

A Study of the Anxiety Levels of Mothers of Children with Mental Disabilities

¹Emine Ahmetoğlu and ²Neriman Aral

¹Department of Preschool Education, Faculty of Education, Trakya University, Edirne, Turkey

²Department of Child Development and Education, School of Home Economics,
Ankara University, Ankara, Turkey

Abstract: The study aims to determine the anxiety levels of mothers of children with mental disabilities and examine whether the sex of these children, number of siblings, birth order and mothers' education level cause a difference in anxiety levels. The study was carried out with the mothers of children with mental disabilities attending Trakya University Education, Research and Implementation Center for Children with Mental and Physical Disabilities in Edirne. A total of 100 volunteer mothers were admitted in the study. Data about the children and their family members were collected through a General Information Form designed by the researchers. A Questionnaire on Resources and Stress developed by Holroyd and translated into Turkish and tested for validity and reliability by Akkök was used to identify the anxiety levels of the mothers having children with mental disabilities. The results showed that the mothers' anxiety levels did not differ significantly according to the variations which are sex of children, number of siblings, birth order and mothers' education level ($p>0.05$). However, the mothers having sons, those whose second or later children were disabled, those with more than one child and those with university degrees were found to have higher anxiety levels.

Key words: Children with mental disabilities, mothers of children with mental disabilities, anxiety

INTRODUCTION

Having a child is a milestone in the life of any family. While families expecting a baby generally experience positive emotions and build their dreams and expectations, they may also experience a certain level of anxiety. This is a perfectly normal process of psychological preparation which intertwines the wish to have a perfect baby with the fear of having a disabled one (Gargiulo, 1985).

The birth of a baby with any disability or noticing the disability in a child leads to the shattering of all positive expectations and to serious social and economic implications for families. These are generally accompanied by intense emotions and anxiety (Küçükler, 1993; Dale, 1996; Ellis and Hirsch, 2000; Mobarake *et al.*, 2000; Emerson, 2003). The sources of such stress include emotional difficulties, lack of information about the disability, discomfort when discussing the disability with other people, behavioral and health problems in children, having to meet many different professionals about treatment and education, efforts to find the right school, the need for more time, money and energy and anxiety about the future. Such stress leads family members and particularly mothers, to have communication problems with their children, have unrealistic expectations from them, meet only physical needs and ignore emotional needs and even reject the child (Küçükler, 1993; Dale,

1996; Ellis and Hirsch, 2000; Mobarake *et al.*, 2000; Emerson, 2003). In such circumstances, the first step of help should include eliminating the conditions creating stress and supporting family members (Gargiulo, 1985; Kucker, 1993; Dale, 1996; Ellis and Hirsch, 2000). Psychological, professional and educational support services help families cope with negative emotions, attitudes and anxiety, accept their children and have a harmonious life again and provide their children with effective and long-lasting education (Kucker, 1993; Akkök, 1991; Anonim, 1999).

Although the assumption that families get negatively affected by having children with disabilities has lost popularity in the recent years, it is widely accepted that some families cope more easily. This has been attributed to the factors such as family itself (size, culture, socio-economic level) and children (the type and severity of disability) and personality traits of family members. The most frequently emphasized factor among these has been the quality of the social support that families receive. Studies have shown that support offered through group sessions to one or more family members within the scope of family counseling offers knowledge and serious psychological support, reduces stress and anxiety levels, increases acceptance and positive emotions of family members and creates positive familial communication (Küçükler, 1993; Mobarake *et al.*, 2000; Akkök, 1991; Hallahan and Kauffman, 1988; Sucuoğlu, 1997;

Wanamaker and Davis, 1998; Pelchat *et al.*, 2003; Tekin, 2000; Weiss, 2002; Manuel *et al.*, 2003). Therefore, research studies are based on self-statements and objective observations of families with disabled children and identifying their needs and anxieties are required along with supportive and cooperative educational programs. These studies may help identify mothers' anxiety areas, determine the variables affecting these and offer effective solutions to the concerns of mothers and families with disabled children. Such studies would help facilitate the social adaptation of disabled children and their family members and thus contribute towards a more positive future for all. Therefore, the present study aims to identify the anxiety levels of the mothers having children with disabilities and investigate whether children's sex, birth order, number of siblings and mothers' education level create any difference in mothers' anxiety levels.

