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Parents' experience of receiving their child's diagnosis of Down's syndrome

Arabi Rasendrakumar[1], Krithika Prabaharan[1], Padmasani Venkat Ramanan[1], Niruby Rasendrakumar[1]

[1]Department of Pediatrics, Sri Ramachandra Institute of Higher Education and Research, Chennai, Tamil Nadu, India.

***Corresponding author:**
Krithika Prabaharan,
Department of Pediatrics,
Sri Ramachandra Institute
of Higher Education and
Research, Chennai,
Tamil Nadu, India.

krithika.prbhrn@gmail.com

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ABSTRACT

Objectives: The objectives of the study were to study the parents' satisfaction with the experience of receiving the diagnosis of Down's syndrome (DS) for their child.

Materials and Methods: Children studying in special schools in the city with DS were identified and a retrospective study of their parents' experience on receiving their child's diagnosis was done using a semi-structured, questionnaire, developed, and validated by us.

Results: Forty-two parents participated. In 7 (16.6%), diagnosis was made in the neonatal period, in 15 (35.7%) between 1 month and 1 year, and in 20 (47.6%) after the 1st year of life. Forty (95.2%) had been given printed information, 32 (76.2%) were provided with contacts numbers of resource centers. Thirty-eight (90.5%) were referred to support groups. Only 9 (21.4%) were provided a timetable of care. Twenty (47.6%) felt that all the positive aspects had been clarified, 15 (35%) felt that all the negative aspects were completely explained, and 29 (69%) felt that the doctor had shown compassion. Overall satisfaction 9.5% were very satisfied with the experience, 45.2% were quite satisfied,11.9% were neutral, 19.1% were quite dissatisfied, and 14.3% were very dissatisfied. The factors significantly associated with satisfaction included having a time table of care, having both positive and negative aspects completely explained and the health-care professional showing compassion at the time of breaking the diagnosis.

Conclusion: Only 54.8% of parents of children with DS were satisfied with the way the diagnosis of their child's condition was broken to them. Efforts to include the factors associated with satisfaction and avoidance of factors causing dissatisfaction will help improve the experience of these parents.

Keywords: Down syndrome, Parents experience, Satisfaction

INTRODUCTION

Down's syndrome (DS) has an overall incidence of 1–1.4/1000 live births in India.[1] This is higher compared to other countries offering prenatal diagnosis for DS. Receiving a diagnosis of DS in their child is a memorable experience for an individual and his or her family.[2] Although much is talked about conveying difficult news by medical professionals, there is very little information on parentse the experience of these parents

Objectives

The objectives of the study were to study the parents' experience of receiving the diagnosis of DS for their child.

MATERIALS AND METHODS

Children 1 month–18 years old studying in special schools in the city with confirmed a diagnosis of DS were identified. A retrospective study was done in May–June 2016 of their parents' experiences on receiving their child's diagnosis of DS. The parents who gave written informed consent and remembered the time they received the news well were included for a face to face interview. Approval for the study was obtained from the Institutional Ethics Committee.

A semi-structured questionnaire in English developed and validated by us was used. The face validity of the questionnaire was established by first having it reviewed by five senior pediatricians familiar with the topic and then an expert biostatistician on question construction. We then ran a pilot test on a subset of survey participants (six parents) to remove the confusing or weak questions.

The parents were interviewed in the language comfortable for them using the questionnaire which consisted of prompts to explore the participants' experience. The responses were noted down simultaneously. The interview was not recorded. Satisfaction was graded on a 5-point Likert scale as very satisfied (5), quite satisfied (4), neither (3), quite dissatisfied (2), and very dissatisfied (1). The Likert scale was employed as it has been most recommended by the researchers that it would reduce the frustration level of patient respondents and increase response rate and response quality.

The collected responses were then entered into a spreadsheet and coded. Descriptive statistics were presented as numbers and percentages. A Chi-squared test was used for comparison between the three groups. $P < 0.05$ was considered statistically significant. For statistical analysis, "Minitab Statistical Software," Version 15 was used.

RESULTS

Overall, 57 parents from three special schools in Chennai were approached, of which 15 either were unwilling to take part or were unable to recall the specific events at the time of diagnosis. Only 42 participated, 40 (95.2%) were mother and 2 (4.8%) were father.

The mean age of the children was 8.5 years. Twenty-three (54.8%) children were boys and 19 (45.2%) were girls. The oldest among the surveyed was 18 years old and the youngest was 6 months old. Thirty-seven (88.1%) mothers had undergone antenatal ultrasound scan which was reported to be normal. In the other five, some abnormal finding was noted and further investigations had been suggested to the parents which they had refused. Twenty-six (61.9%) mothers were above the age of 35 at the time of conception while 30 (71.4%) fathers were above the age of 35. Twelve (28.6%) had a consanguineous marriage. Twenty-five (59.5%) had extended family support.

