UPDATE ARTICLE

ARTICOLO DI AGGIORNAMENTO

Communicating the postnatal diagnosis of Down's syndrome: an international call for change

Cambiare il modo di comunicare la diagnosi postatale di sindrome di Down: una esigenza internazionale

B.G. SKOTKO
Harvard Medical School & Harvard's John F. Kennedy School of Government

Summary

Objectives. To analyze the reflections of mothers in the United States and Spain about how they received a postnatal diagnosis of Down's syndrome (DS) for their children.

Methods. An 11-page survey was mailed to 2,945 mothers in the United States and to 6,125 mothers in Spain.

Results. The majority of mothers reported that their physicians were insufficient and, at times, offensive when delivering a diagnosis of DS. Mothers in both countries claimed that their physicians rarely talked about the positive aspects of DS and did not provide enough up-to-date printed materials or referrals to other parents.

Conclusions. Mothers have now called upon the global community of physicians to improve the way in which postnatal diagnoses are delivered. Specific recommendations are offered herein.

Riassunto

Scopo. *Analizzare le riflessioni di madri in Spagna e negli Stati Uniti sul modo in cui è stata comunicata loro la diagnosi post-natale di sindrome di Down nei loro figli.*

Metodo. *È stato inviato per posta un questionario di 11 pagine a 2.945 madri negli Stati Uniti e a 6.125 donne in Spagna.*

Risultati. *La maggior parte delle madri ha riferito un atteggiamento inadeguato e a volte offensivo da parte del medico nel comunicare la diagnosi di sindrome di Down. Le donne di entrambi i paesi sostengono che raramente i medici parlano di aspetti positivi e non forniscono sufficiente documentazione aggiornata o contatti con altri genitori di bambini Down.*

Conclusioni. *Le madri fanno appello alla comunità medica per migliorare il modo in cui, dopo la nascita, viene comunicata la diagnosi di Sindrome di Down; in questo articolo vengono fornite specifiche raccomandazioni.*

Key words

Down's syndrome • Postnatal • Diagnosis

Parole chiave

Sindrome di Down • Post-natale • Diagnosi

Received: April 21, 2005

Correspondence:
Brian G. Skotko
12 Greenway Ct., Suite 5
Brookline, MA 02446, USA
Tel. +1617 739-0807
Fax +1617 738-0807
E-mail:
Brian_Skotko@student.hms.harvard.edu

Introduction

Despite the increased usage of prenatal testing, the majority of mothers who have children with Down's syndrome (DS) do not learn of the diagnosis until after their child is born [1 2]. Delivering that diagnosis well can challenge even the most practiced physicians, and receiving the news typically alarms the otherwise happy new parents. Until recently, research into this staged drama was limited to mere reflections or very small sample sizes [3-24]. Now, two large comprehensive studies have been carried out in the United States and Spain, analyzing the reflections of mothers who had received diagnoses of Down's syndrome for their children [1 25 26].

The majority of mothers in the United States reported being frightened or anxious upon learning that their child had Down's syndrome [1]. They claimed that their physicians talked little about the positive aspects of DS and rarely provided a sufficient amount of up-to-date printed materials or referrals to other parents. Mothers in Spain also reported feelings of anger, guilt, fear, and anxiety upon receiving the diagnosis for their child [25]. They, too, claimed that they had received poor information and were not given a sufficient number of phone numbers to other parents who had children with DS. The purpose of this research article is to ask: what similarities and differences exist between the way in which a postnatal diagnosis is delivered in the United States and Spain? And, by extension, what common recommendations can be extracted for the international community of physicians?

Materials and Methods

SAMPLE

For this study, surveys were distributed exclusively to mothers of children with DS (as opposed to other family members) in order to standardize the perspectives of our respondents and to record the sentiments of the person most intimately involved with the pregnancy. This study was implemented in the United States and Spain for multiple reasons: (1) the evolution of the disability parent movement in Spain has mirrored, in many ways, that of the United States, (2) Spain has a national Down's syndrome parent organization, allowing for access to a large sample size, and (3) the Institute on Community Integration (INICO) in Salamanca, specializes in disability research, could provide technical support for a widespread survey distribution.

