it was a surprise that my son was born with Down syndrome,” said another.

Many did not realize that the triple screen was an inconclusive test. Said one mother, “I would have liked them to have clearly informed me of the risks after knowing the results.” Others wished to have been offered an amniocentesis for peace of mind and mental preparation:

I would have liked to know beforehand that my son had Down syndrome so that I would have been able to prepare, above all, emotionally and then to have had time to obtain information about the best way to educate my son.

For those who did receive triple screen results suggesting a risk of Down syndrome, physicians did not appear to include adequate amounts of information about Down syndrome in their explanations, nor did they disseminate a sufficient amount of printed materials to the mothers. In these cases, mothers felt pressured by their physicians to have an amniocentesis in order to confirm that the fetus had Down syndrome. Said one mother who had a triple screen and ultrasound,

My gynecologist, seeing from the first ultrasound the possibility of Down syndrome, pressured me to have an amniocentesis in the 12th week of the pregnancy (practically, assuring an abortion) ‘in order to finish with the problem beforehand.’ I did not have it. I did not return, and I changed my doctor.

We directly compared the survey responses from the 45 mothers who had triple screening tests with the 422 mothers who did not. We wanted to answer the question: Was the experience of receiving a postnatal diagnosis different for women who had prenatal screening? On every single survey question, the means from the mothers with triple screening fell within 1 *SD* of the means from those mothers who did not (Table 2). Because no differences emerged, we grouped all women together for subsequent analyses.

Waiting for the Diagnosis

Many expressed frustration over the seemingly long wait for information. “When they communicated the fact that my child had Down syndrome to my husband, they advised that he not tell me anything for another ten days,” wrote one mother. “Nobody would dare give me the diagnosis,” said another. Some mothers feared the worse when they

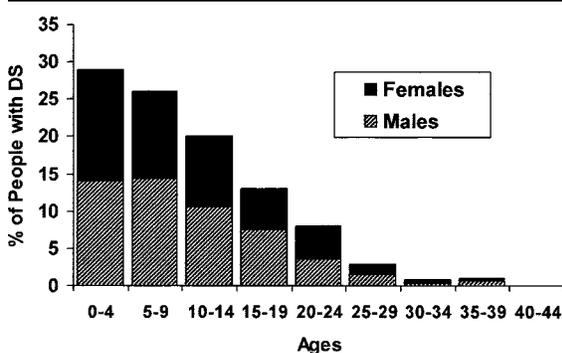


Figure 1 Distribution of ages from people with Down syndrome whose mothers responded to the survey. The majority of people with Down syndrome were under the age of 25 ($M = 10.8$, $SD = 8.08$, $n = 424$), meaning that the mothers provided perspective on postnatal medical support in Spain from 1978–2003.

Table 2 Comparing the Perceptions of Mothers Who Had Triple Screens With Those Who Did Not

Survey question/Response ^c	No triple screen ^a		Triple screen ^b
	Mean ^c	SD	Mean
When I learned that my child had DS^c			
I knew nothing about DS	4.40	2.43	3.80
I felt optimistic	2.27	1.94	2.50
I had suicidal thoughts	1.69	1.73	1.67
I felt anxious	5.14	2.33	5.55
I felt frightened	5.41	2.22	5.84
Physician behavior			
My physician gave me enough numbers of parents who have children with DS	1.84	1.78	2.07
My physician pitied my situation	3.43	2.28	3.67
My physician emphasized the negative aspects of DS	2.71	2.15	2.61
My physician talked about the negative aspects of DS	2.95	2.20	3.14
My physician emphasized the positive aspects of DS	2.57	2.20	2.93
My physician talked about the positive aspects of DS	2.87	2.26	3.49
Printed materials I received from my physician			
Had enough up-to-date information on DS	1.79	1.66	1.98
Was easy to read and comprehend	2.81	2.37	2.95
Helped me to understand DS	2.62	2.27	2.60
Emphasized the positive aspects of DS	1.96	1.77	2.49
Emphasized the negative aspects of DS	1.76	1.59	2.20
Provided an equal mix about the positive and negative aspects	2.19	1.99	2.47

^a $n = 422$. ^b $n = 45$. ^cMothers were asked to rate their level of agreement with the statements on a 1 to 7 Likert scale with 1 = *strongly disagree*, 4 = *neutral*, and 7 = *strongly agree*. DS = Down syndrome.

were separated from their child after birth and had not heard anything for hours. "I did not like the fact that they were hiding my daughter from me, and I did not know whether she was alive or dead," wrote one mother.

