

**Observational Study**

# Challenges and Concerns of Parents with Children with Down Syndrome

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**Submitted:** April 10, 2023

**Approved:** July 14, 2023

**Published:** July 18, 2023

**How to cite this article:** Eddaoudi S, Zouine M, Mehdaoui A, Khabbache K, El-Boussaadni Y, et al. Challenges and Concerns of Parents with Children with Down Syndrome. Arch Psychiatr Ment Health. 2023; 7: 015-017.

**DOI:** 10.29328/journal.apmh.1001048

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**Keywords:** Down syndrome; Prenatal diagnosis; Parent; Impact; Depression



## Abstract

Down syndrome is a common chromosomal abnormality that affects individuals in their physical, cognitive, and social development. The diagnosis of this syndrome in a newborn can be challenging for parents as it may disrupt family dynamics. In this study, we describe the different aspects of the impact of Down syndrome on parents, including psychological, social, and familial impacts. 55 cases participated in this survey; the average age of parents was 34 years old, and mothers represented 96% of the participants. 70% of cases were from urban areas. The average time between diagnosis and parental evaluation was 32.7 months. In 57% of families, the diagnosis of Down syndrome was established only after the third month of pregnancy, and only 5% obtained it during the prenatal period. Depression was reported in 32% of mothers at the time of diagnosis, while one mother exhibited persistent denial of her child's disability. 30% of families indicated that their child with Down syndrome was the source of tension within the couple and that learning difficulties were the main factor of tension, while 1% eventually divorced. 5% of parents regretted having a child with Down syndrome. All mothers expressed concerns about their child's future and are in favor of the establishment of a national screening program for trisomy 21 and dedicated learning centers to ensure social and professional integration.

## Introduction

The arrival of a newborn is generally considered a happy event for parents. However, when the child is born with a diagnosed disability, such as Down syndrome, it can add an additional level of stress for parents [1], which can have a negative impact on their quality of life [2]. Taking care of a child with a chronic disability is a challenging experience for parents [1,2]. The daily stress they feel can have a significant impact on their quality of life and that of their family, especially in the context of primiparity [1]. This situation leads to a series of psychological reactions in parents and obliges them to adopt specific behaviors and attitudes to manage their daily life [2]. To cope with this situation, parents deploy adaptation strategies [2].

## Materials and methods

We conducted an observational survey involving 55 families with children aged 1 day to 10 years with Down syndrome. Participants were recruited from patients hospitalized or having had a consultation in the pediatrics department of the Mohammed VI University Hospital in Tangier. All parents voluntarily agreed to participate in our study with informed consent. Data were collected using a semi-structured questionnaire. Variables studied included parents' age, place of residence, socioeconomic level, level

of education, the time between diagnosis and assessment by parents, circumstances of trisomy 21 discovery, the announcement of Down syndrome diagnosis (when, by whom, and how), parents' satisfaction with this announcement, the impact of trisomy 21 on family dynamics, as well as parents' concerns about their child's future.

## Results

Fifty-five parents representing 55 different families accompanied their children during the study period. They all agreed to participate. There were 50 mothers (90%) and five fathers (Table 1). Their average age was 34.6 years, with extremes of 19 and 57 years. They lived in an urban area in 70% of cases. 54% of mothers have no more than primary education, and 10% are illiterate. On the professional front, 66% of mothers are housewives, 15% of whom had stopped

**Table 1:** Socio-demographic characteristics of parents.

		Count	Percentage
Parents	Mothers	50	90%
	Fathers	5	10%
Socio-economic level	Low	15	27.2%
	Average	30	54.5%
	High	10	18.1%
Mothers' level of education	Illiterate	5	10 %
	Primary	30	54.5%
	secondary	20	355%



working to look after their disabled child. The socio-economic level was low or medium in 82% of cases. The average delay between diagnosis and parental evaluation was 32.7 months. We have found that 45% of mothers were shocked upon receiving the diagnosis and wished to have more explanations about their child's illness. In 57% of families, the diagnosis of trisomy 21 is made prenatally from the 3<sup>rd</sup> month of pregnancy. The diagnosis was announced by the gynecologist in 54% of cases, by the midwives in 28% of cases, and by the pediatrician in only 18% of cases.

