



Original Article

Determining the burdens and difficulties faced by families with intellectually disabled children

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Abstract

Objectives: This descriptive research was conducted with the aim of determining the difficulties families with intellectually disabled children face and their family burdens.

Methods: The research population consisted of the mothers of 220 children who are aged 0-18 and monitored at a Special Guidance and Research Center due to their intellectual disabilities. The sample group was composed of 160 mothers who consented to participate in the research.

Results: Of the children, 36.9% had mild, 43.1% had moderate, and 20% had severe mental retardation. Of the mothers, 48.8% reported they had no one with whom to share the care of the child. Mothers also reported that they felt disappointment (38.8%), bewilderment (48.1%), shock (31.3%), desperation (52.5%), anger (16.9%), guilt (14.4%). Of the mothers, 13.1% blamed others, 61.9% accepted the situation as an act of God, 12.5% had thoughts of committing suicide, and 28.1% suffered from depression. On the "Family Burden Assessment Scale (FBAS)," 7.5% of the mothers got low scores, and 92.5% got high scores.

Conclusion: This research found that most of the families felt anxious about the future, felt like their burden was too much to bear, and expected information and support from healthcare professionals.

Keywords: Difficulties; family burden; intellectually disabled child.

What is known on this subject?

- This research defined difficulties often experienced by families of intellectually disabled children.

What is the contribution of this paper?

- Effective methods for reducing family burden of intellectually disabled children are suggested in this research. This research also examined the stress, perceived social support and care burden of mothers with intellectually disabled children and the approach of healthy siblings to their disabled siblings. In conclusion, it emphasized that families need advice and support from healthcare professionals.

What is its contribution to the practice?

- Awareness levels of health professionals about difficulties experienced by families with intellectually disabled children should be raised. The results of this research reveal the difficulties experienced by families with intellectually disabled children and provide insight for the resolution of these difficulties.

Intellectual disability is a major disorder that can render individuals permanently incompetent and in need of life-long observation, control, care, treatment, and rehabilitation. Moreover, as with other chronic illnesses, the condition affects family members economically, socially, emotionally, behaviorally, and cognitively.^[1,2]

The World Health Organization (WHO) reports that there are approximately 650 million disabled individuals globally, of which 700,000–1,500,000 suffer from intellectual disabilities. Approximately 200 million children have been diagnosed with disability globally;^[3] however, the prevalence of intellectual disability fluctuates between countries. In the United States, 2.5–3% of children are intellectually disabled. Similarly,

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2% of children aged 7–14 are intellectually disabled in the United Kingdom. In Turkey, however, the total percentage of intellectually disabled children among the individuals with disabilities has been reported to be as high as 29.2%.^[4]

The International Association for the Scientific Study of Intellectual Disabilities (IASSID) asserts that public organizations charged with addressing the problems faced by intellectually disabled individuals and their families are inadequate in number, their budget is too limited to be effective, or they have not been provided with sufficient mandate to operate. Additionally, healthcare professionals are unable to effectively identify the difficulties faced by individuals with intellectual disabilities.^[5] To illustrate the extent of the problem, Turkey Disabled Research reported that 84%, 49.2% and 87.7% of intellectually disabled individuals cannot benefit from available healthcare and rehabilitation services, health services, and counseling and family guidance services, respectively.^[6,7]