Receiving the Diagnosis

For the quantitative survey questions, we asked mothers to rate their level of agreement with the statements on a 1 to 7 Likert scale (1, *strongly disagree*; 4, *neutral*; and 7, *strongly agree*). Approximately half of mothers had some knowledge about Down syndrome prior to receiving the diagnosis, whereas the other half did not ($M = 4.33$, $SD = 2.43$, $n = 428$) (see Figure 2). Very few mothers felt optimistic about the experience ($M = 2.29$, $SD = 1.96$, $n = 413$). For those who did, their positive responses were significantly correlated with the fact that their doctors emphasized the positive aspects

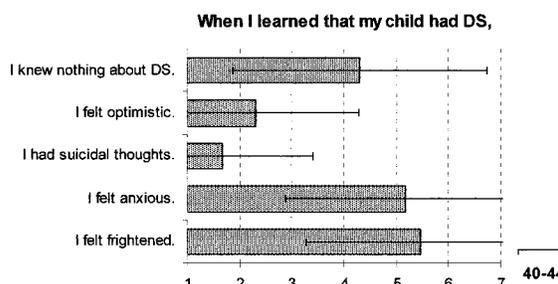


Figure 2 Mothers' reactions to learning that their child had Down syndrome. Mothers were asked to rate their level of agreement with the statements on a 1 to 7 Likert scale. Bars represent means; error bars represent 1 *SD*.

of Down syndrome, $r = .20$, $p < .05$, and the printed materials that they received also emphasized positive news about Down syndrome, $r = .18$, $p < .05$ (see Table 3).

The majority of mothers felt anxious ($n = 424$) and frightened ($n = 420$) ($M_s = 5.18$ and 5.46 , $SD_s = 2.31$ and 2.18 , respectively). "It simply is a bomb that explodes within your heart," said one mom. "I hope my daughter never asks me about how I reacted . . . because I would not lie to her, and the truth would be very painful," wrote another. "[The doctors] provoked a strong nervous breakdown, and I was not able to stop crying," said one mother. Some felt guilty, whereas others were scared of the future. Another mother said:

When I knew that my child had Down syndrome, I was frightened, but it was a fear of the unknown because you only know what you can see . . . you don't know more, and all people with Down syndrome are not the

First-time mothers and those who reported not knowing anything about Down syndrome were statistically more frightened upon learning the diagnosis (fright = $-.18$ pregnancies + $.18$ unknowledgeable, $R^2 = .06$). To be exact, for every prior pregnancy that a mother had, her level of fear upon learning that a current child had Down syndrome would be decreased by $.18$ levels; and, to the contrary, for every self-ranked level that a mother admitted she was unknowledgeable about the subject of Down syndrome, her level of fear would be increased by $.18$ units when given the diagnosis. $F(1, 398) = 1.71$, $p < .01$. Most people ($n = 415$) strongly disagreed that they had suicidal thoughts upon receiving the diagnosis ($M = 1.69$, $SD = 1.72$); however, the feelings were not unanimous. Those who did experience suicidal ideations also responded that they had received printed material that had emphasized the negative aspects of Down syndrome, $r = .20$, $p < .001$ (see Table 3). The mixed stepwise multiple regression analyses did not reveal any significant differences in the mothers' responses from 1972 to 2002.

Delivering the Diagnosis

The majority of mothers felt that they received little to no information from their physicians about Down syndrome (see Figure 3). The mothers disagreed that their physicians talked about ($n = 432$) or emphasized ($n = 406$) the positive aspects of Down syndrome ($M_s = 2.94$ and 2.61 , $SD_s = 2.21$, respectively). However, they also disagreed that their physicians talked about ($n = 407$) or empha-

sized ($n = 403$) the negative aspects of Down syndrome ($M_s = 2.97$ and 2.70 , $SD_s = 2.14$ and 2.21 , respectively). Some examples of mothers' statements are:

My attending physician and his team disappeared.

In my case, nobody told me anything about my daughter.

