



PARENTAL ATTITUDE AND ADJUSTMENT TOWARDS CHILDREN WITH DOWN SYNDROME: A COMPARATIVE STUDY

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Abstract

The present study attempts to compare the attitude and adjustment of parents of children with Down syndrome. Through simple random sampling method the present researchers selected 100 mothers and fathers, who had children with Down syndrome and who were admitted in the institute for the mentally handicapped at Shahid Modares Center of Isfahan in Iran. Parental age group was 30-50 years. Adjustment Inventory, Scale of Parental Attitude towards Mental Retardates, and a personal data sheet were used for data collection. T-test was used for statistical analysis. The results indicated significant difference in emotional and social adjustment and attitude between mothers and fathers. But the attitude between them was not significantly different in family and health adjustment. The results further showed that the social and emotional adjustment and attitude of mothers with children having Down syndrome were better than that of the fathers. But there was no significant difference between the parents in home and health adjustment.

Keywords: adjustment, attitude, parents, child, Down syndrome

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Introduction

The birth of a child with a disability or the discovery that a child has a disability comes as a shock to the parents and often it has a profound effect on the family because every parent wants his or her child to be physically and developmentally perfect. Some children have a temporary or permanent physical or mental disability. These children have special needs that challenge parents to find ways to prepare them the best possible way for the future and to handle any problems that might arise. Children with Down syndrome form part of this group. Down syndrome is the most common genetic problem causing developmental disabilities and mental retardation. In addition to delayed motor development and mental retardation, children with Down syndrome are susceptible to a wide range of health problems such as congenital heart disease, gastrointestinal malformations, and respiratory infection (Rogers & Coleman, 1992).

It is a well established fact that most disorders result from a combination of biological and socio-psychological factors. Down syndrome is one such disorder. Many Down syndrome children are happy and lovable individuals who can go on to become fully integrated into the family with early intervention programs and medical attention. The possibilities for them are almost limitless as they do for normal children. Like everybody else they too have a variety of talents and abilities. And, like other normal people, many people with Down syndrome graduate from high school, attend college, hold meaningful jobs, and may get married and even learn to drive. Still, it is an undeniable fact that no event is more devastating to a family than a child born with a birth defect. There is no test to a family's resilience more severe than the discovery that a child suffers from an incurable disease. Most clinical observations show that parents often exhibit guilt, ambivalence, disappointment, frustration, anger, shame, and sorrow; and their attitude is generally negative (Rao, 1994).

Friedrich and Friedrich (1981) studied the differences between parents of mentally handicapped and healthy children. The results indicated that parents of handicapped children reported less satisfactory marriages, less social support, lower physical well-being than parents of children with no such disability.

Many factors can influence the well-being of a family. Parents definitely constitute the heart of the family. They are the ones who deal with the issues associated with their child's disability and they also shoulder the responsibility of maintaining the household. Surely thus, the adjustment and attitude of the parents are two significant variables in this process. Therefore, it is very important for them as parents to take time to care for themselves as individuals and try to improve their ability, attitude, and adjustment. If they have a positive attitude and are well adjusted, they can be strong and have a successful relationship together (Abbot & Meredith, 1986). The relationship between the parents is a factor that can influence the family's well-being. When the parents' relationship is strong and supportive, it enriches family life for all the members.

An attempt has been made in this article to examine the impact of these variables on mothers and fathers of children afflicted with Down syndrome. We know from the experience of families and the findings of researchers that having a child with a disability affects everyone in a family. The present research has focused on parental dynamics in relation to the presence of a child with Down syndrome and attempted to find differences between fathers and mothers in terms of adjustment and attitude.

During the course of our research we discovered that parents of some of the Down syndrome children need special help and support from professionals such as family counselors and social workers. But as the first step we have to identify their needs and problems. Only after that it is possible to design suitable action plans for them. We have conducted this research precisely with these objectives in mind.