MATERIALS AND METHODS

The study sample comprises the mothers having children with mental disabilities attending Trakya University Education, Research and Implementation Center for Children with Mental and Physical Disabilities in Edirne. A total of 100 volunteer mothers were admitted to the study. Data about the children and their family members were collected through a General Information Form designed by the researchers. The Questionnaire on Resources and Stress developed by Holroyd (1976) and translated into Turkish and tested for validity and reliability by Akkök (1989) was used to identify the anxiety levels in mothers of children with mental disabilities.

The Questionnaire on Resources and Stress consists of eleven sub-scales: Dependency and self-governance, cognitive disorders, limitations on family life, lifelong care, family problems, lack of personal rewards, continuous anxiety over illnesses, physical limitations, financial concerns, preferring care in an institution and hardships for family. In the form which consisted of 66 items, the family members we asked to respond as true or false to the statements about children with disabilities and their home environment. For each respondent, a general anxiety point was calculated by adding the single points obtained on each of the sub-scales and the sum of points obtained on the sub-scales. Respondents could score maximum 6 points on each sub-scale, amounting to 66 points maximum on the general anxiety level. Higher points mean higher anxiety levels. As the study aimed to identify the mothers' anxiety levels, general anxiety level points were considered and the mothers' anxiety levels were interpreted in line with these points.

In order to identify whether disabled children's sex, birth order, number of siblings and mothers' education level create any difference in mothers' anxiety levels, t-test was used in the independent groups consisting of two sub-groups and normal distribution, Mann-Whitney U test was used in the independent groups consisting of two sub-groups and no normal distribution and Kruskal-Wallis variance analysis was used for three or more sub-groups with non-homogeneous variance. Whenever there was a difference, its source was identified by Mann-Whitney U test.

RESULTS AND DISCUSSION

It was seen that 39.0% of the children with disabilities whose mothers were admitted to the study were girls, 61.0% were boys, 26.0% were aged 2-4, 31.0% were aged 5-7, 43.0% were eight or older, 53.0% were first-born children, 47.0% were middle or last-born children, 82.0% were single children, 18.0% had one or two siblings. Among the mothers admitted to the study, 40.0% were primary school graduates, 49.0% were secondary or high school graduates and 11.0% were university graduates. Findings are presented below in tables and interpreted in the light of existing literature.

Table 1 shows that the sex of children with disabilities caused no meaningful difference between the mothers' general anxiety point means ($t(98) = 0.58$; $p > 0.05$). However, mothers with disabled boys had higher anxiety points (39.39 ± 4.49) than those with disabled girls (38.85 ± 4.75). The reason maybe the traditional value placed on having a son in Turkish society and gender roles existing within the country. While girls are expected to be better-behaved and more submissive, boys are expected to be stronger, independent and more mobile. Having a son with limitations may therefore cause mothers to experience a higher level of anxiety in Turkey.

Table 1: Mean, standard deviation and t-test results of mothers' general anxiety points with respect to the sex of children with mental disabilities

| | Sex | | sd | t | p |
|-----------------|-----------------|-----------------|----|------|-------|
| | Girls (N = 39) | Boys (N = 61) | | | |
| | $\bar{X} \pm s$ | $\bar{X} \pm s$ | | | |
| General anxiety | 38.85±4.75 | 39.39±4.49 | 98 | 0.58 | 0.563 |

Table 2: Mean, standard deviation and t-test results of mothers' general anxiety points with respect to the birth order of children with mental disabilities

| | Birth Order | | sd | t | p |
|-----------------|---------------------|----------------------------|----|------|-------|
| | First-born (N = 53) | Middle-or last-born (N=47) | | | |
| | $\bar{X} \pm s$ | $\bar{X} \pm s$ | | | |
| General anxiety | 38.72±5.42 | 39.70±3.38 | 98 | 1.10 | 0.273 |

Earlier studies in the literature present conflicting results about mothers' anxiety and depression levels with respect to the sex of their children with disabilities. Bristol and Schopler (1984) report that boys with disabilities create more anxiety in family members than girls with disabilities. While Firat (2000) corroborates these findings, Beşikçi (2000) reports in a similar study that mothers of girls with disabilities have higher levels of anxiety. Studies conclude that the sex of a disabled child does not affect mothers' anxiety levels also exist in the literature (Beckman, 1983; Akkok, 1989; Duman, 1995; Turkoglu, 2001; Sipahi, 2002).