At the time of disclosing the diagnosis, in 35 (83.3%) of the cases, both the parents were present and out of them, in 7 (16.7%), extended family members were also present. In 7 (16.6%) children, diagnosis was made in the neonatal period, in 15 (35.7%) between 1 month and 1 year and in 20 (47.6%) after the 1st year of life. Thirty-five (83.3%) of them had been given the diagnosis by a pediatrician and 7 (16.67%) were given by others. In 35 (83.3%), it was the parents themselves who first noted atypical development with their child. In 21 (50%) babies, the developmental delay was noticed before the year of age 1 and in 21 (50%) it was after 1 year.

Forty out of the 42 (95.2%) parents had not heard the term DS earlier. Forty (95.2%) had been given printed information after the diagnosis was disclosed. Thirty-two (76.2%) were provided with contact numbers of resource centers. Thirty-eight (90.5%) were referred to support groups.

Ten (23.8%) were referred to an early intervention program before the 1st year of life. Twelve (28.6%) of the children began therapy between 1 month and 3 years and 20 (47.6%) beyond 3 years. Only 9 (21.4%) were provided a timetable of care. Twenty-nine (72.5%) felt that all the positive aspects had been explained, 15 (37.5%) felt that all the negative aspects were completely explained, and 29 (72.5%) felt that the doctor had shown compassion when explaining the diagnosis.

Overall, 4 (9.5%) parents were very satisfied with the experience, 19 (45.2%) were quite satisfied, 5 (11.9%) were neutral, 8 (19.1%) were quite dissatisfied, and 6 (14.3%) were very dissatisfied.

The relationships between the variables studies and parents satisfaction are depicted in [Table 1].

DISCUSSION

Out of the parents of 42 DS children who were interviewed, only 54.7% were satisfied with the experience of receiving the diagnosis. The variables associated with satisfaction were diagnosis in the neonatal period, both positive and negative aspects being explained, time table of care being given and the health-care provider showing compassion. The variables associated with poor satisfaction were someone other than a pediatrician giving the diagnosis and only one parent being present at the time of giving the diagnosis.

This rate of satisfaction noted was similar to that reported in earlier studies.[1] The parent's ability to recall exactly how they felt when initially told of the child's diagnosis indicates the importance of the method of delivery of diagnosis. Subsequently, parents rely on their own resources and coping strategies, together with formal support in taking care of their child.[3-6]

Table 1: Factors influencing parents' satisfaction.

Variable	Quite/very satisfied (*n*=23) *n* (%)	Quite/very dissatisfied (*n*=14) *n* (%)	Neither (*n*=5) *n* (%)	Total	*P*-value
Age at diagnosis					
Neonatal period	06 (85.7)	0 (0)	01 (14.2)	07	0.03292
1 month–1 year	10 (66.7)	02 (13.3)	03 (20.0)	15	0.06273
>1 year	07 (35.0)	12 (60.0)	01 (04.7)	20	0.06174
Diagnosis given by					
Pediatrician	23 (65.7)	09 (22.9)	03 (08.6)	35	0.07190
Others	0 (0)	05 (71.4)	02 (28.6)	07	0.03678
At the time of receiving the diagnosis					
Both mother and father present	22 (62.9)	09 (25.7)	04 (11.4)	35	0.07023
Only one parent present	1 (14.3)	05 (71.4)	01 (14.3)	07	0.05798
Additional supports					
Printed material	23 (57.5)	12 (30.0)	05 (12.5)	40	0.07342
Support group referral	23 (60.5)	11 (28.9)	04 (10.5)	38	0.06187
Positive aspects explained	16 (80.0)	01 (05.0)	03 (15.0)	20	0.03371
Negative aspects explained	12 (80.0)	01 (06.7)	02 (13.3)	15	0.04251
Time table of care	09 (100.0)	0 (0)	0 (0)	09	0.00187
Health-care professional showed compassion	23 (79.3)	01 (03.4)	05 (17.2)	29	0.04723

According to the Center for Disease Control and Prevention, although the risk is more with increasing maternal age, around 80% of babies with DS are born to women younger than 35 as younger women have more babies than older women. In our study, 61.9% of mothers and 71.4% of the fathers were above the age of 35 at the time of conception. Out of the 42 parents interviewed in our study, 95.2% were the mother of the child while in the previous studies, the participation by fathers has been much greater (38–42%).[7] This difference could be because culturally mother is the primary caregiver for children in our country.