They ignored me, and my gynecologist would not pass by my room.

The mixed stepwise multiple regression analyses did not reveal any significance between the mothers' background characteristics and her feelings about how her physician had delivered the diagnosis.

Verbal Explanation

When the diagnosis did come, many mothers were upset that they did not receive additional information about Down syndrome during that same dialogue. "They told us our daughter had Down syndrome and there they stopped in the hall without saying anything more," wrote one mother. "They were dry and short of words," said another. When complete information was given, however, it was received with great appreciation by the mothers. For example,

My geneticist was very kind and explained to us the entire process of the syndrome. Some of the nurses talked to me about a friend that had a child with Down syndrome, and they arranged for us to get to know these parents.

The pediatrician that gave us the diagnosis gave me a very positive vision of Down syndrome, telling me that today they are able to attend universities.

My physician was also the father of a child with Down syndrome and informed me about what I ought to do so that my son received early stimulation. He gave me magazines from the [national parent organization] and the telephone number of the parent association that he belonged to.

The Setting

Some mothers were frustrated by the lack of privacy when the information was delivered. "They gave us the diagnosis with the room full of visitors, when I believe that it is a very delicate moment that requires some intimacy," said one mother. Other mothers were troubled by the fact that their husbands were asked to convey the diagnosis. "I did not like that they gave the diagnosis only to my husband . . . the diagnosis ought to be given to the parents together with the baby," said another.

Table 3 Correlations Between Mothers' Responses to Survey Questions

Mother	A	B	C	D	E	F	G	H
A	—							
B	.32***	—						
C	.46***	.25***	—					
D	.47***	.20***	.67***	—				
E	.76***	.25***	.44***	.46***	—			
F	.25***	.81***	.27***	.21***	.35***	—		
G	.27***	.17**	.26***	.19***	.22***	.15*	—	
H	.25***	.41***	.29***	.35***	.22***	.42***	.14*	—
I	.43***	.21***	.48***	.67***	.50***	.24***	.19***	.44***
J	.35***	.20***	.42***	.60***	.42***	.22***	.19***	.36***
K	.44***	.23***	.49***	.69***	.44***	.24***	.18***	.44***
L	.33***	.19***	.37***	.60***	.37***	.19***	.13**	.38***
M	.05	.03	.07	.01	.08	.08	.08	.07
N	.05	.07	.08	.04	.03	.06	.08	.12
O	.05	.07	.06	-.01	.04	.07	-.10	.20***
P	.12	.08	.05	.11	.20*	.13*	.07	.01
Q	-.05	-.02	-.01	-.07	.01	.01	.09	.01

Note: A: My physician talked about the positive aspects of children with Down Syndrome (DS); B: My physician talked about the negative aspects of DS; C: My physician gave me sufficient telephone numbers of parents who have children with DS; D: My physician gave me sufficient up-to-date printed material about DS; E: My physician emphasized the positive aspects of DS; F: My physician emphasized the negative aspects of DS; G: My physician pitied my situation; H: The printed material that I received emphasized the negative aspects of DS; I: The printed material that I received emphasized the positive aspects of DS; J: The printed material helped me to understand DS; K: The printed material that I received from my physician gave an equal picture of the positive and negative aspects of DS; L: The printed material was easy to read and understand; M: When I had my child with DS, I was frightened; N: When I had my child with DS, I was anxious; O: When I had my child with DS, I had suicidal thoughts; P: When I had my child with DS, I felt optimistic; Q: When I had my child with DS, I did not know anything about the genetic condition.

* $p < .05$. ** $p < .01$. *** $p < .001$.

The Language

The mothers ($n = 402$) disagreed, although weakly, that physicians pitied their situation ($M = 3.45$, $SD = 2.28$). However, many of them felt that the diagnosis could have been delivered with more sensitive wording. "My physician actually told me, 'Your daughter is Down syndrome.' I think it is more correct to say, 'She is a girl with Down syndrome,'" wrote one mother. In a similar variation, another mother remembered her physician saying, "Do you know what Down syndrome is? Well, you have one." Mothers who had children in all different years, most recently 2002, expressed anger that their physician still referred to their child with outdated vocabulary. Said one mother, "It disgusted me to hear for the first time the word, 'mongoloid,' as-

sociated with my son and the cold and aseptic form in which they talked about the topic." The physician's body language was also important to mothers. "One thing that I will never forget was the face of my attending physician, his head down as if he had shame," wrote one mother.

