Egypt. J. Psychiat., 1990, 13: 239-246

Parental Reaction Towards Children Having Down's Syndrome

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ABSTRACT

This work has been carried out to determine parental reaction to a child with Down's syndrome. The study included 30 children with Down's syndrome and 30 healthy children matched for age, sex and social class as a control group.

For every child, a complete medical history and clinical examination were done in addition to the Porteus Mazes intelligence test. The available parent was subjected to the modified Rutter Parental Scale and a modified parental attitude scale.

The results showed a significant difference between cases and controls in each of the scores of acceptance / rejection, dependence / independence and parental reaction as well as in the presence of sleep, motor, sphincteric, speech and behavioural disorders. A significant correlation was found between parental reaction and crowding index and between IQ and the modified parental attitude scale.

INTRODUCTION

Down's syndrome is a condition with life-long implications for physical appearance, intellectual achievement and general functioning of the affected child. Parents whatever their race, religion or socio-economic background are devastated to learn that their new baby has Down's syndrome (Moore, *et al.*, 1977).

Because the parents have not been prepared for the birth of a handicapped child, they may lack the necessary coping mechanisms to face the reality. Some parents fail to cope for a long time and this affects their attitude towards the child (Wilker, 1983).

This explain how important is the determination and understanding of parental reaction as that will help much in providing effective support for parents helping them to cope with the condition, plan for the future of the child and apply the best methods of behaving with him. The present study tries to identify the parental reaction to having a child with Down's syndrome following physical and intellectual evaluation.

SUBJECTS AND METHOD

The present study comprised 2 groups:

The case group included 30 children diagnosed as Down's syndrome by chromosomal studies. They were selected from special schools for mentally retarded as well as from the Genetics out-patient clinic, Ain-Shams University Hospital.

Their ages ranged from 6 to 15 years, 7 were females and 23 were males. As they were received from different places, they belonged to different socio-economic levels.

This group was compared to a control group formed of 30 normal children matched with the case group as regard age, sex, and socio-economic status. The control group was selected from the vicinity of the case group (relatives-neighbours).

The following were done for every child from both groups:

(1) A complete medical history with special emphasis on milestones of development.

(2) A complete clinical examination.

(3 Assessment of IQ using the Porteus Mazes intelligence test.

Meanwhile the available parent of each child was subjected to:

a) The Modified Rutter Parental Scale to identify any behaviour, speech, sleep, sphincteric and motor disorders, social relations of the child and socio-economic status of the family. By quantification of the variables, we obtained the social relation score.

b) A modified Parental Attitude Scale (Assar, 1987) which measures 4 main parental attitudes towards the child:

- acceptance / rejection.
- dependence / independence.
- consistency / inconsistency.
- discrimination / equalization.

The sum of the 4 components is termed the parental attitude score.

RESULTS

The mean IQ of cases was 35.5 ± 7.3 while that of control group was 107.3 ± 5.8 ($t = 30.8$ and $P < 0.01$).

The mental retardation was severe (IQ = 20-34) in 53% of cases, moderate (IQ= 36-51) in 43.3% and mild (IQ= 52-67) in 3.3%.

So, most Down's children showed severe and moderate retardation.

Most parents in the study were troubled by the fact of having a retarded child. Many of them cried during the interview. The major distress appeared

TABLE I

Comparison between Cases and Controls in Results of the Modified Parental Attitude Scale

Variable	Group	Mean	T Value
Acceptance / Rejection score	Case	11.07 ± 2.97	3.10 * $p < 0.05$
	Control	13.30 ± 2.59	
Dependence / Independence score	Case	4.93 ± 2.97	9.36 * $p < 0.05$
	Control	11.30 ± 2.59	
Parental reaction score	Case	32.77 ± 8.04	3.63 * $p < 0.05$
	Control		
Social relation score	Case	8.47 ± 3.64	1.05 * $p < 0.05$
	Control	9.30 ± 2.37	

* = Significant

TABLE II

Correlation between the Results of the Modified Parental Attitude Scale and Other Variables

Correlation Matrix	IQ	Child social relation score	Crowding Index @
Dependence / independence score	0.34 *	0.15 *	0.13
Acceptance / rejection score	0.33 *	0.49 *	0.23
Parental reaction score	0.46 **	0.003 **	0.34 *

* = Significant $p < 0.05$

** = Highly significant $p < 0.01$

@ Crowding index = $\frac{\text{No.of rooms in house}}{\text{No.of family members}}$

when they thought of their children's future especially after their death. On the other hand, some parents accepted the condition, considering it the will of God or a punishment for past transgressions.

To alleviate their guilt, some parents asked questions about pregnancy, drug intake, irradiation and consanguinity, while others tried to inquire directly about the cause of the condition.

No significant relation was elicited between child's sex and each of the following scores.

-Acceptance / rejection.

- Dependence / independence.

- Parental reaction.

The remaining results are tabulated as follows.