Table 2 reveals that the birth order of children with disabilities caused no meaningful difference between mothers' general anxiety points ($t(98) = 1.10; p > 0.05$). However an analysis of mothers' general anxiety points reveals that those of mothers whose middle- or last-born children are disabled have higher anxiety points (39.44 ± 5.12) than those whose first-born children are disabled. Relationships between siblings may give anxiety to mothers. Older children usually face problems due to having a younger sibling with disabilities, feel jealousy and have psychological adaptation difficulties (Ahmetoglu and Aral, 2004). Such negative relationships between siblings, coupled with feelings of guilt on mothers' part for not giving enough time to their healthy children, exacerbate mothers' existing anxiety. Additionally, mothers' age may also be another factor increasing anxiety. The health conditions of mothers may change with old age, they may be worrying about the future of their children or they may simply believe that the disability was caused by a late pregnancy.

As can be seen in Table 3, the number of siblings of children with disabilities caused no meaningful difference in mothers' general anxiety points ($U = 604.50; p > 0.05$). However mothers with two or more children have higher levels of anxiety than those who have a single child. This may be attributed to the increased need for time, money and energy in bigger families. Additionally, the nature of relationships between siblings and the feelings of guilt experienced by mothers who feel that they cannot spare the same amount of time for each child may also lead to more anxiety.

As shown in Table 4, the education level of mothers caused no meaningful difference in their general anxiety points ($X^2 = 0.239; p > 0.05$). Other studies have concluded that mothers' education level alone does not create any difference in anxiety and stress levels (Turkoglu, 2001; Sipahi, 2002; Akkok *et al.*, 1992). However, it can be seen from the table that mothers who are the graduated of university have higher anxiety levels than others. This may be because mothers with higher

Table 3: Mann-Whitney U test results of mothers' general anxiety points with respect to the number of siblings of children with mental disabilities

| | Number of siblings | | U | p |
|-----------------|---------------------|----------------------------|--------|-------|
| | Single child (N=82) | One or two siblings (N=18) | | |
| General anxiety | Mean of rows 48.87 | Mean of rows 57.92 | 604.50 | 0.228 |

Table 4: Kruskal Wallis test results of mothers' general anxiety points with respect to their education levels

| Sub-scales | Mothers' education level | | | Sd | χ^2 | p |
|-----------------|--------------------------|---------------------------|--------------------|----|----------|-------|
| | Primary (N=40) | Secondary and high (N=49) | University (N=11) | | | |
| General anxiety | Mean of rows 45.23 | Mean of rows 52.61 | Mean of rows 60.27 | 2 | 2.86 | 0.239 |

education may have had to give up other roles such as domestic roles. Previous studies have shown that mothers who assume most of the responsibility of looking after children with disabilities may experience negativities in parental functioning and that the daily lives of mothers are more deeply affected than that of fathers, such as reduced participation in social activities (Emerson, 2003; Pelchat *et al.*, 2003; Shapiro and Title, 1990; Krauss, 1993).

CONCLUSION

It was found that no meaningful difference existed between the general anxiety point means of the mothers admitted to the study with respect to the disabled children's sex, birth order, number of siblings and mothers' education level ($p > 0.05$). However, it was observed that the mothers with sons, the mothers whose second or later-born children have disabilities, the mothers with more than one child and the mothers with university degrees experience higher levels of anxiety than others.

RECOMMENDATIONS

In line with these findings, the following recommendation may be made to decrease mothers' anxiety and support their children:

- The difficulties in family life start with the discovery of the difficulties their children are experiencing and the first medical diagnosis. Therefore, health personnel working in hospitals should operate with a team spirit, be informed and sensitive about the emotions experienced by families, explain the families possible sources of support following diagnosis and inform them about treatment and education opportunities and related institutions as well as the situation of their children.

- Private education and rehabilitation institutions may monitor the changing needs of families of children with disabilities and put them into contact with experts so they become better equipped with information.
- Support programs should be offered to enable families of children with disabilities to contact other similar families, receive individual and group counseling services for mothers, fathers and siblings, make use of “family education programs” to provide parallel education at home and school and thus encourage family members to participate actively in the education of their children.
- Economical and reliable daycare centers for children with disabilities may particularly decrease the limitations in mothers’ social lives. Additionally, centers where children with disabilities can stay later in life may reduce the amount of anxiety that families have about the future of their children.
- Legal arrangements need to be made to ensure that society and the state offer more and better quality services to children with disabilities and their families.
- The media should raise social awareness and sensitivity about issues such as spouse choice, pregnancy, family and parent education and living a different life by organizing activities such as programs, seminars, courses and sessions.

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