Support From Other Parents

Mothers ($n = 408$) strongly disagreed that their physicians gave them a sufficient number of phone numbers from parents who already had a child with Down syndrome ($M = 1.87$, $SD = 1.80$). "I believe that it is important to put mothers in contact quickly with other families that have sons or daughters with Down syndrome," wrote one mother. When put in contact with a parent support group, mothers

Table 3 Extended

I	J	K	L	M	N	O	P	Q
—								
.71***	—							
.77***	.75***	—						
.69***	.85***	.79***	—					
.01	.04	-.01	.05	—				
-.05	.08	.01	.06	.40***	—			
.02	-.01	-.03	-.05	.15**	.18**	—		
.18	.06	.13	.08	-.22***	-.25***	-.11	—	
.01	.03	-.03	-.03	.18***	-.01	.02	-.04	—

often noted that being given the opportunity to speak with other families helped them the most. “A nurse was the biggest help to us; he already had a child with Down syndrome and he was able to put us in contact with the parent association where they helped us much,” wrote one mother. Another mother spoke about her local parent support group, “They were the only ones that informed me about

all the aspects of Down syndrome, positive and negative.” Still another said, “After the birth of my son, [our local parent support group] came to the hospital to visit us and, from that moment, they have advised and helped us with everything.”

Printed Materials

Most mothers ($n = 408$) strongly disagreed that their doctors had given them enough up-to-date information on Down syndrome ($M = 1.81$, $SD = 1.68$) (see Figure 4). “The information that they gave me at the time of birth was scarce—that is, nothing,” wrote one mother. Said another, “I did not receive any information, neither good nor bad, from the doctor or the hospital.” The material that they did receive was not easy to read ($M = 2.83$, $SD = 2.33$, $n = 342$) and did not help them better understand Down syndrome ($M = 2.62$, $SD = 2.26$, $n = 368$). The material neither emphasized the positive nor the negative aspects of Down syndrome ($M = 2.22$, $SD = 1.97$, $n = 349$). “My gynecologist was very loving with me but he did not give me more information than that which was purely medical or statistical,” said one mother. Another noted:

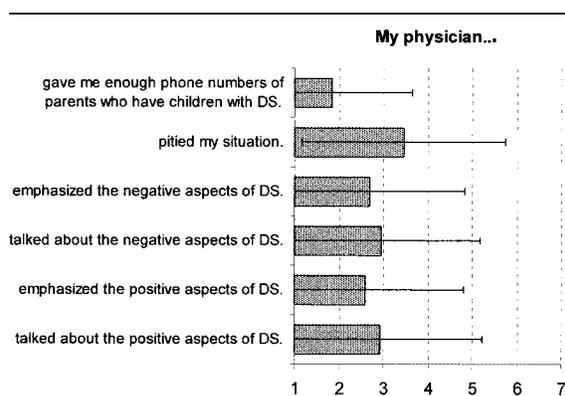


Figure 3 Mothers' opinions about physician behaviors when delivering the diagnosis of Down syndrome. Mothers were asked to rate their level of agreement with the statements on a 1 to 7 Likert scale. Bars represent means; error bars represent 1 *SD*.

They only commented to me that I need not worry because my child would talk and walk and when I asked for more information, he told me that with this, I already knew what I needed to know, and that I should not insist on something new because I was being annoying.

Those mothers who did reply that the printed material had helped them to understand Down syndrome also reported higher income levels (understanding = .17 income, $R^2 = .02$). Although the fit of this model was weak and the number of respondents who provided income levels was low, the prediction was, nonetheless, significant, $F(1, 164) = 5.08, p < .05$. The mixed stepwise multiple regression analyses did not reveal any significant differences in the mothers' responses about the printed materials between 1972 and 2002.

