



The birth of a child with Down's syndrome. The impact of the first parent interview

The birth of a child with congenital malformations or genetic syndromes is a relatively common occurrence: 3 to 4% of live births have some major malformation, important enough to endanger their life or development; this situation is accompanied by high family, social, and medical impact which may have tragic consequences.¹

The impact of this scenario can be devastating because one of the greatest stigmas in life is having a child born with some deformation; parents, in the majority, do not imagine that their child may have a malformation. This can cause them a veritable shock and they may not properly understand the information, not accept it, and the child may have serious problems.

The first interview with the parents of a child with suspected Down's syndrome is decisive to determine his or her future. Acceptance is the foundation and motor to start treatment. If it is not achieved, the possibilities for care diminish and the likelihood of rupture in the family increases.²

On many occasions, when there is proper prenatal control, some anomalies can be detected in the course of a pregnancy and the parents will be informed, allowing the situation to be addressed appropriately. In many countries birth of children with severe malformations has diminished; as a result of timely detection during gestation when parents opt to interrupt pregnancy. Optimum prenatal control is a healthcare benefit to which many pregnant women lack access.

Among congenital or genetic disorders, the most feared by parents is Down's syndrome, perhaps because it is the best known or the most stigmatized; although today the outlook for such children has changed enormously and they can now aspire to a highly acceptable quality of life, happiness, and life expect-

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tancy; however, ignorance on the subject is still widespread.³

Parents' reactions

The first interview is of crucial importance for parents and for the child's future; it is recommended to give parents the news as soon as possible, even in the delivery room or operating theater, preferably in the presence of the baby, and is possible, both parents, with precise, clear, and understandable information. Medical terms and technicalities should be avoided, telling the parents: "we think your child has Down's syndrome, because he/she has a series of characteristics in his/her phenotype that make the diagnosis highly probable." Then mention the need to confirm it by karyotype. Information like this implies great responsibility and should be confirmed. Parents are often grateful for direct information, which need not be abrupt.

When we act this way, usually with the infant present to describe the most important physical traits, summarizing the main problems of persons with Down's syndrome and encouraging the parents to decidedly help their son or daughter, the parents almost always respond well and make a commitment to their child. In simple terms, both parents are informed that children with Down's syndrome are like all others, with the same rights as any other child, and with the same values, although the difference is that they have greater needs, because they have certain disadvantages. They are informed that they all have mental retardation, in varying degrees, some more, some less, and that the level of brain development depends, to a large extent, on the commitment their parents make to help them and provide them with stimulation and rehabilitation. They are also informed that half of them have some form of heart disease and may have other problems; however, with appropriate and timely care; the vast majority

can be corrected. It is important to insist that if they receive support, these children can become self-sufficient, go to school, learn to read and write, and in the future develop the skills necessary to practice a simple trade, all with a program of comprehensive care that allows them to lead a fulfilling and decent life. With this kind of positive information, most parents assume the commitment to helping their children, whose future is promising. It is important to emphasize that this first interview should be handled by the most experienced person available because inexperienced physicians are often delegated to give these difficult news.⁴

When the information is abrupt, hard, and impersonal, it conveys a negative image of the child; if we mention only the disadvantages, all we inspire is the parents' anger and ineffective management of their grief, and it can easily trigger the disintegration of the family and deficient help for the child.

It is important to listen to the parents, without interrupting; try to show empathy; give clear, comprehensible explanations; avoid giving vague and technical information. A single interview may not be enough, and it may be possible to provide fuller information at follow-up appointments. It is also extremely important that the parents be properly informed, for which they must be given specific healthcare guides for persons with Down's syndrome, which contain ample information on the medical, ethical, and legal issues facing these children, victims of fate. Spain, the United States, Great Britain, Argentina, and Mexico have such materials provided by their public healthcare sector, which offers accurate and easily accessible information.⁵