In Spain, 6,125 surveys were distributed to mothers on the mailing lists of (1) the Down's syndrome parent groups associated with national Down's syndrome organization, Federación Española del Síndrome de Down, (2) the Fundación Síndrome de Down de Cantabria, and (3) the Fundación Síndrome de Down de Madrid. Because there is no national database of families who have children with DS in the United States, 2,945 surveys were distributed through 5 DS parent support groups, chosen for their large membership size and geographic distribution: the Mile High Down's syndrome Association (Colorado), Triangle Down's syndrome Network (North Carolina), Massachusetts Down's syndrome Congress (Massachusetts), Down's syndrome Association of Los Angeles (California), and the Down's syndrome Association of Rhode Island (Rhode Island).

SURVEY INSTRUMENT

An 11-page survey instrument, previously described [1 2 25 26], was translated into Spanish and English and received approval from the Committee on Human Studies at Harvard Medical School. The survey gathered both quantitative and qualitative data with yes/no questions, open-ended questions, and a series of statements 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" being "neutral", and "1" meaning "strongly disagree").

DATA ANALYSES

For this current study, the Kruskal-Wallis test was used to measure the significance between the means of mothers' responses in Spain and those from the United States. Reported here are the p values. The means and SDs used to calculate this significance were taken from previous papers [1 25 26].

Results

RESPONDENTS

Of the 2,945 surveys mailed in the United States, 1,250 (42.4%) were returned. Of these, 43 were excluded because they were completed by fathers, and 81 were excluded because they were returned with an indication that the respondent did not want to or could not complete the questionnaire. An additional 141 were completed by mothers who had received a prenatal diagnosis based on amniocentesis results, and 103 underwent some form of prenatal screening with no confirmatory chronic villus sampling (CVS) or amniocentesis testing. These results are reported elsewhere [1 2]; analyzed here are the remaining 882 responses.

Of the 6,125 surveys mailed in Spain, 501 (8.2%) were received. Of these, 29 were excluded because they were completed by fathers or other family members. An additional 5 were completed by mothers who had received a prenatal diagnosis based on amniocentesis results, and 45 were from mothers who had triple screen analyses without further prenatal testing. These results are reported elsewhere [25 26]; analyzed here are the remaining 422 responses.

The majority of the mothers from the United States and Spain were white, Catholic, and college graduates, although the religious identification of women in Spain tended to be more uniform (Tab. I). When her child with DS was born, the average mother was 32.3 years of age in the United States (SD = 5.6) and 33.7 in Spain (SD = 6.61). Approximately 29% of the mothers from the United States and 39% of those from Spain were over the age of 35 when they had their children with Down's syndrome. Mothers from the United States provided perspective on postnatal medical support from 1964 to 2003 (Fig. 1); mothers from Spain provided commentary from 1978-2003 (Fig. 2). Changes in these opinions have slowly improved over time in both of these countries; the evolution is described in previous reports [1 25 26].

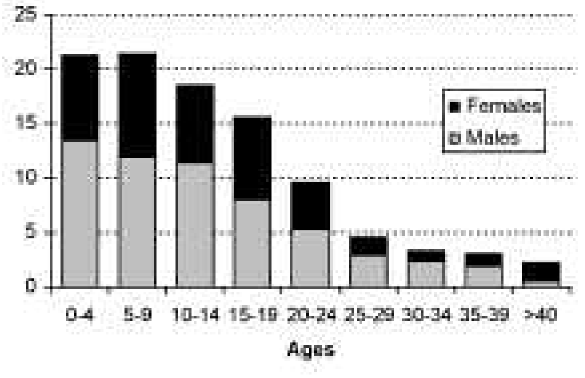
REACTIONS TO RECEIVING THE DIAGNOSIS

The response upon learning that a child has DS is similar between countries: Mothers consistently reported being frightened and anxious (Tab. II). While those in the United States tended to have more anxiety (United States: M = 5.8, SD = 1.7; Spain: M = 5.14, SD = 2.33; $p < 0.01$), the fear level between mothers were statistically similar. In neither country was suicidal ideation common. About half of the mothers in Spain and the

Tab. I. Characteristics of Mothers Responding to the Survey.