Changes in Physician Behavior

The mixed stepwise multiple regression analyses only revealed one significant difference in physician behaviors between 1972 and 2002. Physicians appeared to have increased, albeit in a very minor way, their efforts to give out phone numbers of other parents who have children with Down syndrome (see Figure 5: satisfaction level = -0.17 , child's age, $R^2 = .03$). This means that for every one unit increase in a child's age, all other variables held constant, the mothers' satisfaction level decreased by .17 units, $F(1, 374) = 10.84, p < .01$. In other words, parents of younger children with Down syndrome remembered their physicians giving out more

phone numbers than did parents of older children with Down syndrome. To be precise, mothers who had children in 2002 would be predicted to report a satisfaction level that was 1.7 units higher than those of mothers who had children in 1992. It is important to note, however, that 408 parents remained dissatisfied, and their responses never surpassed the neutral mark, despite the increase ($M = 1.87, SD = 1.80$). All other physician behaviors did not show any statistical change over time.

Discussion

Delivering and receiving news that a child has Down syndrome is not a positive experience for most physicians and mothers. Mothers reported feeling anxious, frightened, guilty, angry, and, in rare cases, suicidal upon receiving the diagnosis for their child. Most mothers felt that their physicians gave an inadequate amount of information. According to the majority of mothers, their physicians delivered the diagnosis in a quick and sterile manner, rarely talking about the positive aspects of Down syndrome. Mothers strongly disagreed that they were given enough printed materials by both their physicians and their hospitals. Only in a seemingly rare number of cases were mothers referred to parent Down syndrome support groups or given the phone number of a family who has a child with Down syndrome. Not much has changed since

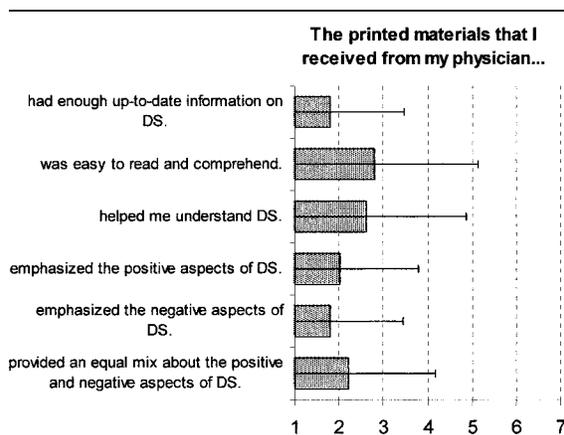


Figure 4 Mothers' opinions about the printed material that they received from their physician. Mothers were asked to rate their level of agreement with the statements on a 1 to 7 Likert scale. Bars represent means; error bars represent 1 SD.

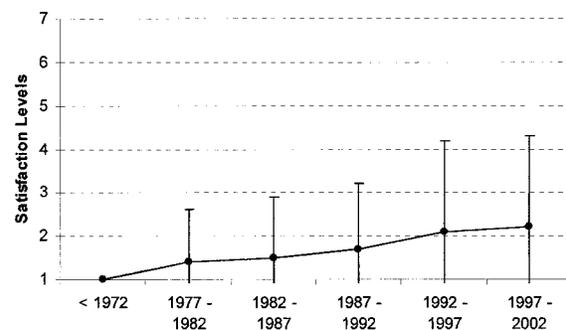


Figure 5 Mothers' satisfaction levels between 1972 and 2002 for the statement, "My physician provided enough telephone numbers of parents who have a child with Down syndrome." Physicians increased, albeit in a very minor way, their efforts to provide phone numbers (satisfaction level = -0.17 , child's age, $R^2 = 0.03$). Despite the increase, however, satisfaction levels never surpassed the neutral mark of 4.

1972. Physician behavior improved over time for only one variable; and even then the comments changed from strong dissatisfaction to mere dissatisfaction.

Recommendations for Health Professionals

From the qualitative and quantitative analyses of the survey responses, mothers recommended that health professionals change multiple components of postnatal support services. Many of these current recommendations are consistent with previously published studies and are noteworthy for the fact that mothers around the world have been making many of the same suggestions for several decades, implying little progress has been made. Here, for the first time, we have reported the recommendations from women in Spain, and these suggestions are based on the largest number of survey respondents to date.

1. *Health care professionals should clearly explain the results of prenatal testing.*

We never asked directly whether a mother had a false negative prenatal screening test result, but multiple mothers reported in the free-response section that this happened. When these women received a postnatal diagnosis for their child, they often felt that their physicians made a mistake in interpreting the prenatal test. It is incumbent upon physicians to explain as clearly as possible the sensitivities and specificities of each prenatal screening test.