Becoming a parent can be one of the most rewarding feelings a person can experience in life. This experience may be tainted, however, upon discovery that the child is intellectually disabled.^[7] Depending on the degree of disability, having an intellectually disabled child causes parents to face economic problems and issues regarding the child's education. It also leads to various problems such as diminished social environment and considerable lifestyle changes.^[7,8] When families learn that their child is intellectually disabled, they typically experience stages of uncertainty, shock, denial, guilt, anger, and depression before reaching acceptance. Parents often move back and forth between these various stages or might even remain in one particular stage.^[6,7,9] The reactions of family members might be affected from their personalities, education levels, socioeconomic status, and the attitudes of those around them. When an intellectually disabled child is born, the family must adjust to a new lifestyle and many marriages may fail as a result.^[10] Some families isolate their child to cope with this situation, thereby reducing their own social circles. Healthy siblings of disabled children also show mixed reactions. While some siblings accept the situation, others may experience feelings of anxiety about the future, a sense of isolation, and an inability to understand why their sibling is different from other people, and may get negatively affected from this situation.^[9,11–13] Regardless of their coping mechanisms, the important outcome is that intellectually disabled children are accepted by their families for who they are, and for everyone to obtain the support they need to readjust to their lives.^[14,15]

Services provided to meet the needs of families with intellectually disabled children requires multidisciplinary teamwork between doctors, nurses, special needs educators, speech therapists, audiologists, physical therapists, psychologists, social workers, dieticians, family therapists, and other specialists according to the particular situation. Nurses should be continually involved in this cycle to effectively support

families with intellectually disabled children at clinics, rehabilitation centers, and within the community. Such support should encompass providing education families related to their child's toilet training, dressing/undressing, eating, sleeping, and personal hygiene, and guidance on establishing methods to cope with stress and problem-solving techniques.^[1,6,7]

The purpose of this research was to identify the difficulties experienced by families with intellectually disabled children and their family burden, and to propose effective methods to reduce this burden. The research was designed to support the literature on stress, perceived social support, and the burden of care in mothers of children with mental retardation.

Materials and Method

Design

A descriptive design method was used to identify the difficulties experienced by families with intellectually disabled children and the family burden. Research data were collected between September and December 2012.

Participants and Procedure

The research population was comprised of the mothers of 220 children, aged 0–18, attending a Special Guidance and Research Center in Istanbul due to intellectual disabilities. During the data collection period, 42 of the mothers cannot be contacted (as they did not regularly come to the center), and 18 mothers declined to participate in the research so these individuals were excluded from the evaluation. The sample of the research included 160 mothers with intellectually disabled children attending a Special Guidance and Research Center in Istanbul. All participants gave informed consent.

The families at a Special Guidance and Research Center were informed about the purpose and scope of the research. After informed consent was obtained, the information form and questionnaire were administered during face-to-face interviews for a 20-minute time period.

Investigation Questions

- What are the difficulties experienced by mothers with intellectually disabled children?
- Do families get sufficient information and support from health professionals?
- What are the interpersonal relations between family members and their environment?
- At what degree are the family burden levels of families with intellectually disabled children?

Dependent Variables

Scores of families with intellectually disabled children on the Family Burden Assessment Scale.

Independent Variables

Gender, birth order, age, number of children in the family, educational status, income level of family, family members who support the child's care.

Data Collection Tools

Participants completed a 50-item personal information questionnaire and the Family Burden Assessment Scale (FBAS) that was developed and tested for validity and reliability by Sari et al. (2006).^[16]

The Personal Information Questionnaire

This form included 15 open- and closed-ended questions on gender, birth order, type of disability, degree of intellectual disability, age of the children, number of children in the family, educational status of mother and father, income level, any chronic diseases in the mother and father, consanguineous marriages, others with disability in the family and others involved in the child's care.

The Family Burden Assessment Scale (FBAS)

This scale consists of six subscales that identify the extent of economic burden, perception of inadequacy, social burden, physical burden, emotional burden, and time burden. All items are scored as 1–5. One being "Never" to five being "Always". A score of over 97 points reflects a high family burden, whereas a score of 97 or lower reflects a more acceptable family burden. The Cronbach's alpha value for the scale is 0.92.^[16]

Data Analysis

Data were evaluated using Statistical Package for the Social Sciences (SPSS Inc., Chicago, IL, USA) version 15. The data were analyzed using numbers, percentages, means, standard deviations.

Research Ethics

Istanbul Medipol University Research Ethics Committee gave permission to undertake the research. Both verbal and written consents were collected from participating families.