Background Characteristics	United States (%)	Spain (%)
Race		
White	84.8	99.0
Hispanic or Latino	8.1	0.0
Asian	3.5	0.0
Black	2.2	0.0
American Indian or Alaska Native	0.1	0.0
Other	1.2	1.0
Religion		
Catholic	42.9	88.0
Christian (unspecified)	16.7	6.0
Protestant (unspecified)	6.9	0.0
None	5.0	6.0
Other	28.5	0.0
Educational Level		
Basic education not completed	0.3	4.0
Basic education	0.9	24.0
Graduated from high school	29.2	30.0
Graduated from university	48.5	32.0
Received Masters degree	17.5	3.0
Received doctorate degree	3.4	3.0
Other	0.0	4.0

Fig. 1. Distribution of ages of people with DS whose mothers responded to the survey in the United States. The majority of people with DS were < 35 years of age (M = 10.5 years, SD = 13.9 years; N = 929), but the mothers were able to provide perspective on postnatal medical support from 1964 to 2003.



United States had some prior knowledge about DS prior to receiving the diagnosis, whereas the other half did not. In sum, neither group of mothers felt positive upon receiving the diagnosis, with mothers from Spain feeling even more gloom (United States: M = 2.9, SD = 1.9; Spain: M = 2.27, SD = 1.94; $p < 0.001$)

PHYSICIAN BEHAVIORS

When their physicians explained DS for the first time, mothers in both the United States and Spain reported that these doctors neglected to talk about the positive aspects of the condition (Tab. II) (United States: M = 3.0, SD = 2.1; Spain: M = 2.87, SD = 2.26; $p = 0.06$). About half of the mothers in the United States suggested that their physicians talked about negative aspects of DS (such as, medical complications and cognitive difficulties), and some reported that their pediatricians emphasized these aspects. The same responses could be found in Spain, but the majority of these mothers reported that their physicians did not talk about the positive aspects either, suggesting that they received little to no information at all (Tab. II).

Mothers from both countries expressed a wish that they had learned of the diagnosis as soon as their physicians suspected it [1 25]. They took note of the "silence" that seemed to surround their child's birth, sensing that their physicians were trying to avoid telling them something. Mothers reported that this hesitancy by physicians only contributed to mounting fear and anxiety. Many of the mothers also reported, with anger, that they were informed without their partner present and often in a public setting [1 25]. By contrast, mothers who had their partners present appreciated the added support, and those who had their own rooms were grateful for the privacy to express their emotions, as needed.

In both countries, mothers reported that some physicians are still (even today) using offensive language. In some cases, both in Spain and the United States, physicians intimated that the birth of a child with DS was regrettable, and in other circumstances, pediatricians used antiquated and derogatory vocabulary, such as the "M word" [1 25].

Mothers in both countries also felt that they were not provided with enough telephone numbers of other parents who have a child with DS [1 25]. While the feelings

Tab. II. Comparison Between Mothers' Responses in the United States and Spain to Postnatal Diagnosis.

Responses	United States* M‡	United States* SD	Spain† M‡	Spain† SD	p value
When I learned that my child had DS					
I had no prior knowledge about DS	4.1	2.4	4.40	2.43	0.08
I felt positive	2.9	1.9	2.27	1.94	< 0.001
I had suicidal thoughts	1.6	1.6	1.69	1.73	0.51
I felt anxious	5.8	1.7	5.14	2.33	< 0.01
I felt frightened	5.5	2.0	5.41	2.22	0.30
Physician Behavior					
My physician provided me with enough telephone numbers of parents of a child with DS	2.4	2.1	1.84	1.78	< 0.001
My physician provided me with enough up-to-date printed material on DS	2.4	2.0	1.79	1.66	< 0.001
My physician pitied me	3.7	2.2	3.43	2.28	0.03
My physician emphasized the negative aspects of DS	3.7	2.1	2.71	2.15	< 0.001
My physician told me about the negative aspects of DS	4.1	2.1	2.95	2.20	< 0.001
My physician emphasized the positive aspects of DS	3.0	2.0	2.57	2.20	< 0.001
My physician told me about the positive aspects of DS	3.0	2.1	2.87	2.26	0.06
The printed materials that I received from my physician					
were easy to read and comprehend	4.0	2.2	2.81	2.37	< 0.001
were helpful for understanding DS	3.7	2.2	2.62	2.27	< 0.001
emphasized the positive aspects of DS	2.9	2.0	1.96	1.77	< 0.001
emphasized the negative aspects of DS	3.1	2.0	1.76	1.59	< 0.001
provided equal mixture about the positive and negative aspects	3.0	1.9	2.19	1.99	< 0.001

* N = 882. † N = 422. ‡ 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).

in Spain were more grim (Tab. II) (United States: M = 2.4, SD = 2.1; Spain: M = 1.84, SD = 1.78; $p < 0.001$), the mothers in the United States rarely reported that they had received a referral. Those who did, valued the emotional support, educational materials, networking, and social opportunities provided by these parent groups.

