

## Difficulties of mothers living with mentally disabled children

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### Abstract

**Objective:** To determine the difficulties of mothers living with children suffering from intellectual disabilities, and the influence of socio-demographic factors aggravating the situation.

**Methods:** The study was conducted from September to December 2009 in Odemis, Izmir in western Turkey, in one public-sector and two private-sector rehabilitation centres for disabled children. The research sample consisted of mothers with primary responsibility for 168 disabled children between the ages of 3 and 18 years. Data was collected using a pre-designed Personal Information Form, which had two sections. The first part contained 20 items about the socio-demographic data of the families and the children, their knowledge about mental disabilities and support for childcare. The second part consisted of 18 items which related to the most frequently encountered problems in terms of daily care, as well as the financial, psychological and social aspects. Data, collected through face-to-face interviews spanning 30-40 minutes, was analysed using analysis of variance and student's t test.

**Results:** Of the 168 mothers, 64 (38.1%) said they experienced sadness; 72 (42.9%) anger; and 32 (19.1%) felt lonely. As many as 92 (54.8%) mothers were blamed by their in-laws for the disability in their respective children. Only 50 (29.8%) parents in the study said they had "sometimes" felt acceptance of their disabled child.

**Conclusion:** The psychological situation of parents with disabled children is an issue of particular concern, and psychological consultancy and guidance should be provided to such families to enable them to overcome their negative emotions and the consequent problems.

**Keywords:** Mentally disabled, Children, Family, Psychological support. (JPMA 62: 776; 2012)

### Introduction

Marriage and having children are generally the happiest moments of one's life. Not every child, however, is capable of using certain mental abilities such as the perception of surrounding stimuli, evaluation of perceptions, conceptualisation, judgement, learning and making connection between things that are learned or experienced. In addition, these children tend to live in their own world or have a physical or motor disability. These children are defined as 'handicapped children,' who fall behind their peers in mental, physical, social or medical development.<sup>1-3</sup>

More than a billion people are estimated to live with some form of disability, or about 15% of the world's population (based on 2010 global population estimates). This is higher than previous World Health Organization estimates, which date from the 1970s and suggested a figure of around 10%. There is a higher disability prevalence in lower-income countries than in higher income countries.<sup>4</sup> There are approximately more than 5.5-6 million people who are physically, mentally or socially handicapped in Turkey, which accounts for 12.29% of the population.<sup>3</sup>

According to the data of the Turkish Statistical Institute in 2007, there are 1,673,550 disabled people, 59% of whom are male. It has been reported that 16.158 people are mentally disabled in Turkey, which accounts for 0.48% of the total disabled population.<sup>4,5</sup>

The diagnosis of mentally or physically handicapped children is likely to be a traumatic experience for their families.<sup>2-6</sup> Having a disabled child tends to influence the lives, emotions and behaviours of family members. Most parents have expectations to raise a normal child, and hold hopes and expectations for planning the future of the child. In contrast, parents whose child has some impairment, may experience dramatic changes in social life, expectations, plans, work life and their financial status.

Several studies have demonstrated that mothers and fathers, particularly the mothers, of physically or mentally handicapped children, experience more stress than the parents of healthy children, and experience higher levels of anxiety.<sup>7-9</sup>

Families may experience shock, a sense of denial and guilt, increased sadness, and may not accept the differences of the child. They tend to make an effort to paper

up the differences of their children in an attempt to overcome the problem.<sup>10,11</sup> Families are likely to adapt in order to satisfy the needs for the development and education of the child after accepting their disability. They should tailor to their new lives by giving the necessary attention and love to such children. Mothers who are able to accept and adapt to their child's lifestyle are more likely to have a healthy relationship with their children and the social environment. This is only possible with the integrated education, which is defined as the education of the handicapped children in normal schools together with their healthy peers.<sup>2-11</sup>

The most common disability in Turkey is mental retardation. Mental retardation is generally used to describe the children who develop and learn slower than the normal children. Hence, they struggle to survive in their personal and social lives without any support. Children need good care and education in order to take their places in society. These needs are provided primarily by the family, especially by the mothers. Therefore, it is important to determine the difficulties that a mother encounters during the education and care of a disabled child. The current study was conducted to determine the difficulties of mothers with mentally disabled children, and the effects of socio-demographic factors on these difficulties.

