



**COMPARISON THE WORRY AND HOPE IN MOTHERS HAVING CHILDREN
AUTISM AND DOWN SYNDROME**

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ABSTRACT

The present research aimed at comparing Worry and hope between mothers having children Autism syndrome and Down syndrome. The research used a descriptive- comparative method and the sample of study included 60 mothers having children suffering from autism and down syndromes. The sample was selected among all mothers having children in age of 6-12 who were suffering from autism and Down syndrome in Kerman in 2014. In order to measure the variables of the research we used two questionnaires, the Pennsylvania worry questionnaire and the scale of aptitude toward hope among adults. The results show that the amount of worry and hope among mothers having children suffering from autism is different from mothers having children suffering from Down syndrome. The Worry between mothers having children with autism syndrome was more than mothers having children with Down syndrome. The level of hope between mothers having children with Down syndrome was higher than mothers having children with autism syndrome.

Key words: Hope, Worry, Autism, Down syndrome

INTRODUCTION

Mental retardation is not a disease but is the result of an illness process in brain whose feature is limitation in the function of intelligence and adaptation. Often, the reason for mental retardation is not clear and its consequences will emerge from intelligence and skill disorders. In mid 1800's most of mental retarded children were taken to special training centers because Researchers believed that such children can return to their family when they receive sufficient trainings and they can operate better in society. Those residential centers for retarded children were mostly common in mid 1955 until people became aware of non-hygienic and crowded conditions and sometimes the malfunctioning of such centers. This began the deinstitutionalization movement. Since late 1965 up to now, few retarded children have been sent to special centers and the concept of involvement in school environment and normalization in life situation among groups and majority of citizens has received lots of importance (Kaplan and Saduk, 2007), Genetic features of people are transmitted from parents to children via 46 chromosomes to fetus, equally 23 chromosomes from mother and 23 chromosomes from father. But sometimes the fetus receives an extra chromosome and in fact 47 chromosomes are

transferred to it. This extra chromosome will delay mental and physical growth of the fetus. Unfortunately no one exactly knows the reason behind this happening and till now no method is defined to prevent it. If you heard that your baby has lower than the average level of mental and cognitive abilities, short legs and arms, weak muscles, flat side view, almond eyes, small ears, and short neck, do not panic! Your baby suffering from Down syndrome can also achieve his partial independent life through awareness and accurate caretaking. The genetic disorder of Down syndrome emerges because of all or part of an extra chromosome and one out of every 800 children shows the symptoms accompanied with a decrease in recognition abilities, weak physical growth, and changes in skin color. Although Down syndrome is not preventable, in case of having enough knowledge and information we can recognize it in pregnancy or the pre birth period. In this case, we can largely help the baby to achieve his partial independency (Milanifar, 2007; Afrooz, 2006). Autism is a condition in early childhood and is recognized with impairments in social interactions and communication, limited and bizarre interests. Most people suffering from autism have average retardation with an IQ

level of 35-50. Although measuring intelligence among such children is difficult, almost 3/4 of them have mental retardation. Generally, more mental retardation increases the possibility of autism. Anyway, low turnover in patients with IQ level of 20 and lower, show retardation in examinations on autism and recognition tools of autism may result in inaccurate recognition in very low IQ people. However, retarded children pose irreparable harm to families. Vulnerability of families against this impairment is such that their mental health will be severely hurt (Narimani, Agha Mohammadian, Rajabi, 2007), in a way that all hopes and ambitions of a family will ruin and difficulties will begin (Pisula, 2002). The difficulties involve organizing routine family activities with treatment sessions of children, emotional adaptation with special conditions of the child (Raeis Dana, Kamali, Tabatabaei, Shafaroudi, 2009), spending lots of time to determine the method of treatment, providing home cares, handling school problems, and the behavioral problems of retarded children (Baker, Blacher, Edelbrock, 2002). Many families who have retarded children should accept the truth that their children have special situation and it will engage them for a life. Studies show that negative effects of having an unable or retarded child will create