PRINTED MATERIALS

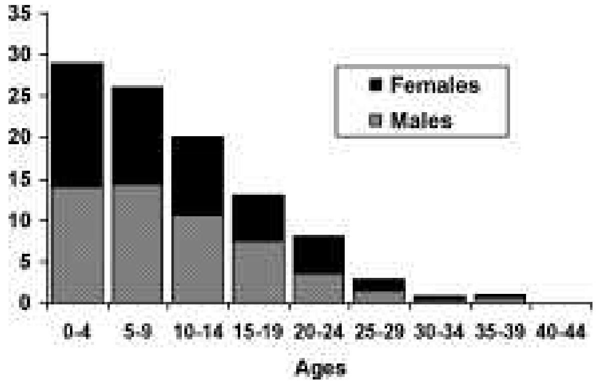
Nearly all mothers in both the United States and Spain reported that their physicians did not provide them with enough up-to-date printed materials on DS, with the mothers in Spain reporting even less (Tab. II) (United States: M = 2.4, SD = 2.0; Spain: M = 1.79, SD = 1.66; $p < 0.001$). While mothers in the United States reported that the little information that they did receive was easy to read and comprehend, the literature did not provide a balanced approach of the positive and negative aspects of DS (Tab. II).

Discussion

Mothers in both the United States and Spain rarely reported that the birth of their child with DS was a positive experience. They were frightened and anxious upon receiving the diagnosis and frustrated that their physicians failed to explain the positive aspects of DS, provide up-to-date printed materials, or offer the contact information for local parent support groups. While statistical differences emerged between Spain and United States, the differences ranged between terrible and just bad (Tab. II). Mothers in Spain tended to respond with more dissatisfaction for their physicians. This could be explained by (1) cultural differences between the two countries, (2) differences in physician practices in Spain and the United States, or (3) both.

To the extent that national laws reflect the consent of the people, Spain and the United States have different cultural respects for individuals with Down's syndrome. Spanish laws assume that mothers would want to terminate a child with Down's syndrome if diagnosed prenatally. According to Articles 144 and 145 of the Spanish penal code (Organic Law 10/1995, November 23, 1995), a woman is legally allowed to terminate a pregnancy only if (1) her life is at risk by continuing the pregnancy, (2) the pregnancy is the result of rape, or (3) the fetus would be born with grave physical or psychological defects. The reasoning for the third case, as outlined in the law, is to "avoid the birth of persons with high probability to be unhappy and with a subminimal quality of life". The purpose is also to "avoid disturbance of the parents and the family atmosphere". Article 2 of the Ministerial Notice of Health and Consumption (July 31, 1985) outlines which "physical and psychological defects" qualify; among those included

Fig. 2. Distribution of ages from people with Down syndrome whose mothers responded to the survey in Spain. 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 from 1978 to 2003.



are "chromosomal alterations". Therefore, as codified in its laws, Spain suggests that people with Down's syndrome lead unhappy and sub-minimal lives. When a mother in that country has a child with Down's syndrome, with no prenatal testing, she will need to confront a medical system – and a society – that operates by these principles. In the United States, by contrast, all terminations are legally permissible before the second trimester and, in some rare cases, during the third trimester. Mothers may electively choose to abort a fetus prenatally diagnosed with Down's syndrome, but there is no national law singling out genetic conditions. Unlike Spain, the United States has not codified the elective terminations of people with Down's syndrome. To this extent, the United States might be more accepting of people with disabilities, as reflected in the comparatively more positive responses from its mothers. Mothers' attitudes from other countries are likely dependent, in part, on their society's appreciation for individuals with exceptionalities.

