Case report

# Continuing a Pregnancy After Receiving a Prenatal Diagnosis of Down Syndrome in Spain

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# Condensation

Mothers who have children with Down syndrome in Spain strongly agreed that prenatal support services are in need of immediate repair.

# Abstract

Spain is a country that has incentives—both legal and financial—for women to terminate fetuses prenatally diagnosed with DS. Of the 6,125 surveys mailed to mothers who had children with DS in Spain, only 4 reported that they had received a prenatal diagnosis. According to these mothers, physicians rarely discussed the positive potentials of children with DS, and mothers strongly agreed that their prenatal support services were absolutely poor. Positive changes on how such services can be improved are suggested.

Key words: Down syndrome, amniocentesis, prenatal support

## Introduction

No quantitative or qualitative reports have yet documented the cases of mothers in Spain who decide to continue a pregnancy with a prenatally diagnosed fetus with Down syndrome (DS). Spanish laws assume that mothers would opt for terminations. 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 [a "therapeutic abortion"], (2) the pregnancy is a result of a rape [an "ethical abortion"], or (3) the fetus would be born with grave physical or psychological defects [a "eugenic abortion"]. 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 sub-minimal quality of life." The purpose is also to "avoid the 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 for "eugenic abortions." Among those included are "chromosomal alterations." Therefore, the termination of fetuses prenatally diagnosed with DS is legally permissible; and, since Spain is a country with universal health care coverage, these terminations are defrayed through tax money.

For this case report, 6,125 surveys were mailed to mothers who had children with DS in Spain through a previously described protocol [1]. The purpose of these surveys was to assess mothers' perspectives on the process or receiving prenatal and postnatal support for their children with DS. Only 4 of the 467 respondents had received a definite diagnosis through amniocentesis and chose to continue the pregnancy. A case study report is merited as no other accounts exist of women in these circumstances. For the first time, these mothers answer: Why did you decide to continue your pregnancy? And how supportive were your physicians?

## Case report I

Mother #1 identified herself as a white Catholic. In 1998, she was 38 years old when she gave birth to her daughter with DS in the province of Huesca. A physician, herself, this mother also had one additional child. She decided to have an amniocentesis since her triple screen and advanced maternal age put her at an increased risk of having a child with DS. Prior to having the test, this mother already had a strong understanding of DS.

Mother #1 strongly agreed that the purpose of the amniocentesis was clearly explained to her. She was "neutral," however, in whether the details and risks were explained well. She reported feeling strong pressure from her physician to have the amniocentesis.

Mother #1 received the results of her amniocentesis over the phone and without her husband present. According to this mother, the results of the amniocentesis were not explained in a manner that she was able to understand, even given the fact that she was a physician. After receiving the diagnosis of DS, she felt extremely frightened and anxious. Her physician did not give her any details about the positive or negative aspects of DS, nor did he provide sufficient amounts of printed materials on DS. The mother was not referred to parents who already had children with DS, and a disturbing "silence" surrounded the delivery of the diagnosis. Mother #1 strongly felt that the physician pitied her situation, although the physician did not give his opinion about what he would do in this situation. After receiving the results, the mother strongly felt rushed and pressured into making a decision about the continuation of her pregnancy. “They only insisted on an abortion,” she wrote. “The other option was a crazy one.”

This mother decided to continue her pregnancy for three reasons: the opinion of her husband, her religion, and her conscience. Once she made this decision, she firmly felt that her physician did “nothing” to help. The physician did not provide any printed materials, referrals to other families, or explanations about the positive and negative realities of DS. When asked if her prenatal support services were of exceptional quality, this mother responded with absolute strong disagreement.

## Case report II

Mothers #2 identified herself as a white Catholic. In 2000, she was 40 years old when she gave birth of her son with DS in the province of Barcelona. She had a college degree and two prior pregnancies (one elective termination and another spontaneous termination). She decided to have an amniocentesis because of her advanced maternal age and for her own “conscience.” (No triple screen or ultrasound were done prior to the amniocentesis.) This mother indicated that, prior to the amniocentesis, she already had a strong understanding of DS.