2. *Information, suspicions, and thoughts should be conveyed to the mothers immediately.*

Many mothers described with frustration, and oftentimes anger, a disturbing silence that followed the birth of their child. Physicians avoided checking on them, and nurses did not make eye contact. For some mothers, the separation from their child lasted for many hours. During all of this, mothers were frightened and scared, not knowing what was happening to their child. Mothers prefer to know what the doctor is thinking right away—no matter how unsettling the thoughts—rather than waiting for a definitive diagnosis. This result confirms observations made from previously published studies with smaller sample sizes (Carr, 1970; Cooley, 1993; Cunningham, 1994; Cunningham & Sloper, 1977; Gayton & Walker, 1974; Krahn et al., 1993; Lucas & Lucas, 1980; Murdoch, 1983; Quine & Rutter, 1994; Stone, 1973).

3. *Physicians should deliver the diagnosis with both the mother and father in a private setting.*

In many cases, the physicians delivered the diagnosis of Down syndrome to the father and either requested or assumed that he would share the news with his wife. Mothers insisted that it is unfair and inappropriate to ask fathers to deliver the news because the fathers were just as shocked as the mothers. Whenever possible, the mothers requested that physicians share their suspicions about Down syndrome with both parents in a private setting, free from other visitors and hospital staff. These recommendations are consistent with previous studies (Cooley, 1993; Cunningham, 1994; Cunningham & Sloper, 1977; Garwick et al., 1995; Gayton & Walker, 1974; Klein, 1993; Krahn et al., 1993; Lucas & Lucas, 1980; Murdoch, 1983; Poeschel & Murphy, 1976; Stone, 1973).

4. *When delivering the diagnosis, health care professionals should use sensitive and compassionate language.*

Mothers request that physicians never use the “M word” and, when talking to others, physicians should refer to the child as a child and not a syndrome. Because not all people share the same religious beliefs as their physicians, mothers also request that doctors avoid saying that children with Down syndrome are “gifts from God.” The need for physicians to use more sensitive and respectful language has been noted in multiple studies (Berg et al., 1969; Cooley, 1993; Cunningham, 1994; Cunningham & Sloper, 1977; Hedov et al., 2002; Krahn et al., 1993; Lucas & Lucas, 1980; Poeschel & Murphy, 1976; Quine & Rutter, 1994; Stone, 1973).

5. *Health care professionals should give additional factual information right away.*

Mother after mother expressed frustration about receiving a curt announcement that their child had Down syndrome without any additional information. Mothers ask that physicians take their time to explain the genetic cause of Down syndrome and include information about what the future may look like for their child. Physicians should include factually positive information but not neglect to mention the challenges that children with Down syndrome can encounter, consistent with previous recommendations (Cooley, 1993; Cunningham, 1994; Cunningham & Sloper, 1977; Hedov et al., 2002; Krahn et al., 1993; Quine & Rutter, 1994; Springer & Steele, 1980; Stone, 1993).

6. *Health care professionals should provide parents with an up-to-date reference list of printed materials.*

Most mothers were frustrated by the lack of information that they were given following the birth of their child, consistent with previously published reports (Cooley, 1993; Cunningham, 1994; Garwick et al., 1995; Gayton & Walker, 1974). Comprehensive parent-to-parent guides and health manuals have been available in Spanish for quite some time. In 1980, El Ministerio De Sandidad y Seguridad Social published the book *Estimulación precoz en casa: Guía práctica para los padres*, a translation of the book by Cunningham and Sloper (1978). In 1984, the journal *Revista Síndrome de Down* began publication for parents and professionals. and, as early as 1985, Centro de Educación Familiar Especial published *Síndrome de Down*; and in 1986 Maria José Bucket Cancel published *Programs de Stimulation Tympana en Nines con Síndrome de Down*. Therefore, health care professionals cannot claim that there has been a lack of publications. Mothers request that, at minimum, hospitals provide them with a bibliography of the most current literature on Down syndrome. The reference list should not just be confined to medical texts, but should include positive stories, biographies, and parent-to-parent guides.