Yet, despite the differences, mothers in the United States and Spain have agreed that the birth of a child with DS need not be a gloomy affair if physicians consider espousing a few recommendations. Independently, mothers from both countries were asked to provide commentary on how their health care provider could improve, and from hundreds of pages of submitted reflections emerged many common suggestions:

1) *The person to deliver the diagnosis should be a physician*. When a mother learns about the diagnosis of DS for her child, she is certain to have questions and concerns. Mothers who received the news from nurses, lactation specialists, and, in some cases, volunteers did not feel that they received sufficient information or support;
2) *The physician should deliver the diagnosis with both parents together, whenever possible*. In many cases, pediatricians or neonatologists inform the father about the diagnosis of DS, obligating him to share the news with the mother. Mothers have insisted that it is both unfair and inappropriate to ask fathers to fulfill such a role since they are often just as shocked and unfamiliar with DS as the mothers. More commonly, mothers are informed alone without the comforting support of their partner. Frightened and anxious, they report intense difficulty in repeating to the fathers what a physician had explained to them. In short, the physicians should wait, within reason, for the father to be present when delivering the diagnosis. If the father of the child is not readily available, the physician should explain the news to the mother and offer to review everything again when the father returns;
3) *The physician should deliver the diagnosis in a private setting*. Receiving the diagnosis for the first time can be emotionally taxing for some, if not most, mothers. Those mothers who received the unsuspecting diagnosis with other family members present or with a hospital roommate nearby reported intense anger for their physician. Mothers ask that physicians bring the mother and father into a private room to explain DS. If possible, a private room should also be offered after the diagnosis is conveyed so that the couple has space to explore their deep emotions;
4) *The physician should convey the diagnosis as soon as he or she suspects it*. One of the most common sources of frustration – and anger – among mothers was a period of "silence" that seemed to loom around the birth of their child. Mothers felt avoided, as though they could not get any answers from physicians or the medical staff. The hesitancy from doctors to convey their suspicions contributed immensely to the anxiety surrounding the day. Rather than waiting for the diagnosis to be confirmed with a genetic karyotype, a physician should share with parents his or her suspicions about DS and what steps should be taken to confirm the diagnosis. Mothers said they valued transparency in the decision-making process. Of course, a physician can also inappropriately inform a mother too soon. Some mothers were informed while episiotomies were being sutured. In sum, a physician should convey the diagnosis when he or she suspects it, but not until a mother has settled from the birthing process itself;
5) *The physician should use sensitive language*. The tone of the conversation is frequently established by the first words used by the physician. Instead of saying "I'm sorry" or "I have some bad news to share," physicians should first congratulate parents on the birth of their child. Mothers emphasized that having a child with DS is not a tragedy and should not be introduced as one. Also, the "M word" is wholly derogatory and no longer deserves a place in medical nomenclature;
6) *The physician should include the positive aspects of DS when explaining the diagnosis*. Mothers would like to receive a balanced and accurate portrait of DS. Many reported that their physicians failed to

mention any of the positive possibilities and realities for people living with DS today. Mothers considered it the responsibility of physicians to stay informed of the educational and social potentials of children with DS. Knowing the scientific literature alone is not sufficient. Physicians can find useful information about the achievements of people with Down's syndrome in *Common Threads: Celebrating Life with Down Syndrome* [27], *Down Syndrome: Visions for the 21st Century* [28], and *Down Syndrome: A Promising Future, Together* [29];

7) *The physician should not share his or her personal opinion*. Mothers requested that physicians offer sound medical advice based on the most up-to-date information. Unless specifically requested by the mother, personal opinions are not warranted. Some mothers felt that their decision to have a child with DS was being questioned by their physicians;
8) *Parents should be provided with up-to-date printed material*. When the diagnosis is being shared, physicians should provide up-to-date printed material on DS. Many mothers suggested the books: *Babies with Down Syndrome: A New Parent's Guide* [30]; *Common Threads: Celebrating Life with Down Syndrome* [27]; *Life as We Know It: A Father, a Family, and an Exceptional Child* [31]; *Count Us In: Growing Up with Down Syndrome* [32]; and *A Parent's Guide to Down Syndrome: Toward a Brighter Future* [33]. When printed materials cannot be provided for financial reasons, a reference list of the most current literature should be substituted. One such list can be found on the web page for the National Down Syndrome Congress in the United States (http://www.ndsccenter.org/resources/print.htm);
9) *The physician should offer the contact information of a local support group*. Mothers repeatedly stated that their local DS parent support groups were of invaluable help, especially during the first few years of a child's life. Every physician should know the contact information of the local DS support group in their area. Oftentimes, a national DS parent organization, like the National Down Syndrome Society in the United States, maintains a directory of these groups online for easy and ready access.