## Subjects and Methods

The research was conducted in Odemis, Izmir in west of Turkey, in one public- and two private-sector handicapped children's rehabilitation centres. One-third of the private rehabilitation centres located in Odemis did not allow any research to be conducted in their facilities.

The descriptive study was performed between September and December, 2009, and involved mothers with 180 mentally disabled children who were registered with one of the three centres. Sample method based on selection criterion was not used in this study, except for voluntary participation by the mothers. The content validity of the data collection form was evaluated prior to actual data collection by administering it to the mothers of 10 disabled children at one of the private facility. Upon the conclusion of this pilot test, revisions were made to one question that was found difficult to understand by the participants. Two of the mothers with a child enrolled in the private centers refused to participate, while the 10 mothers who participated in the pilot test were not included in the study. The sample, as such comprised mothers with primary responsibility for 168 disabled children, between the ages of 3 and 18.

The pre-designed and pre-tested Personal Information Form had two sections. The first part contained 20 items about socio-demographic data of the mothers and the

children, their knowledge about mental disabilities and support for childcare. The second part included 18 items which related to the most frequently encountered problems - difficulties experienced in daily care, financial, psychological and social difficulties. The frequency of family problems were classified as 'never,' 'rarely,' 'sometimes,' 'often' and 'always.' Accordingly, it was based on a scoring system from 0 to 4. Cronbach's Alpha coefficient was used for reliability analysis of the data collection form.

Approvals were obtained from the Ethical Committee of the Ege University Odemis School of Nursing, and written permission to conduct the research was also acquired from the administrators of the rehabilitation centres. Interviews were conducted with parents who had primary responsibility for the care of their disabled children. As all participants consisted of mothers, the sample comprised mothers alone. The mothers included in the research were informed about the purpose and method of the study as well as the fact that their participation was on a voluntary basis which allowed them to withdraw from the study at any time upon their consent. Mothers who agreed to participate in the research for the completion of the Personal Information Form were involved in face-to-face interviews which took approximately 30 to 40 minutes. The data were collected over a 3-month period and analysed by using analysis of variance (ANOVA) and Students t test.

## Results

Of the children, 80 (47.6%) had an intellectual disability, 51 (30.4%) had autism, and 37 (22%) had cerebral palsy (CP). When the socio-demographic features of the families were evaluated, 72 (42.9%) mothers were in the 32-37 age bracket; 122 (72.6%) were primary school graduates; 135 (80.3%) were housewives; 80 (47.6%) had physical health problems; and 104 (61.9%) of the mothers stated to have a mental disorder.

Besides, 22 (13.1%) mothers were found to have another relative with mental disabilities in their families; 136 (81%) had difficulties in fulfilling their childcare needs; 74 (44%) received childcare support; 68 (40.5%) got to know about their children's conditions, themselves; and 38 (22.6%) were informed by the doctors.

The age of group distribution of the disabled children showed 30 (17.9%) were 3-6 years old; 100 (59.5%) were 7-12 years old; and 38 (22.6%) were 13-18 years old. It was observed that 59.5% were males; 14.3% had no siblings, 71.4% were the result of a normal delivery. Of the children, 58 (34.5%) had parents who were blood relatives. The majority of the sample, 145 (86.3%), belonged to nuclear families; 78 (46.4%) had a balanced family income; 90 (53.6%) had below-average income;