Recommendations for a good interview

- a) Listen
- b) Try to show empathy



- c) Give summarized information
- d) Explain clearly
- e) Try to confirm the parents' understanding; remember that the information alone is not enough
- f) Do not use medical technicalities
- g) Discuss the positive aspects of the child
- h) Offer information on the problems of these children

The parents' first reaction is usually of incredulity and frustration: "it can't be," "there must be a mistake," "you need to do more tests" are reactions we hear frequently. This corresponds to the phase of denial on receiving unwelcome news. It is a defense mechanism that parents use to confront the situation. This stage is followed by anger. The parents blame one another, as though one of them were guilty. When the parents have received accurate, comprehensive, sympathetic information and come into contact with other parents who have had the same experience, they tend to gain awareness and have an easier time accepting the situation; the couple is strengthened and are better able to help the patient.

PSYCHOLOGICAL REACTIONS TO THE IMPACT

All persons experience, over the course of our lives, situations of pain and loss; the birth of a child with special needs is one of the hardest to assimilate and the process of accepting the reality is crucial in ensuring that the child's needs are met, for education, planning for the future, and the psychological and social wellbeing of the family. The process is not the same for everyone; it depends on multiple factors: the parents' personality, their existential situation, their human qualities, their spiritual development, and their philosophical approach to life; however, the most common scenarios are:

Acute phase

The first reactions are: confusion and exhaustion; they are varied and atypical and there is no way to articulate psychological defenses to pain. Some parents evade the situation; others go silent, retreat into isolation; others become aggressive.

Elaboration phase

We can observe varied reactions in parents: from omnipotence and fantasies, in hopes of doing something that will solve the problem immediately. They see various specialists, trying to find different answers, to believe that "this isn't really happening," "the diagnosis is wrong." They may recur to alternative medicine. This period is characterized by intense evasion and frustration, impotence, insecurity, fear, aggression, depression, sadness, isolation; parents retreat into solitude to avoid the irritating comments of others. Isolation is one of the reactions that can be most harmful to the child and his or her parents.

Rebuilding phase

Most parents succeed in starting this phase with adaptive responses; some never manage it and experience their child's disability with profound rejection. At this stage the opinions of qualified, experienced healthcare professionals, who speak the truth, are especially helpful in this stage.

In 2010 the University of Antioquia published the article: "The effect of a discouraging prediction," with the aim of learning how healthcare workers communicate the news of the birth of a child with Down's syndrome, based on an interview applied to 20 mothers of patients with Down's syndrome.

The results obtained show that, in general, the news is given in a cold and detached manner,



from the perspective that the child's disability is irremediable.⁶

Most doctors convey the idea saying that a boy or girl with Down's syndrome will have many problems. How the parents receive the news does not favor their encounter with their child and casts uncertainty over the outlook for the mother and the child.

Actions that facilitate acceptance

1. Here and now. We need to put our feet on the ground, in the proper dimension, with accurate information. It is important to encourage parents to face the situation bravely. The child will need their reliability.
2. There is always a way to help. Parents need to receive precise information on the problem so that they understand that the child is a person with special needs, with qualities, and with dignity.
3. Strengthen ties with family and friends; find professionals with moral authority, values, and expertise, who give their opinions and advice with serenity, calm, and objectivity, to widen the horizon.

CONCLUSIONS

Research on Down's syndrome focuses, primarily, on associated pathologies, on cytogenetic

and neurodevelopmental studies, etc. There is limited information on families' reactions to the diagnosis of a child's disability. There are many affective deficiencies in this first encounter: ineffective communication can cause the news to be a traumatic experience for the parents. Empathetic pain refers to discomfort with the need to communicate "bad news." Such discomfort may be due to the fear of causing pain or suffering, or not knowing how to handle the parents' reaction. As medical personnel we need to be sensitized and prepared to handle the initial diagnosis of patients with Down's syndrome, because we may be called upon to give parents their first information on the subject in the most appropriate form, taking into account that it is a decisive fact that has a powerful influence on the future of the patient and his or her family.

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