TABLE III

Comparison between Cases and Control Groups as Regards Behavioral Difficulties

Variable	Case (n=30)		Control(n=30)		X 2
	No	%	No	%	
1) Sleep disorders			3	10 %	
a) Insomnia	4	13.3 %	-	-	0.16
b) Nightmares	4	13.3 %	1	3.3 %	4.29 *
c) Sleep terrors	7	23.3 %			5.19 *
2) Sphincteric disorders			1	3.3 %	
a) Nocturnal enuresis	17	56 %	-	-	20.32 **
b) Diurnal enuresis	10	33 %			12 **
3) Speech disorder			4	13.3 %	
a) Delay in starting speech	30	100 %	1	3.3	45.89 **
b) Other difficulties like stammering and faulty articulation	16	53.3 %			18.47 **
4) Motor disorders			5	16.7 %	
a) Hyperactive	19	63.3 %	-	-	13.61 **
b) Hypoactive	1	3.3 %	2	5.7 %	1.02
c) Abnormal movements	17	46.7 %			17.33 **
5) Behavioral disorders			2	6.7 %	
a) Hiding objects or throwing them from window	12	40 %	10	33.3 %	9.32 **
b) Continuous fights	9	30 %	3	10 %	0.08
c) Destruction of anything he gets in hands	10	33.3 %	-	-	4.81 *
d) Temper tantrums	12	40 %	6	20 %	15 **
e) Self - negligence	10	33.3 %			1.36

* = Significant $p < 0.05$

** = Highly significant $p < 0.01$

TABLE IV

Correlation between Parental Reaction Score and Behavior Disorders in Cases and Controls

Variable	Parental reaction score of cases			X^2	Parental reaction score of controls			X^2
	Low	Medium	High		Low	Medium	High	
leep disorders								
ı) Insomnia	1 3.3 %	3 10 %	-	0.01	-	3 10 %	-	0.83
›) Night mares	2 6.7 %	2 6.7 %	-	1.83	-	-	-	-
:) Sleep terrors	4 13.3 %	3 10 %	-	5.83 *	-	1 3.3 %	-	0.26
phincteric disorders								
ı) Nocturnal	5 16.7 %	12 40 %	-	0.81	-	1 3.3 %	-	0.25
›) Diurnal	2 6.7 %	8 26.7 %	-	0.09	-	-	-	-
peech disorders								
.) Delay in starting	7 23.3 %	23 76.7 %	-	-	-	3 10 %	-	7.28 *
›) Other difficulties	4 13.3 %	12 40 %	-	0.05	-	1 3.3 %	-	0.26
lotor disorders								
) Hyperactive	4 13.3 %	12 40 %	-	0.15	-	5 16.7 %	-	1.5
) Hypoactive	1 3.3 %	-	-	3.40	-	-	-	-
) Abnormal movements	3 10 %	14 46.7 %	-	0.70	-	2 6.7 %	-	0.5
ehavioral disorders								
) Hiding or throwing	1 3.3 %	11 36.7 %	-	2.51	-	2 6.7 %	-	0.54
) Continuous fights	2 6.7 %	7 23.3 %	-	0.01	-	9 30 %	-	1.09
) Destruction	2 6.7 %	8 26.7 %	-	0.09	-	3 10 %	-	0.83
) Temper trantrums	4 13.3 %	8 26.7 %	-	1.12	-	-	-	-
) Self - negligence	1 3.3 %	9 30 %	-	1.49	-	6 20 %	-	1.88

= Significant $p < 0.05$

DISCUSSION

The future of the handicapped children including those with Down's syndrome is brighter and more dynamic today than ever before. Positive attitudes towards the handicapped and advances in educational and behavioural techniques is present to meet their needs.

In the midst of this optimism, professionals must exercise caution, as parents must face the dark reality of the birth of a mentally handicapped child, a fact that cannot be discounted. The birth of a handicapped child is a stressful event that creates a crisis (Parks, 1977).

In the current study, most of cases of Down's syndrome had severe to moderate mental retardation with a mean IQ of 35.4. This is in agreement with Carlin *et al.*, (1978) and Koussef (1978) who estimated the IQ of Down's children to be variable with a mean around 40.

In the present study it was noted that the Down's child with a higher IQ score was more accepted by his parents who encouraged him to be independent. In agreement, Barber (1963) reported that the attitudes of parents of mentally retarded children were influenced by the intellectual capacity of the child. On the other hand, Worchel and Worchel (1961)demonstrated, through comparison of the attitudes of parents towards retarded and non-retarded children, that parents were rejecting the retarded. We also noticed that some parents tried to compensate for their children's handicap by an overprotective attitude. So our results are in agreement with Slouth *et al.*, (1978) who suggested that parents of mentally retarded children are more protective. This overprotection can easily become a maladaptive response that inhibits development of independency by the mentally retarded child (Hall, 1984).