Mother #2 strongly agreed that the purpose, technical details, and risks of the procedure were clearly explained. She was encouraged by her physicians to have the amniocentesis done, and she personally wanted to do so. She did not feel encouraged by her physician to terminate the pregnancy.

Mother #2 received the results of her amniocentesis over the telephone without her husband. She strongly agreed that her physician explained the results in a manner that she could understand them; however, she felt frightened and anxious upon hearing them. The physician did not indicate what he would do if he were in this mother's situation. After receiving the results, this mother indicated that her physician did discuss both the positive and negative realities of DS. However, she strongly felt that she was given an insufficient amount of up-to-date printed materials and referrals to other families. This mother did not feel that her physician pitied her, but she did feel pressured into making a decision on whether to continue or terminate the pregnancy.

This mother decided to continue her pregnancy for multiple reasons: the opinion of her spouse, her conscience, knowing a person with DS, having seen children with DS on television or in a movie, and a previous experience of having a spontaneous termination. Once she decided to continue her pregnancy, her physician did not provide her with any up-to-date literature or referrals to families who already had children with DS. The mother writes that she and her husband would have been interested in receiving printed material "about the state of her child's health." The physician did, however, give some examples and suggestions on how best to raise her child. To this end, Mother #2 strongly agreed that her prenatal support services were exceptional.

## Case report III

Mothers #3 identified herself as a Spanish Christian. In 2002, she was 27 years old when she gave birth to her son with DS in the province of Córdoba. She completed grade school and made approximately 8.400€ each year. This was her only pregnancy. The amniocentesis was performed because of results from an ultrasound, which indicated that she had more amniotic fluid than normal. Prior to the amniocentesis, she believed that she already had a strong understanding of DS.

Mother #3 strongly agreed that the purpose, technical details, and risks of the amniocentesis were clearly explained to her. She wanted to have the test, and her physician encouraged (but did not pressure) her to do so.

This mother received the results in person without her husband. After receiving the results, she felt strongly optimistic (and reports no feelings of fear or anxiety). Her physician did not encourage her to terminate the pregnancy and did not convey his personal opinion. According to this mother, however, the physician did not provide sufficient details about the positive and negative realities of DS. No printed materials were given on DS, and no referrals to other parents were made. This mother did feel that her physician strongly pitied her, and she felt extremely pressured into making a decision on whether to continue or terminate the pregnancy. "I felt terrible each time that I had to go to another meeting. They told me to abort, that I was too young for this burden. I felt terrible because I wanted to have my child. They intended to frighten me, that my child would not have normal measurements like his head, etc," she wrote.

Mother #3 decided to continue her pregnancy because of the opinion of her spouse and her conscience. After she decided to continue her pregnancy, she strongly disagreed that the health care professionals had given her a sufficient amount of printed materials or referrals to other parents. "[The doctors] had not helped me with absolutely anything until [my local DS support group] came to visit," she wrote. When asked if her prenatal support services were of exceptional quality, this mother responded with absolute strong disagreement.

## Case report IV

Mothers #4 identified herself as a white Catholic. In 1995, she was 35 years old when she gave birth to her son with DS in the province of Cantabria. She earned a college degree and had four other pregnancies. This mother decided to have an amniocentesis because of atypical ultrasound results. Prior to this test, this mother admits that she had absolutely no understanding of DS.

Mother #4 strongly agreed that her physician clearly explained the purpose, technical details, and risks of the amniocentesis. She firmly wanted to have the test, and her physician encouraged her to do so.