Literature Review

Research studies have indicated that parents of children with disabilities experience higher levels of stress than do parents of children without disabilities and that this stress adversely affects their adjustment and attitude (Beckman, 1991; Dyson, 1997; Rodriguez & Murphy, 1997). In psychological terms, they are required to experience the loss of the expected "normal" child, accept the fact of having a "less-than-perfect" child, integrate the child into the family, and accept the lifelong responsibility of rearing a child who is "different". The long-term uncertainty of the child's viability (Gowen, Johnson-

Martin, Goldman, & Appelbaum, 1989), future health, growth, and ultimate level of functioning and the family's ability to meet the child's needs (Harris & McHale, 1989) are factors further adding to the parents' psychological stress and altering their adjustment and attitude. Physiologically, parents have to spend most of their time and energy on taking care of their child. They have to maintain their child's health and manage his/her emotional and behavioral problems and train him/her in everyday skills. Hence, they will have only limited time for themselves (Barnett & Boyce, 1995; Shek & Tsang, 1993; Singhi, Goyal, Pershad, Singhi, & Walia, 1990). Socially, the additional daily responsibilities, together with social discrimination against people with mental handicaps, cause them to withdraw from social activities. Often they have to spend a lot of money on medical and psychological care of their child, and this has a profound effect on the financial security of the family (Harris & McHale, 1989; Singhi et al., 1990).

Studies on families have indicated that rearing a child with a mental handicap represents a serious crisis. It is potentially disrupting, and it adversely affects the health status of its members (Beckman, 1991; Seligman & Darling, 1989). Parents of handicapped children report experiencing chronic sorrow (Damrosch & Perry, 1989), diminished self-esteem (Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986), and an increased level of depression (Bristol, Gallagher, & Schopler, 1988). They are less optimistic and self-efficacious (Cheng & Tang, 1995). They demonstrate negative attitudes and tend to be self-blaming (Damrosch & Perry, 1989). Prolonged stress on mothers might lead to deterioration in their physical and mental health (Sarafino, 1994) and this in turn further affects the child's biopsychosocial well-being. The relationships and influences between the handicapped children and their families are reciprocal and circular (Crnic, 1990). However, there is now an increasing consensus that the multiple challenges associated with parenting a child with Down syndrome do not necessarily lead to negative consequences for families (Dyson, 1991; Krauss, 1993; Scott, Atkinson, Minton, & Bowman, 1997; Turnbull et al., 1993; Van Riper, Ryff, & Pridham, 1992).

Studies have also reported significant differences between parents of children with disabilities and those of non-disabled children on measures such as self-esteem, depression, marital relationship, and individual and family functioning (Gowen et al., 1989; Harris & McHale, 1989; Van Riper et al., 1992). Rao (1994) conducted a study on "Behavior disorders in moderately

mentally retarded children and the relation to parental attitude” (pp. 27-31). The sample comprised of parents of 60 moderately mentally retarded boys and girls. The findings of this study indicated that parents have a negative attitude towards their children with mental retardation. The most important implication of this study is a stress on the need for uplifting the parent’s social and psychological well-being. It is expected that it will help the parents to deal effectively with their children who are experiencing the problem. Although these studies provide useful information for understanding how the variables influence families, the results are too different from one another to fit into any particular pattern.

Objectives

In view of the above, the researchers have set the following objectives:

1. To determine the differences in family adjustment between fathers and mothers who have children with Down syndrome;
2. To determine the differences in health adjustment between fathers and mothers who have children with Down syndrome;
3. To determine the differences in emotional adjustment between fathers and mothers who have children with Down syndrome;
4. To determine the differences in social adjustment between fathers and mothers who have children with Down syndrome;
5. To determine the differences in attitude between fathers and mothers who have children with Down syndrome.

Method

Hypotheses

The hypotheses formulated in the study are as follows:

1. There is a significant difference in family adjustment between fathers and mothers who have children with Down syndrome;
2. There is a significant difference in health adjustment between fathers and mothers who have children with Down syndrome;

3. There is a significant difference in emotional adjustment between fathers and mothers who have children with Down syndrome;
4. There is a significant difference in social adjustment between fathers and mothers who have children with Down syndrome;
5. There is a significant difference in attitude between fathers and mothers who have children with Down syndrome.

Sample

One hundred parents (50 fathers and 50 mothers) with children who have Down syndrome who were admitted in the institute for the mentally handicapped at Shahid Modares Center of Isfahan, Iran, participated in the study. They were selected on the basis of the random sampling method. Parents came from diverse backgrounds such as rural and urban areas. Their education and income levels was also considerably different. The age and educational background and the areas the parents belonged from have been tabulated and graphically represented below (see Tables 1, 2, and Fig. 1).