tension and pressure among family members specially the mother (Tajeri, 2008). Mother is the first person who has a direct contact with the child. Emotions such as guilt and deprivation that result from the abnormality of the child can drive mother into isolation and make her unwilling to establish an intimate relationship with people and also decreases her self-confidence and self-understatement. In this regard, she will be upset with low spirit, depression, and health risks resultants (Narimani, Agha Mohammadian, Rajabi, 2007). Retarded children play a part in the adaptability and the physical and mental health of mothers and often have negative effects on her (Salovita, Ltalinna & Leinonen, 2003; Gupta & Singhl, 2004).

Lots of researches have compared the mental health and life satisfaction of mothers with unable and retarded children. These studies showed that the amount of social adaptability, (Kuhsali, Mirzamani, Karimlu & Mirzamani, 2008), mental health (Narimani, Agha Mohammadian, Rajabi, 2007) and marital satisfaction (Deini, Bahrami, Davarmanesh, Biglarian, 2006) is lower among mothers having retarded children in comparison with mothers of normal children, while stress (Khoshabi et al, 2009), upbringing complexity

(Khorramabadi, Pouretamad, Tahmasebian & Chimeh, 2009) and using contrastive worry-oriented approaches when encountering complexities (Rajabi, Pushne, Ghojari Bonab, 2009) are so much higher among mothers having retarded children compared with mothers having normal children.

Other studies showed that mothers of retarded children are more involved in behavioral disorders of their children than fathers and experience more mental problems. Therefore, they need more support in this regard. Mothers having retarded children may not be able to stand the problems of their children and become discouraged to achieve their goals by negative emotions (Ogeston et al, 2011), and this has an impact on their lives. The studies in this domain with psychological elements such as worry and hope among mothers of different groups of retarded children are limited and divergent in a way that some studies suggest that mothers of children suffering from autism have complexities and worry more than chronic diseases (Shu, Lung & Chang, 2000). For example (Ogeston et al, 2011), in a study regarding the comparison between hopes and anxieties among mothers having children suffering from a sort of autism disorder (199 mothers) and Down's syndrome (60 mothers) showed that mothers

having autism children had less hope and much worry toward future in comparison to mothers having children with Down's syndrome. Leoid and Hostings (Lloyd & Hastings, 2009) also in a research investigated the relation between hope and mental health among 198 mothers having retarded children, autism and Down syndrome children. They found that mothers having children suffering from autism had less hope and mental health compared to the other groups and mothers having retarded children had a lower level of hope and mental health compared to mothers having children with Down syndrome. On the other hand, the results of a research by Koidmir and Tusoun (Koydemir & Tosun, 2009) on investigating the effects of having an autism child on the life of mothers in the form of a semi-structured interview involving 10 mothers having autism children showed that psychological experiences of these mothers were similar to the experiences of mothers having children suffering from other disabilities.

Most of investigations in Iran on families having retarded children are about taking care and rehabilitation of an unable child and fewer studies have focused on comparing mothers having unable children in different groups. So, the present research tries to

investigate some of psychological situations of mothers playing a main role in emotional and behavioral disorders of children , and tries to scientifically know and reflect the results to parents and the related officials in order to ease the pain and effects of having an unable child.

On the other hand what we expect and also other studies have confirmed is that concerns and problems related to mental health of mothers having unable children is higher than mothers having normal children. Also different researches have shown that the severity of retardation among children has an impact on the level of worry and stress of a mother but we exactly do not know if psychological elements such as hope and worry among mothers are different in various disabilities. Therefore, the present research aims to psychologically compare worry and hope among mothers of children with autism and Down syndrome.