**Table-1: Distribution of Parents According to the Problems in Their Families.**

Difficulties	Never	Rarely	Sometimes	Often	Always
	Number (%)	Number (%)	Number (%)	Number (%)	Number (%)
Uncomfortable with public views on disabled children	33 (19.7)	24 (14.3)	22 (13.1)	34 (20.2)	55 (32.7)
Anxiety about children's future	12 (7.1)	17 (10.1)	25 (14.9)	47 (28.0)	67 (39.9)
Communication problems in social life	32 (19.1)	29 (17.2)	36 (21.4)	44 (26.2)	27 (16.1)
Feeling self guilt and accusing themselves	49 (29.1)	27 (16.1)	37 (22.0)	32 (19.1)	23 (13.7)
Economic difficulties in childcare	14 (8.3)	21 (12.5)	39 (23.2)	51 (30.4)	43 (25.6)
Difficulties in providing special devices for childcare	40 (23.8)	37 (22.0)	24 (14.3)	35 (20.8)	32 (19.1)
Communication problems between family members	58 (34.6)	29 (17.2)	39 (23.2)	22 (13.1)	20 (11.9)
Communication problems between mother and father	63 (37.5)	34 (20.2)	27 (16.1)	25 (14.9)	19 (11.3)
Frequently making statements to family members and society about children	27 (16.1)	24 (14.3)	40 (23.8)	45 (26.7)	32 (19.1)
Consultancy Need for childcare	17 (10.1)	23 (13.7)	36 (21.4)	49 (29.1)	43 (25.6)
Difficulties in physical care of children	15 (9.0)	21 (12.5)	32 (19.1)	55 (32.7)	45 (26.7)
Difficulties in controlling the child's behaviours	12 (7.1)	16 (9.6)	24 (14.3)	49 (29.1)	67 (39.9)
Anxiety for possible accidents or harms that children could encounter	15 (9.0)	17 (10.1)	20 (11.9)	47 (28.0)	69 (41.0)
Difficulties in sharing the problems of disabled child	27 (16.1)	28 (16.7)	43 (25.6)	45 (26.7)	25 (14.9)
Compliance problems of disabled child with siblings	65 (38.7)	24 (14.3)	26 (15.5)	35 (20.8)	18 (10.7)
Inability to give adequate care to other children	50 (29.8)	20 (11.9)	29 (17.2)	30 (17.9)	39 (23.2)
Feeling isolated from the society	30 (17.9)	31 (18.3)	33 (19.7)	47 (28.0)	27 (16.1)
Accepting disabled child	31 (18.4)	39 (23.2)	50 (29.8)	26 (15.5)	22 (13.1)

**Table-2: The Relation between the Mean Difficulty Levels of Childcare and the Mother's Social Support Status.**

Difficulty Level of Childcare	Mothers with social support (n=74) X±ss	Mothers with no social support (n=94) X±ss	T	P
The Mean Score of the Questionnaire	56.86±10.55	56.01±9.90	1.290	0.258

while none of the families had a surplus income.

Of the 168 mothers, 64 (38.1%) stated that they experienced deep sadness; 72 (42.9%) reported anger; and loneliness was stated by 32 (19.1%). In this study, mothers expressed that the reasons for disability were generally congenital (62.5%) than disease-induced (18.5%) and unknown (19.0%). In the analysis of the people who put blame on the mother, 54.8% of the mothers were implicated by their husband's family.

Upon the evaluation of parents based on the problems in their families, it was observed that there had 'never' been a compliance problem between the disabled child and their siblings in 65 (38.7%) families; there had 'rarely' been communication problems between the parents in 34 (20.2%) families; 50 (29.8%) families had 'sometimes' felt acceptance of their disabled child (Table-1). On the other hand, it was determined that 51 (30.4%) families 'often' encountered financial problems in childcare; 55 (32.7%) had physical difficulties in childcare; 69 (41.0%) 'always' had anxiety about possible accidents and harms that the child could encounter; and 67 (39.9%) families were worried about the children's future and had difficulties in controlling the child's behaviours. Cronbach's Alpha coefficient was 0.782, and the total score received from the second part of the Personal Information Form varied

between 0 and 72.

The total mean score of the Personal Information Form was 38.80 ±1.64. When the relationship between the mean scores of families' problems and their socio-demographic properties were observed, it was found that there was no statistically significant difference between socio-demographic characteristics and the difficulties of families in terms of the age group of the mothers, gender and the age group of the handicapped children, and the mean difficulty levels of families ( $p>0.01$ ).

When the relation between the mean difficulty level of childcare and the social support status were evaluated, the families with social support were found to have higher scores. This difference was not statistically significant ( $t=1.290$ ;  $p>0.01$ ) (Table-2).

When the mean difficulty levels of childcare and the status of having mentally disabled family members were compared, the mean scores were found to be higher in families with no other disabled family members. The difference was statistically significant ( $t=8.542$ ;  $p<0.01$ ).

## Discussion

The healthiest environment for children from birth onwards is the family which comprises primary caregivers for the development, growth, knowledge acquaintance of

children and assumption of social responsibilities by the children. If the child has disability, the accountability of the family only increases.

Daily care for children with disabilities is different from that of normal children due to the special care that needs to be provided. Some or all of immobilised children's activities of daily living are dependent on someone else.