Another good book (Stray-Gundersen, 1995) is available. In addition, the book *Bebés Con Síndrome de Down* by Stray-Gundersen (1995) is available. Whenever possible, it would be ideal for the hospital (or the parent support groups who visit new parents in the hospital) to provide these printed materials, at no cost, to the mothers. Doing so minimizes the stress and anticipation involved in finding them.

7. *If needed and/or requested, a counselor should be available.*

Based on the analyses from the mixed stepwise multiple regressions, we found it difficult to predict which mothers, based on their background characteristics, are going to feel optimistic or pessimistic about the birth of their child with Down syndrome. Only one variable—the number of pregnancies—was associated with fear levels; but even then, the fit of the model was very weak. As such, hospitals should be ready to make counselors available for any mother who has a child with Down syndrome, consistent with previously published recommendations (Krahn et al., 1993).

8. *Health professionals should not question a mother's decision to have her child.*

After their child had been born, many mothers were insulted and oftentimes angered when they needed to explain why they chose to continue the pregnancy, if prenatal tests were offered. Mothers like to be congratulated just as any new mother, and health care professionals should support the parents with the same behaviors they use with any other delivery. According to one mother, the best part of the process was when the doctors “gave me congratulations: I had had a son.”

9. *Hospitals and birthing clinics should establish partnerships with local parent support groups.*

Almost every mother suggested it would be helpful to be connected with a local parent Down syndrome support group, consistent with previously published recommendations (Cooley, 1993; Cunningham, 1994; Cunningham & Sloper, 1977; Gayton & Walker, 1974; Klein, 1993; Lucas & Lucas, 1980). In those cases where a phone number was given or, even better, when a representative of the support group came to the hospital, the mothers were extremely grateful. Hospitals should establish a working relationship with local parent support groups, which can provide practical knowledge in addition to establishing the beginnings of a long-term support relationship.

All nine of these recommendations are tangible, in many ways, because they would be easy to implement. Furthermore, application of these items might have lasting positive impacts on parents' ability to adapt and cope for years to come. Summers, Behr, and Turnbull (1988) hypothesized that family members may change their subjective perceptions of raising a child with a disability by invoking three cognitive-coping strategies: (a) attributing a cause for the event, (b) establishing a sense of mastery or control over the event and over one's life, and (c) enhancing one's self-esteem. The recommendations made by parents in this study support each of these dimensions.

Some physicians might, however, ask, Is dissatisfaction not inevitable with the disclosure of an unexpected postnatal diagnosis such as Down syndrome? Mothers in our study commented on their emotions independent of their policy recommendations, suggesting that they were able to distinguish between their sadness associated with the actual diagnosis and their frustrations with the events surrounding the diagnosis. Previous research also

supports the conclusion that dissatisfaction is avoidable. Cunningham et al. (1984) surveyed the perceptions of two cohorts of mothers with a child who had Down syndrome—those who received a diagnosis under normal protocols practiced by their physicians and those who received a diagnosis under a “model service,” where physicians were trained to incorporate all of parental suggestions published up to that time (Berg et al., 1969; Carr, 1970; Cunningham & Sloper, 1977; Drillien & Wilkinson, 1964; Gayton & Walker, 1974; Lucas & Lucas, 1980; Pueschel & Murphy, 1976; Springer & Steele, 1980; Stone, 1973). In the model service cohort, 100% of mothers reported that they were satisfied with the delivery of the diagnosis for their child; in the control group, only 20% of mothers expressed similar satisfaction (Cunningham et al., 1984). The conclusion seems obvious: When parental suggestions are implemented, satisfaction levels improve.

Future Research

For the first time, the recommendations of mothers have been confirmed with a robust sample size in one central questionnaire. Prior to this study, the perceptions and suggestions of parents were mostly limited to small focus groups of less than 50 persons. This made the comparison among groups difficult and the recommendations for change weak. The time is now ripe to begin an aggressive research agenda on postnatal medical support. As an immediate measure, every hospital and medical clinic should conduct a needs assessment among its own patients. Specifically, mothers should be asked no later than 6 months after receiving a postnatal diagnosis how the process could have been better. Hospitals and medical clinics should also evaluate its health care professionals on an annual basis to determine whether they are incorporating the recommendations outlined in this article.