Table 1. Frequency of age of fathers and mothers with children with Down syndrome

Parent	Age	Number	Percent
Father	30-35	9	9
	36-40	14	14
	41-45	16	16
	46-50	11	11
Mother	30-35	15	15
	36-40	18	18
	41-45	17	17
	46-50	00	0.0

Table 2. Education levels of the parents

Parent	Illiterate	No Diploma	High School Diploma	Bachelor's Degree	Post-Graduate Degree
Father	-	17	17	13	3
Mother	-	22	15	13	0

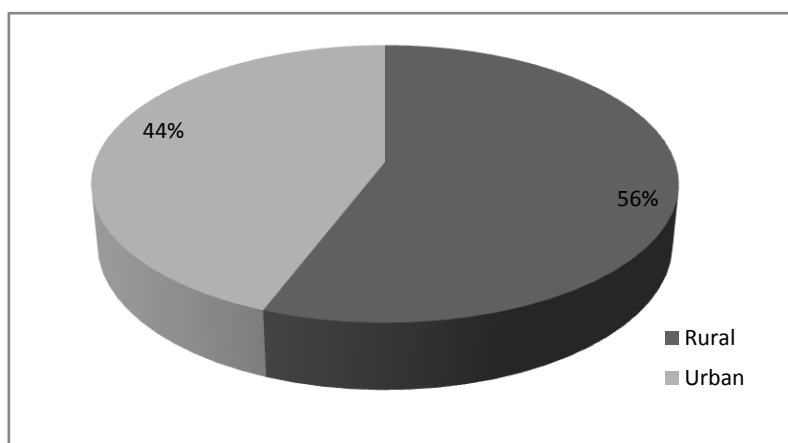


Figure 1. Parents' physical location

Data and Measurement Scales

The following instruments were applied in this study:

Personal Data Sheet. It had been designed by the researchers and it included questions related to age, location and level of education and income of the parents.

Adjustment Inventory. Adjustment Inventory was originally developed by Bell (1961). It was adapted in Iran by Dr. Symon in 1986. The test is primarily meant for adults and it has five sections. For the purpose of the present study only four selected areas of adjustment (family, emotional, health and social) have been used. Reliability coefficient of this test, by using the Gottman splitting method, was equal to .76 and by using Cronbach's alpha it was equal to .79.

Scale of Parental Attitude towards Mental Retardates. This scale consists of 40 questions and it is designed to elicit responses of the parents in terms of attitude towards their problem children. This scale was used by Ravindranadan and Raju (2007) in their study. In the present study Cronbach's alpha coefficient was about .80.

Statistical methods

In this study the statistical methods consist of

1. Descriptive statistics, and
2. Inferential statistics by applying independent t-test.

Procedure

To begin with, the Scale of Parental Attitude towards Mental Retardates was translated from English to Persian. The questionnaire was translated into Persian because Persian is the mother tongue of the participants. To ensure the reliability and validity of data the questionnaire was pre-tested by four university professors of English and after confirming the accuracy of translation, the scale and the questionnaires were given to participants. Participants were informed about the purpose of the survey orally and they could also read the research aims listed at the beginning of the questionnaire. Participants were not compelled to fill out the questionnaires. The questionnaires did not collect participants' identity. However, those participants who wished to participate in further surveys could optionally mention their e-mail addresses and/or telephone numbers. Out of all only 35 participants provided their electronic addresses and/or telephone numbers.

Results and discussion

As noted already, independent t-test was used for analyzing the data in the present study. The results are presented in the tables below. Table 3 shows that there were no statistically significant results ($t(98) = 1.75$; $p = .091$) in family adjustment; and also no difference for health adjustment ($t(98) = 0.11$; $p = .78$). Therefore the first and second research hypotheses are rejected since it has been found that there is no significant difference between fathers and mothers in family and health adjustment.

Table 3. Independent t-test results for family and health adjustment

Parents	Family Adjustment					Health Adjustment				
	M	SD	df	t	p	M	SD	df	t	p
Fathers	17.1	1.79	98	1.75	.09	11.1	2.76	98	0.11	.07
Mothers	17.75	1.24				11.03	1.8			

Table 4 shows statistically significant differences at alpha level .0001, specifically for emotional adjustment ($t(98) = 3.56$; $p < .000$), and also for social adjustment ($t(98) = 2.44$; $p < .000$). Therefore, the research hypotheses number 3 and 4 are supported. In other words, there are significant differences between

fathers and mothers in the way they adjust emotionally and socially when they have children with Down syndrome.