This mother received the results by phone with her husband present. After learning of the prenatal diagnosis of DS, she felt extremely frightened and anxious. Her physician shared some of the negative aspects of DS with her but made no mention of any positive realities. According to this mother, the physician did not give sufficient printed materials on DS, nor did he provide any referrals to other families who had children with DS. This mother reports to feeling extremely pressured into making a decision on whether or not to continue the pregnancy. “The geneticist indicated to me that we needed to talk immediately about aborting and did not plant another alternative,” she wrote.

She decided to continue the pregnancy for three reasons: the opinion of her spouse, her religion, and her conscience. She strongly disagreed that her physician was of help in coming to this decision. She indicated that she still did not receive any current printed materials on DS nor was she offered the phone numbers of other parents. “We asked for the telephone numbers of some association that could help us, and it was the Fundación Síndrome de Down de Cantabria that helped us enormously,” she wrote.

When asked if her prenatal support services were of exceptional quality, this mother responded with absolute strong disagreement.

## Discussion

It is a rare event in Spain for women to continue a pregnancy after receiving a prenatal diagnosis of DS. While the physicians in Spain seemed to do a fine job in explaining the technical details of an amniocentesis, they appeared to have delivered diagnoses with little to no explanations of DS and offered no printed materials or referrals to parents who already had children with DS. Mothers were frightened and anxious after receiving the results and anchored onto their conscience, their partner's opinion, and their religion when deciding to continue their pregnancies.

Prenatal medical support unequivocally needs to be improved in Spain. However, why is the number of women needing such support so extremely low? Part of the answer likely stems from Spanish law and culture in which the selective abortion of fetuses with DS is legally permitted. Such a system expects that a woman who receives a prenatal diagnosis of DS would want to terminate the pregnancy; there are both legal and financial incentives to do so. Either consciously or subconsciously, mothers and health care professionals likely act upon these pressures. Physicians might assume that women would want to pursue what is permissible by law, and mothers might assume that such an action is what is expected of them.

An open question remains: what is the impact of prenatal screening in countries where all abortions are legal and in those where none are permissible? In the United States, there are no legal selective pressures to terminate fetuses with DS; such terminations are as permissible as any other. Caruso, Westgate, and Holmes studied the impact of prenatal detection of fetuses with DS on elective terminations from 1972 to 1994 at Brigham and Women's Hospital in Boston, Massachusetts [2]. In mothers older than 35 years old, the use of elective termination increased to 80% after prenatal testing was made available. In mothers younger than 35 years old, the termination rate increased to 50–65%. In both age groups there was a significant decrease in the portion of fetuses with DS who were born. Denmark is another country where all abortions are legally permissible. However, unlike the births in Boston, the incidence of DS increased from 1980 to 1998 according to numbers obtained from the Danish Cytogenic Central Register, considered complete in its record of all born and prenatally discovered cases of DS [3]. So, in countries where there is no legal or financial pressure to terminate a pregnancy with DS (i.e., all terminations are equally permissible by law), the decision to continue or terminate a pregnancy is likely governed by personal and societal pressures. Perhaps, there is more societal pressure to terminate a fetus with DS in the United States than there is in Denmark. Alternatively, disability-rights advocates in Denmark might be more influential than those in the United States. The answer is, at best, inconclusive, and more international research must be conducted before our understanding of such pressures is sharpened.

In countries where no abortions are legally permissible (e.g., Chile or El Salvador), what functions does prenatal testing for DS serve? If parents are not allowed to terminate and if an amniocentesis, itself, carries an added risk of miscarriage, under what circumstances would a woman ask for the procedure? One could hypothesize that the incidence of DS has remained stable or, at maximum, only slightly decreased through the use of clandestine abortions. Still, one would predict that the incidence of DS in these countries is higher than in countries like the United States or Spain.  In short, three legal societies exist: (1) one in which all abortions are illegal, (2) one in which all abortions are legal, and (3) one in which only selective abortions, like those for fetuses with DS, are allowed.  Future studies must delineate how these legal pressures interface with cultural and societal mores before we understand the true nature of mothers' decision-making processes.

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