As with all retrospective studies, this research is subject to recall bias. The mothers answered the survey with an average of 11 years of hindsight in the United States and 10 years in Spain. Because of the clarity in which they responded, however, receiving an unexpected diagnosis might represent a true flashbulb memory – complete, accurate, and immune to forgetfulness [34-36]. This study is also subject to selection bias. Only mothers who were members of DS support groups were sampled. It is possible that only mothers who had the most difficult experiences coping with the birth 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 in either country, and since there are no national databases of families who have children with DS, using support groups remains the most robust distribution mechanism. The response rate from mothers in Spain was also low, compared to that of the United States. Possible explanations include: (1) mothers in Spain are not as accustomed to receiving research questionnaires in the mail as are the families in the United States, (2) mothers from the United States were more apt to respond since the researcher was their citizen while mothers from Spain were reluctant to respond to someone from another country, or (3) a combination thereof.

Between Spain and the United States, however, more than 1,300 mothers have now called for a reform in the way physicians deliver a diagnosis of Down's syndrome. Previous research in England, Scotland, Ireland, Sweden, and Australia also suggested that women are strongly dissatisfied with the way in which the diagnosis of DS is conveyed [3,4,6,7,11,12,14,17,19,21,23]. Clearly, the worldwide community of pediatricians and neonatologists have now received a mandate for improvement. Mothers are asking that physicians engage in an international dialogue on how best to implement their recommendations. While the communication of such sensitive diagnoses will continue to remain challenging, one thing remains clear: the time for change is now. Let us begin.

Acknowledgements

Financial support was provided by the Tim White Fund and the Mental Health & Developmental Disability scholarship from Children's Hospital Boston, the Dybwad International Scholarship, and Harvard Medical School's international scholarship and part-time research grants.

I sincerely thank Allen Crocker, M.D., for his expansive wisdom and warm support throughout my endeavors. I further thank Ricardo Canal Bedia, Ph.D., of the University of Salamanca, for his co-authorship on my studies in Spain. Maria Victoria Martin Cilleros provided administrative assistance with the assembly and collection of surveys in Spain, and Antonio Pascual of FEISD and Jesus Florez, M.D., Ph.D., of the Fundación Síndrome de Down de Cantabría arranged for the distribution. José Florez, M.D., translated the survey into Spanish, and Kerim Munir, M.D., Deborah Metzel, Ph.D., David Helm, Ph.D., Carola Eisenberg, M.D., Edward O'Rourke, M.D., Amy Doling, Ph.D., Renata Thronson, and Elizabeth Pinsky provided excellent feedback on survey drafts. Gary, Sharon, Allison, and Kristin Skotko helped assemble the research mailings in the United States, and Linda Barth, Michelle Schwab, Claudia Lowe, Suzanne Shea, and Marian Chen helped with the distribution to the DS support groups in the United States.

References

[1] Skotko B. *Mothers of children with Down syndrome reflect on their postnatal support*. Pediatrics 2005;115:64-77.

[2] Skotko B. *Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers*. Am J Obstet Gynecol 2005;192:670-7.

[3] Berg JM, Gilderdale S, Way J. *On telling the parents of a diagnosis of mongolism*. Br J Psychiatry 1969;115:1195-6.

[4] Carr J. *Mongolism: Telling the parents*. Dev Med Child Neurol 1970;12:213-21.

[5] Cooley WC. *Supporting the family of the newborn with Down syndrome*. Compr Ther 1993;19:111-5.

[6] Cunningham CC, Morgan PA, McGucken RB. *Down's syndrome: Is dissatisfaction with disclosure of diagnosis inevitable?* Dev Med Child Neurol 1984;26:33-9.

[7] Cunningham CC, Sloper P. *Parents of Down's syndrome babies: Their early needs*. Child Care Health Dev 1977;3:325-48.

[8] Drillien CM, Wilkinson EM. *Mongolism: When should parents be told*. BMJ 1964;ii:1306.

[9] Drotar D, Baskiewicz A, Irvin N, Kennell J, Klaus M. *The adaptation of parents to the birth of an infant with a congenital malformation: A hypothetical model*. Pediatrics 1975;56:710-7.