Table 4. Independent t-test for emotional and social adjustment

Parents	Emotional Adjustment					Social Adjustment				
	M	SD	df	t	p	M	SD	df	t	p
Fathers	11.8	3.01	98	3.65	.000	14.6	2.18	98	2.44	.000
Mothers	13.7	2.52				15.65	1.75			

Table 5 shows statistically significant results at .001 level in regards to parents' attitudes ($t(98)=5.19$; $p<.000$); therefore the research hypotheses number 5 is supported. In other words, there is a significant difference between fathers' and mothers' attitude.

Table 5. Independent t-test for difference in attitude

Parents	Mean	SD	df	t	p
Fathers	9.55	3.14	98	5.19	.000
Mothers	12.25	2.31			

Discussion

The primary intention of this study was to examine the differences in perceptions, adjustment, and attitudes between fathers and mothers who have children with Down syndrome. Parents showed different emotional adjustment towards children with Down syndrome and their social adjustment was also affected. Society plays an important role in their adjustment. This may depend on how society views children with Down syndrome. Some fathers may feel ashamed of their children with Down syndrome and consider them a burden. Others may consider it their duty to defend their children with Down syndrome when the fact is pointed out to them by members of society, or they may worry about what people think about the whole situation. In addition, some studies (e.g., Harris & McHale, 1989; Barnett & Boyce, 1995; Shek & Tsang, 1993; Singhi et al., 1990) show that parents of children with disabilities have to spend a lot of money, time and energy on medical and psychological care, attend to their emotional and behavioral problems and cultivate in them everyday life skills so as to make things easy for them. Since usually fathers take greater

financial responsibility, they are under greater pressure, and this pressure influences their adjustment and attitudes.

Mothers, in comparison with fathers, stay a lot more at home and have no strong relationships with others in the society. They are not required to answer any accusations or criticism society might level against their handicapped children. Thus, mothers fare better when it comes to social adjustment. Other research findings have shown that parental attitudes can be affected by religious beliefs as well. People belonging to different religious groups may perceive life situations differently. Attitudes related to familial, social and emotional problems and issues can vary according to religious beliefs of the particular individuals (Ravindranadan & Raju, 2007). Usually mothers have strong religious beliefs and perhaps for this reason they show better attitudes than fathers.

On the whole, findings of this study largely confirm the results of the previous studies. For example, Beckman (1991), Dyson (1997), and Rodriguez and Murphy (1997) have indicated that adjustment and attitude of parents of children with disabilities are different from that of parents of children without disabilities because the former experience a greater level of stress. According to Damrosch and Perry (1989) parents of handicapped children report more negative attitude and self-blaming. Our findings thus support results of the previous studies to a large extent.

Conclusions

The present study has established that, specifically in Iranian society, mothers and fathers show different emotional and social adjustment towards their children with Down syndrome. Society and culture do play an important role in their adjustment. It depends to some extent on how society views children with Down syndrome. Some fathers may feel shy of the fact that they have children with Down syndrome and consider them a burden. Others may think that it is their responsibility to defend their handicapped children, or they may endlessly worry about them because of the perceived social disapproval. Iranian mothers, because of the fact that they stay mostly at home, do not regard it as their primary responsibility to answer the charges of society.

Therefore, they are a lot better adjusted in social and emotional terms. Also, the findings show that mothers have better attitudes than fathers.

Limitations and suggestions for further research

There are a number of limitations associated with this study. Some of these limitations, however, suggest avenues for future research. Some of the limitations originate in constraints with regard to time and money, while others stem from the limitations of literature on the subject. The literature has been limited because it is one of the first efforts to explicitly differentiate between adjustment and attitude of mothers and fathers of children with Down syndrome.

1. Further studies should focus on indicators such as stress, financial position of families, the role of culture, and other topics.

2. Our sample size and regional application might limit the extent to which our results can be generalized. Future research should examine whether our findings can be generalized and extended to include other samples and settings.

3. The study employed quantitative methods. In view of this method, there was only a limited exploration of the underlying ideological issues and the respondents' subjective experiences, and as a result interpretations were ignored. This further limits the extent to which these findings can be generalized. Further studies are required to confirm and elaborate the findings of the present study. These future studies should employ qualitative methods to gain access to the respondents' own understanding of their behavior.

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