As evidenced by the copious notes and letters that accompanied survey responses, mothers remember the deliveries of their children with Down syndrome with clarity and crisp detail, even those whose deliveries took place nearly 25 years ago. Neuroscientists have described such unusually vivid phenomena as flashbulb memories (Brown & Kulik, 1977; Conway et al., 1994; Finkenauer et al., 1998; Wright & Gaskell, 1995). Future retrospective studies can and should benefit from parents' abilities to recall the births of their child. As an example, researchers should explore the sentiments of fathers

after receiving a postnatal diagnosis of Down syndrome for their child. Additional investigators could sample parents who received postnatal diagnoses other than that of Down syndrome. The diagnosis of Down syndrome is, in many ways, a staged drama: The unique characteristics are manifest immediately at birth, and in nearly all cases, the diagnosis is made before the mother leaves the hospital. Are parental emotions, needs, and concerns different when children have diagnoses with unscripted timetables? When children are diagnosed weeks, months, or years after delivery, do the reactions of mothers and fathers change? Within the past decade, such research has been sparse and limited to small sample sizes (Hasnat & Graves, 2000; Sloper & Turner, 1993). Featherstone (1980), whose son was born with multiple cognitive and developmental disabilities from a toxoplasmosis infection, described feelings that she believed are experienced by all parents who have children with disabilities: fear, anger, loneliness, and guilt. Future researchers should assess the applicability of these feelings to all childhood disabilities and with larger sample sizes.

Another important component that needs to be studied is the perspectives of physicians and other health care professionals. It would be interesting to determine the correlations between physicians' characteristics (e.g., age, training, years of practice) and parental satisfaction levels. The current study was limited to mothers' observations, but future researchers might interview physicians and their patients, linking the reflections between the two groups.

Of course, physicians across the world practice within different medical systems. To date, research from England, Scotland, Ireland, Spain, Sweden, Australia, and the United States suggest that women are strongly dissatisfied with the care they receive following a postnatal diagnosis. Are these sentiments shared by mothers from other countries? What impact do different medical models have on mothers' satisfaction levels?

Limitations of Current Study

As with all retrospective surveys, our current study is subject to recall bias. The mothers answered the survey with an average of 10 years of hindsight, and an open question remains: Would the mothers have answered similarly about their experiences if surveyed right after the birth of their children? From the clarity in which mothers have described

their postnatal support services, however, it appears that receiving the diagnosis of Down syndrome for a child is a true flashbulb memory—accurate, complete, and never forgotten (Brown & Kulik, 1977; Conway et al., 1994; Finkenauer et al., 1998; Wright & Gaskell, 1995). A previous longitudinal study also supports this conclusion (Carr, 1988). In England, 21 mothers who had children with Down syndrome were interviewed before their child was 2 years old and again, with identical questions, 21 years later. Mothers were asked about how they felt when they received a diagnosis of Down syndrome for their child, how the diagnosis was made, and what could be improved about support services. Across the 10 questions that were asked, 82% of the replies were essentially the same after the 21-year interim. In truth, we did not sample the immediate raw opinions of mothers after the birth of their child, but it is reasonable to assume that their opinions have not morphed much.

The present study is also subject to selection bias. The mothers who responded to this survey represented only 2% of all mothers in Spain who had children with Down syndrome. It is possible that only mothers who were most upset by their postnatal support services decided to respond to the survey request. Still, this is the largest sample size of women who received postnatal medical support in any country, to date. In Spain, mothers are unaccustomed to receiving mailed questionnaires, and there is no particular reason to believe that our respondents were different than any other mothers who have children with Down syndrome throughout the country. At minimum, even if every other mother would have answered the survey oppositely, the problems identified in this study were real ones for a sizable number of mothers.

Implications

Despite the best efforts of Down syndrome advocates, 25 years have passed with little progress made in postnatal medical supports, according to mothers. The birth of a child is a highly anticipated and emotional time for any parent. When a previously planned birth is made more complex with a diagnosis of Down syndrome, physicians and medical staff must be careful to share the news with utmost sensitivity and respect for the mother. It is irresponsible and inappropriate for health care professionals to ignore recommendations made by mothers in this study. Their suggestions are not revolutionary, costly, or difficult to implement. In fact,

they are rather embarrassing reminders of how uncivilized some health care professionals have become or remained.

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