The majority of parents (62%) were not satisfied with the care team when the diagnosis was announced. Parents reported various reasons for their dissatisfaction, including a lack of information about the disease in 20% of cases, a lack of clarification about the prognosis in 26% of cases, and a lack of understanding of the explanations provided by the medical team in 16% of cases.

Depression was reported in 32% of mothers at the time of diagnosis, while one mother presented persistent denial of her child's disability. We also observed that 30% of families reported that their child with Down syndrome was the source of tension within the couple, with learning difficulties being the main factor of tension in 38% of cases, financial stress in 28% of cases, emotional stress in 11% of cases, communication conflicts in 15% of cases, and cultural differences in 8% of cases. While a minority (1%) ended up in divorce.

In addition, 5% of parents regretted having a child with Down syndrome, this minority explains this regret by several reasons such as the financial difficulties seen as the loads of the trisomic child, the lack of support by society the difficulties of learning, the lack of information on the disease and the difficulties of learning. While 95% said they were proud of their child.

## Discussion

Our study aimed to describe the different aspects of the impact of Down syndrome on parents of children with this condition, including psychological, social, and familial impacts. The results of our study showed that parents of children with Down syndrome face challenges and significant concerns from the moment of diagnosis.

### Psychological impact

Our study revealed that 45% of mothers were shocked at the time of diagnosis and wished to receive more information about their child's condition. In addition, 32% of mothers experienced depression at the time of diagnosis, and one mother continued to deny her child's disability. These results are consistent with previous studies that have reported high levels of distress, anxiety, and depression among parents of children with Down syndrome [3]. The rate of depression is statistically higher among mothers than fathers in our study. Although some studies have already reported a significant

link between depression and gender [4], the issue remains controversial due to inconsistent results from studies and the limited number of investigations conducted to examine differences in the impact of childhood disability between mothers and fathers [4]. The higher prevalence of depression among mothers could be explained by their greater involvement in the care of their children and their less stable professional situation [5]. In fact, in our study, 18% of parents who had stopped working to fully dedicate themselves to their disabled child were mothers.

### Social and familial impact

Our study revealed that 30% of families reported that their child with Down syndrome was a source of tension within the couple, with learning difficulties being the main factor. In addition, 1% of families reported divorcing due to the presence of a child with Down syndrome. These results are consistent with previous studies that have reported a higher risk of divorce and relational difficulties among parents of children with disabilities, including those with Down syndrome [3,6]. Some parents report negative experiences related to the education of their child with Down syndrome. Studies have shown that parents who had their child with DS at a younger age are more likely to feel embarrassed, possibly because they lacked self-confidence and were more affected by social stigma. In contrast, parents who had their child with DS at an older age are less likely to feel embarrassed. In a minority of cases in our sample, about 5% of parents express intense regrets about having a child with Down syndrome [3,7,8].

### Diagnosis announcement

The announcement of a diagnosis of Down syndrome, whether during the prenatal or postnatal period, can be a crucial and potentially traumatic moment for most parents [9]. Parents may experience denial of the situation, as shown by the majority of parents studied. This difficult event affects not only the parents but also the healthcare professionals involved in prenatal screening and postnatal care, as it can have a significant impact on the family's future [10]. Although there is no standardized method for delivering the news, it is crucial that all healthcare professionals involved are aware of the importance of this moment and their role in supporting the parents [10,11]. Parents' reactions to the announcement of a disabled child can include deep emotional shock, similar to death, which can symbolize the loss of the imagined child and the reality of having to live with the actual child, in the case of a child with Down syndrome [12].

The archaic ideas of death, monsters, or mutilation may stem from a discrepancy between the parent's expectations and the child's reality in the room. Other characteristics, such as emotional detachment, the emergence of death-related ideas, and the deterioration of relationships with the child and between parents, have also been identified by Visier and Roy (1985) [13].



## Conclusion

It is a duty to continue promoting inclusivity, acceptance and support for individuals with Down syndrome and their families in all aspects of life. Together, we can make a meaningful impact and create a more inclusive and compassionate society for everyone. Let us continue to advocate for the rights and well-being of individuals with Down syndrome and work towards a more inclusive and accepting society. Together, we can make a positive difference in the lives of these individuals and their families.

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