METHODOLOGY

The design of the present study was descriptive, casual-comparative. The population included all mothers having children suffering from autism and Down syndrome aging from 6 to 12 in Kerman in 2014. Because of the severe inaccessibility of them, 60 mothers were selected using available sampling (30 mothers having

autism children and 30 mothers having Down syndrome children) and answered two questionnaires. The Pennsylvania worry Questionnaire (PSWQ) is a 16-item scale which measures severe worry and under control based on a 5-point Likert scale ranging from strongly untruthful to strongly truthful (Davy & Wells, 2006). The total score of the questionnaire is 16-80. In a research by Dehshiri, Golzari, Borjali, and Sohrabi, (Dehshiri, Golzari, Borjali, Sohrabi, 2010), the similarity coefficients of these questionnaires were reported not only about the patients suffering from worry (0.86), but also about the patients suffering from other worry disorders such as social fear (0.94), simple fear (0.95), operational obsession disorder (0.94), panic disorders (0.93) and agoraphobia (0.94). Also, the internal similarity coefficients in the questionnaires of normal groups was high and reported to be from 0.90 to 0.91 , (Dehshiri, Golzari, Borjali, Sohrabi, 2010). The validity of reexamination of these questionnaires between clinical staff and students was between 0.74 and 0.92. In the present research the validity of this questionnaire was also calculated using Cronbach alpha at 0.86.

Schneider scale of adult hope: This 12-item questionnaire is designed by Schneider

(Snyder, 1995) for the age of 15 and higher and includes two sub-scales of path and motivation. This questionnaire analyses the answers in an 8 degree spectrum from 1 (strongly wrong) to 8 (strongly right). The domain of marks can be from 8 to 64. In a research by Golzari (Golzari, 2007) on 660 female students in Tehran, the reliability of the scale was calculated at 0.84 using Cronbach alpha. In the present research the validity of this scale was calculated at 0.88 using Cronbach alpha.

RESULTS

The age range of mothers participating in the present research was 25 - 52 with the average of 35.13 years and standard deviation of 4.67. This was 6 to 12 years with the average of 8.75 and the standard deviation of 2.79 for children. Also in table 1, the average and standard deviation of worry and hope of samples are presented.

The average score of worry for mothers having autism children was 53.89 and the average of worry score in mothers having Down syndrome children was calculated at 49.81. Also, the average score of hope among mothers having autism children was 43.54 and the average score of hope among mothers having Down syndrome children was 48.36.

As we can see in table 2, according to t-value ($t=2.48$) and the significance level of $p<0.001$, there was a significant difference between the worry of mothers having autism and Down syndrome children. So, according to the averages, the worry level among mothers having autism children (53.89) was more than the average worry among mothers having Down syndrome (49.81). This shows that the worry level among mothers having autism children was more than mothers having Down syndrome children. According to the significance level of Luin test, the worry of mothers having autism and Down syndrome children, the variances of two groups are different.

As we can see in table 3, according to the t-value ($t=1.85$) and the significance level of $p<0.01$, there was a significant difference between hope among mothers having autism children and mothers having Down syndrome children. So, according to the average levels, the hope of mothers having Down syndrome children (48.36) was higher than the average of hope in mothers having autism children (43.54). This shows that the level of hope was higher among mothers having children suffering from autism and mothers having children suffering from Down syndrome and the variances of two groups were not similar.

Table 1: the table is rate of children with autism and Down syndrome

	Down syndrome	Average	Autism	Standard deviation
concern	53.89	9.05	49.81	8.43
Hope	43.54	6.91	48.36	7.14

Table 2: the table is concerning independent rate of mothers who have children with autism and mothers who have children with Down syndrome

Group	mean	Standard deviation	T rate	Significance level	Lown scale	Significance level
Autism syndrome	30	53.89	9.05	2.48	0.01	9.92
Down syndrome	30	49.81	8.43	-	-	-

Table 3: mothers who have children with autism and mothers who have children with Down syndrome

Group	Average	Standard deviation	T rate	Significant level	Lowin scale	Significant level
Autism syndrome	30	43.54	6.91	1.85	0.02	4.45
Down syndrome	30	48.36	7.14	-	-	-