When the diagnosis was made in infancy, satisfaction was significantly higher. However, when the physical characteristics and developmental delay are mild, diagnosis is often delayed. Studies show that parents who do not know the etiology of their child's delayed mental development suffer more emotional stress compared to parents whose child has a diagnosis of DS.[8]

Parents who were given by health professionals other than a pediatrician reported less satisfaction. Ideally, the parents, obstetrician, and pediatrician should meet jointly with the couple to explain DS, especially when the diagnosis is made in early infancy and the anomaly scan has been reported normal.[9]

Most of the parents (95%) had not previously heard the term DS. Other studies have also revealed that most lay persons would not have heard of DS before and would rely on their primary physician for complete details.[9] and parents are more likely to be satisfied when the diagnosis is accompanied by printed information which they can refer to later and when contact numbers of resource persons are shared. In our study, 95.2% had been given printed information after disclosure,76.2% were provided with contacts numbers of other parents of children with DS, and 90.5% were referred to support groups. In a previous study from Pakistan of 19 children with DS, no parent had been given printed information or contact number of support groups,[10] while in Spain, 19.3% received printed material and 15% received contact numbers of other parents with DS children. In our study, only 21.4% were provided a timetable of care and these parents were more satisfied. It would be advisable for health professional to hand out a timetable of care as this significantly affects the satisfaction level in parents with a DS child.

In our study, 47.6% felt that the doctor had explained all the positive aspects of DS but only 35.7% felt that all the negative aspects were covered. This suggests that our health-care professionals should check the understanding of the parents after delivering the news. While it is important that parents understand the associated intellectual deficits, the positive aspects and the talents and abilities of these children also need to be emphasized. In a Spanish study, 74% felt doctors emphasized the positive aspects and 61% felt that negative aspects were clearly discussed.

Most parents (69.0%) felt that the doctor had shown compassion while delivering the news and this was more in the group with good satisfaction. Although the previous studies have also shown that parenttisfactiond the associated intellectual deficits, the positive aspects and the talentsediatrician, most parents can distinguish between their reaction to the diagnosis and the way in which it is delivered.[11,12] In our study, no patient had prenatal diagnosis suggesting that when prenatal diagnosis of DS is made the family chooses to terminate the pregnancy.

Mothers who receive a prenatal diagnosis of DS and continue with their pregnancies can experience a better birthing process compared with their counterparts who first learn about the diagnosis postnatally. Receiving the diagnosis in advance allows parents the necessary time to reconcile their own emotions and prepare for the child, if they choose to continue with the pregnancy.[13]

There were some limitations in our current study. Most of the participants were mother and hence the difference between the experiences of mother and father could not be analyzed. As it was a retrospective study in which parents were requested to recall events long after the actual diagnosis, there is a likelihood of recall bias. Parents could have forgotten essential information regarding the diagnostic process or information provided but most parents in this study seemed to recall events clearly. This can be attributed to flashbulb memory.[7,13,14]

CONCLUSION

- Only 54.8% of parents of children having DS were satisfied with the way the diagnosis was given to them
- Diagnosis in infancy, getting a timetable of care, having both positive and negative aspects completely explained, and the health-care professional showing compassion at the time of the diagnosis significantly increased the likelihood of parental satisfaction
- The factors that increased the likelihood of dissatisfaction included delay in diagnosis, not having the spouse alongside, and being told the diagnosis by a person other than the pediatrician.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Conflicts of interest

There are no conflicts of interest.

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Questionnaire

Parents experience on receiving their child diagnosis of Down's syndrome

Information about the child
Child diagnosed with DS
Child sex
Child age
Date of birth
Mode of delivery
Birth weight
Place of birth
Baby's birth order
Child's age when diagnosed
Antenatal care
Ultrasound
NT scan
Any other test done

Information about the parents		
	Father	**Mother**
Parental age at conception		
Consanguinity		

Information about the family
Type of family
Siblings
Family history of DS

Disclosure of diagnosis

1. Who delivered the diagnosis?
    - Pediatrician
    - Others: Neonatologist/obstetrician/family physician.
2. Where any family members present at the time when the diagnosis was delivered to you?

Diagnostic process and support received after disclosure

1. When did you notice atypical development in your child?
2. When was the definitive diagnosis about your child given to you?
3. Did the doctor/health professional explain the positive aspects of having a child with DS?
4. Did the doctor/health professional give a complete account of the negative aspects?
5. Was any printed information or resources provided to you?
6. Were you given contact numbers/ information for those you could contact about DS?
7. Were you referred to any local support groups
8. Were you provided a timetable of care?
9. What was the age of the child when he/she was referred to an early intervention program

Overall experience

Very satisfied	Quite satisfied	Neither	Quite dissatisfied	Very dissatisfied