This situation may cause families of disabled children to experience difficulty with their care. In our study, caretakers for the mentally disabled children experienced the most difficulties with physical care (feeding, dressing/undressing, assistance with elimination, bathing, carrying and so on), lower intellectual ability and inadequate communication skills.<sup>12</sup> Several studies have found that the majority of disabled children needed supervision or extra assistance in the majority of their activities of daily living.<sup>13-15</sup>

In the present study, more than half (59.5%) of the children with mental disabilities were male. Generally, disabled male children are two times higher than the number of disabled females. Similarly, in a study, 28.0% of children were females and 72.0% were males.<sup>16</sup> In another study in all age groups, it was reported that approximately two-thirds (59.7%) of the disabled people in Aydin were males.<sup>17</sup> In another study, 54.1% of the disabled participants were males and 45.9% were females.<sup>18</sup> In the Turkish Disabled Research conducted in 2002 on the distribution of disability type according to gender, more males (59.0%) were found than females (41.0%) in all disability types.<sup>4</sup>

In this study, mothers stated that the reasons underlying the disabilities were generally congenital (62.5%), followed by disease-induced (18.5%) and unknown (19.0%). In a study, two-third of mothers who stated the cause of their children's disability as congenital were found to have no idea about the reason of the disability.<sup>19</sup> In one study, the reason of disability was found to be congenital in 63.6% of the children, disease-induced in 15.5% and unknown in 20.9%.<sup>1</sup> In another study, the reason of disability was unknown in 50.8% of children, and genetic diseases in 21.4%.<sup>20</sup> In a study, the reason of the disability was determined as congenital in 65.1% children.<sup>21</sup> According to the report of the Turkey Disabled Research (2002), the reason of the disability was asphyxia during the last stage of the delivery (10.4%) in mentally handicapped children, and genetic and inborn defects (23.4%) in visually handicapped children.<sup>22</sup>

The care of mentally disabled children is a liability on the families, particularly the mothers who are most affected by this situation. It has been reported that mothers spend more time with mentally handicapped children, and therefore have more responsibilities regardless of whether the child is

a minor or a teenager, living at home or elsewhere.<sup>23</sup> Furthermore, it has been reported that the frequency of psychological problems such as somatic complaints, depression and anxiety disorders is higher among mothers with disabled children.<sup>24</sup> Mothers of children with disabilities who were evaluated in terms of their personality and emotional conditions concluded that having a child with mental disabilities has a negative effect on parent functionality and the daily life of the mother more than the father.<sup>25,26</sup> In several studies, it has been indicated that mothers of disabled children give up other roles in society, attend less to social activities, and have less social life due to their increased responsibilities for childcare.<sup>27,28</sup> The results of the present study were consistent with the literature.

When the relation between the mean difficulty level of childcare and the social support status were investigated, mothers with social support were found to have higher scores. This difference was not statistically significant ( $t=1.290$ ;  $p>0.01$ ). The social support, in particular from the relatives, is very crucial for the parents with disabled children. Support from society plays an important role in sharing the values and feelings and, as a result, helps to fulfill social roles, leads to acceptance, and overcome new roles and identifications. In addition, adequate social support influences the behaviour and development of children and families in various ways, and is suggested to prevent negativity, and improves their functionality through education. Parents who share the responsibilities with others and are supported by society are less likely to feel isolated. Therefore, they can handle problems more easily.<sup>14</sup> In a study, it was agreed that families with handicapped children need support from people around them.<sup>17</sup>

When the mean difficulty levels of childcare and the status of having mental disabled family members were compared, the mean scores were found to be higher in families with no other disabled family members. The difference was statistically significant ( $t=8.542$ ;  $p<0.01$ ). This finding demonstrated that the families with disabled family members encountered less difficulty due to their experiences from other family members.

Contrary to available literature, the current study found that social support had no effect on the mean difficulty levels of childcare. However, the mean score was influenced by having a family member with mental disability.

## Conclusion

The psychological condition of parents with disabled children is a matter of particular concern. Psychological consultancy and guidance need to be provided to such families in order to enable them to overcome their negative emotions and problems. To

increase the support of family members and relatives, appropriate programmes should be implemented. Family support groups should be formed in rehabilitation centres in both public and private sectors and the participation of affected family's relatives should be encouraged.

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