[10] Garwick A, Patterson J, Forrest BC, Blum W. *Breaking the news: How families first learn about their child's chronic condition*. Arch Pediatr Adolesc Med 1995;149:991-7.

[11] Gath A. *Parental reactions to loss and disappointment: The diagnosis of Down's syndrome*. Dev Med Child Neurol 1985;27:392-400.

[12] Gath A, Gumley D. *Down's syndrome and the family: Follow-up of children first seen in infancy*. Dev Med Child Neurol 1984;26:500-8.

[13] Gayton WF, Walker L. *Down syndrome: Informing the parents*. Am J Dis Child 1974;127:510-2.

[14] Hedov G, Wikblad K, Annerén G. *First information and support provided to parents of children with Down syndrome in Sweden: Clinical goals and parental experiences*. Acta Pædiatr 2002;91:1344-9.

[15] Klein SD. *The challenge of communicating with parents*. J Dev Behav Pediatr 1993;14:184-91.

[16] Krahn GL, Hallum A, Kime C. *Are there good ways to give 'bad news'?* Pediatrics 1993;91:578-82.

[17] Lucas PJ, Lucas AM. *Down's syndrome: Breaking the news to Irish parents*. Ir Med J 1980;73:248-52.

[18] MacDonald AC, Carson KL, Palmer DJ, Slay T. *Physicians' diagnostic information to parents of handicapped neonates*. Ment Retard 1982;20:12-4.

[19] Murdoch JC. *Communication of the diagnosis of Down's syndrome and spina bifida in Scotland (1971-1981)*. J Ment Defic Res 1983;27:247-53.

[20] Pueschel SM, Murphy A. *Assessment of counseling practices at the birth of a child with Down's syndrome*. Am J Ment Defic 1976;81:325-30.

[21] Quine L, Rutter DR. *First diagnosis of severe mental and physical disability: A study of doctor-parent communication*. J Child Psychol Psychiatry 1994;7:1273-87.

[22] Springer A, Steele MW. *Effects of physicians' early parental counseling on rearing of Down's syndrome children*. Am J Ment Defic 1980;85:1-5.

[23] Stone H. *The birth of a child with Down's syndrome: A medico-social study of thirty-one children and their families*. Scott Med J 1973;18:182-7.

[24] Van Riper M. *A change of plans: The birth of a child with Down syndrome doesn't have to be a negative experience*. Am J Nurs 2003;103:71-4.

[25] Skotko BS, Canal R. *Postnatal support for mothers of children with Down syndrome*. Ment Retard 2005;43:196-212.

[26] Skotko BS, Canal R. *Apoyo postnatal para madres de niños con síndrome de Down*. Revista Síndrome de Down 2004;21:54-71.

[27] Kidder CS, Skotko BS. *Common threads: Celebrating life with Down syndrome*. Rochester Hills, MI: Band of Angels Press 2001.

[28] Cohen WI, Nadel L, Madnick ME, eds. *Down syndrome: Visions for the 21st century*. New York, NY: Wiley-Liss 2002.

[29] Hassold TJ, Patterson D, eds. *Down syndrome: A promising future, together*. New York, NY: Wiley-Liss 1999.

[30] Stray-Gundersen K. *Babies with Down syndrome: A new parent's guide*. Bethesda, MD: Woodbine House 1995.

[31] Bérubé M. *Life as we know it: A father, a family, and an exceptional child*. New York, NY: Vintage Books 1996.

[32] Kingsley J, Levitz M. *Count us in: Growing up with Down syndrome*. San Diego, CA: Harcourt Brace 1994.

[33] Pueschel S. *A parent's guide to Down syndrome: Toward a brighter future*. Baltimore, MD: Paul H. Brookes 2001.

[34] Brown R, Kulik J. *Flashbulb memories*. Cognition 1977;5:73-99.

[35] Conway MA, Anderson SJ, Larsen SF, et al. *The formation of flashbulb memories*. Mem Cognit 1994;22:326-43.

[36] Finkenauer C, Luminet O, Gisle L, el-Ahmadi A, van der Linden M, Philippot P. *Flashbulb memories and the underlying mechanisms of their formation: Toward an emotional-integrative model*. Mem Cognit 1998;26:516-31.