As regards the child's sex, the current study did not show any significant relation with parental reaction. So we agree with Barber (1963) who reported that the attitude of parents of mentally retarded children was not influenced by sex. On the other hand, because parents are expected to care more about their son's achievements, it has been suggested that fathers are less likely to accept mental handicap in their sons (Levin, 1966) and to be generally more accepting of the presence of mentally handicapped daughters (Grossman, 1977).

While the majority of Down's syndrome cases are described to be pleasant, outward going, affectionate, and sociable (Cunningham, 1988) many of our cases exhibited manifest conduct disorders. Reid (1980) estimated that to be around 27% of cases a percentage comparable to our results (33.3% destructiveness, 40% throwing objects from windows) but far from the 6.9% of conduct disorders described by Okasha *et al.* (1983) in their sample of mentally retarded children.

Cunningham (1988) reported that aggressiveness, irritability and attention-seeking behaviour were associated with low affection shown towards the child by his parents. The poor level of language and communication skills as well as the limited abilities in self-helping such as self-dressing offered another explanation.

The presence of behavioural disorders in Down's syndrome may indicate some sort of disturbance in the child's psychology; notably a neurotic tendencey or predisposition, a finding that is concordant with the notion that mental retardation by itself may change the patient's psychology (Mudgil *et al.* 1982).

Although some families may be in a state of chronic sorrow or afflicted by chronic stress or lack of information about essential services, many families with handicapped child, meet the day to day problems that the handicap creates with patterns of behaviour that differ from those found in families of normal children (Russel, 1985).

We conclude that parents are in a continuing need for practical help and emotional support. Professionals may play a key role in helping parents to overcome their disappointment and frustration and

above all to plan for the future need of their handicapped child. On behalf of the community, more care should be directed towards establishmment of institutes that could accommodate children with mental handicaps in general particularly those who are trainable and educable.

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ABSTRAIT

La Réaction des Parents vers les Enfants du Syndrome de Down

Ce travail était fait pour déterminer la réaction des parents vers un enfant avant le Syndrome de Dowm.

L'étude a compris 30 enfants du syndrome de Down et 30 enfants en assortant l'age, le sexe, la classe sociale, comme groupe de contrôle.

Pour chaque enfant, une histoire medicale complète et un examen clinique ont été fait, en plus de l'examen d'intelligence Porteus Mazes. Pour les parents on a présenté l'échelle paternel modifié de Rutter et l'échelle d'attitude paternel modifié.

Les resultats ont montré une différence significative entres les cas et les contrôles dans chacun des points suivants: accéptation / rejet, dépendance / Indépendance et la réaction paternele, en plus, la présence du sommeil et les désordres moteurs, sphincteriques, de parole et de la conduite. Une corrélation significative été trouvée entre la réaction des parents, le "Crowding index", le quotient d'intelligence, et l'échelle d'attitude paternel modifieé.

الموجز

رد فعل الآباء تجاه ابنائهم المصابين بزملة داون

الهدف من اجراء هذا البحث هو تحديد رد فعل الآباء تجاه ابنائهم المصابين بزملة داون شملت مادة البحث ٣٠ حالة مشخصة بهذا المرض وعينة ضابطة مكونه من ٣٠ من الاطفال الطبيعين تضاهى عينة الحالات من حيث العمر والجنس والحالة الاجتماعية والاقتصادية.

تم أخذ تاريخ المرض مع عمل كشف طبى كامل على كل طفل بالاضافة الى اختبار متاهات بورتيوس للذكاء. كما تم عمل مقابلة مع الآباء وتم تطبيق اختبار الاتجاهات الوالدية المعدل (عسر ١٩٨٧) على كل من الابوين أو من حضر منهما مع تطبيق مقياس (رتر) المعدل.

اظهرت نتائج البحث وجود فروق ذات دلالة احصائية بين العينتين فى المتغيرات الاتية: التقبل والرفض – التبعية والاستقلال – الاتجاهات الوالدية. كما ظهرت فروق بين المجموعتين فى صورة وجود اضطرابات فى النوم والكلام والحركة والسلوك. وكذلك ظهرت فروق ذات دلالة احصائية بين نتائج الاتجاهات الوالدية ومعامل الازدحام وبين مقياس الذكاء واختبار الاتجاهات الوالدية.

لذلك يمكنا القول بأن آباء الاطفال المصابين بزملة داون فى حاجه مستمرة للمساعدة والتدعيم العلمى والنفسى ويجب على المتخصصين فى هذا المجال ان يساعدوهم فى التغلب على ما يمكن أن يصيبهم من احباطات وأن يخططوا لاحتياجاتهم المستقبلية بخصوص هؤلاء الاطفال. ومن ناحية اخرى فانه يجب على المجتمع أن يوفر اماكن لرعاية هؤلاء الاطفال المعوقين فكريا وخاصة الذين يمكنهم تلقى تدريبات أو برامج تعليمية مناسبة لمستواهم الفكرى.