DISCUSSION

The results show that the amount of worry among mothers having children suffering from autism is different from mothers having children suffering from Down syndrome. So according to the average score between mothers having autism children (53.89) and the average of worry between mothers having Down syndrome children (49.81), we can say that the amount of worry among mothers having autism children is higher than mothers having children suffering from Down syndrome. The results are consistent with those of Queedmeer and Tosun (Koidmir & Tusoun, 2009) They showed that, the experiences of mothers having Down syndrome children were higher than the experiences of mothers having children with other disabilities and all these mothers experienced higher levels of stress and depression under the effect of their children. To explain these findings we can say that because in most cultures, the responsibility of a child is more on his mother than on other members of the family, having an unable child (regardless of the type of disability) can lead to so many concerns for the mother. So the role that a type of disability has is not important. But the findings are not consistent with those of Augston, Macintosh, and Mayer (2011), who reported that mothers of autism children had more worry about future than mothers of Down syndrome children. Our findings were not also in line with the results of Khoramabadi, et al, (2009)who showed that the stress of being parents in mothers of autism children was significantly higher than mothers of normal children. We can note the low information level of the sample of children with disability as an explanation of this heterogeneity which resulted in high worry levels in all groups. In addition, this heterogeneity may be resulted

from the difference in the investigated groups or the difference in the tool used for measuring the amount of worry in researches.

Also the results showed that the amount of hope between mothers having autism children and Down syndrome children has a significant difference. So according to the averages, the hope in mothers having Down syndrome children (48.36) was higher than the average amount of hope scores of mothers having autism children (43.54). This shows that the amount of hope among mothers having Down syndrome is higher than mothers having autism children. These findings are consistent with the results of Augeston, Macintosh, and Mayers (2011), based on the fact that mothers having autism children have less hope compared to mothers having Down syndrome children. Likewise, the results of the study of Leoid and Hostings (2009) showed that mothers of children suffering from autism had lower scores in hope and mental health compared to mothers having retarded children. In explanation of the lower level of hope among mothers having autism children compared to other mothers, we can point to some weakening features of autism disorder compared with other disabilities such as verbal, communicational, behavioral, and social disorders which cause so much complexities in families such as the need of caretaking, education, and special and continuous treatment of autism children. Also, limited improvement of autism children in education and treatments and their vague future are among other factors which can explain the lower level of hope among mothers of autism children.

CONCLUSION

On the whole, according to the results of the present study we can say that the role of mothers against disabled children is serious and daunting and mothers of retarded children are faced with intolerable mental, economic, and social pressures. This in fact can decrease their hope and increase their worry. But such retardations and effects are compensable because in so many cases, the lower level of information of mothers about their children's disability is a factor which results in various anxieties and less hope. So it is recommended that mothers having disabled children participate in training sessions to increase their information and knowledge about the characteristic and communicational features of their disabled children. Also, the distribution of scientific materials in a simple understandable language can contribute to the awareness of mothers. Creating shared working groups by parents aiming at sharing their experiences about their retarded children can help families in seek of support and increase their hopes. Providing education compatible with their needs can decrease the possibilities on mothers against their

children. This decreases the worry and increases the hope among them. So, it is recommended to consider the skills and needs of such children in an educational process.

In the present research, there are some limitations in sampling which can affect the results. The samples are limited to mothers having autism children and Down syndrome children who visited rehabilitation and training centers (mothers who did not visit such centers are not investigated). Omission of some samples due to illiteracy, heterogeneity of the sample group in terms of education level, economic and social situations, and refusing to answer some questions are among the limitations. Thus, it is recommended to prevent these limitations by sampling people who are homogeneous in terms of education, social and economic situations as far as possible. According to the importance of family members' roles especially the father in the quality of mothers' lives, it seems that it is necessary to have other factors impressing mothers with the situation of the child such as personal features, mental conditions, and emotional situations of other members of the family. In addition, the effects of economic factors should be considered. Also, it is recommended to carry out similar studies on fathers having retarded children and other family members; this will provide the possibility of a comprehensive comparison.

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