Results

Participant Characteristics

Table 1 presents the distribution of the identifying characteristics of intellectually disabled children. Most of the children were female (56.9%), first-born (48.1%), congenitally disabled (70%), and had a moderate case of intellectual disability (43.1%). The mean age of the children was 10.6±3.7 years.

Table 2 presents the distribution of the identifying characteristics of the families.

Table 1. Identifying characteristics of the intellectually disabled child

Characteristics	n	%	Mean±SD
Gender			
Male	69	43.1	
Female	91	56.9	
Order of birth			
First child	77	48.1	
Second child	50	31.3	
Third child or above	33	20.6	
Type of disability			
Congenital	112	70.0	
Acquired	48	30.0	
Degree of intellectual disability			
Mild	59	36.9	
Moderate	69	43.1	
Severe	32	20.0	
Age (years)			10.6±3.7
Age at diagnosis (years)			3.2±2.6

SD: Standard deviation.

As can be seen, 41.3% of the families had two children, and over half of the mothers (58.1%) and fathers (56.3%) were elementary school graduates. As reported by the mothers, most of the families (66.9%) were in the middle-income bracket, 88.1% of the mothers and 92.5% of the fathers had no chronic disease, 59.4% were not in consanguineous marriages with their spouses, 88.1% did not have other disabled individuals in the family, and 48.8% of the children were being cared for exclusively by their mothers.

Family Burden Assessment

When asked about their initial emotional response upon learning of their child's disabilities, the most common response reported by mothers was anxiety about the future (91.9%), thinking that this is an act of God (61.9%), desperation (52.5%), bewilderment (48.1%), disappointment (38.8%) and having thoughts of committing suicide (12.5%) (Table 3).

According to the mothers' statements, 57.5% of healthy siblings had a warm, close, and protective relationship with their disabled sibling. In addition, 40% played with their sibling, 38.8% were supportive and participated in the sibling's care, 15.6% felt jealousy, 13.8% were tired of the sibling, 11.9% behaved with nervousness and anger, 8.8% showed signs of regression, 6.9% felt embarrassed, 6.3% shied away from and feared the sibling, and 6.3% became introverted as a result of their sibling's presence (Table 4).

Of the families, 36.9% sometimes sought information and support from health care professionals, while 32.5% reported that they had never received information and support. This is despite 67.5% of mothers suggesting that they felt a need to

Table 2. Identifying characteristics of families

Characteristics*	n	%
Number of children in the family		
1 child	31	19.4
2 children	66	41.3
3 children or more	63	39.4
Educational status of mother		
Literate	48	30.0
Elementary school	93	58.1
High school and above	19	11.9
Educational status of father		
Literate	34	21.3
Elementary school	90	56.3
High school and above	36	22.5
Income level of family		
High	18	11.3
Moderate	107	66.9
Low	35	21.9
Mother having a chronic disease		
Yes	19	11.9
No	141	88.1
Father with chronic disease		
Yes	12	7.5
No	148	92.5
Consanguineous marriage		
Yes	65	40.6
No	95	59.4
Other disabled family member		
Yes	19	11.9
No	141	88.1
Others involved in the child's care		
No	78	48.8
Sibling	14	8.8
Spouse	45	28.1
Family elders	23	14.4

*More than one choice was marked.

seek advice from health professionals (Table 5).

In terms of the social impact reported by mothers, 65.6% identified problems between members of the family as a result of the presence of the intellectually disabled child, 56.3% said that they could not dedicate sufficient time to their other children, 79.4% indicated that they were in contact with other families with disability children, and 87.5% reported they had no connection to any pertinent support societies or organizations (Table 6).

The majority of mothers (92.5%) received a score higher than 97 on the FBAS, indicating that the families of an intellectual disability children in this research experienced a high degree of burden (Table 7).

Table 3. Mothers' responses upon learning of child's disability

Emotion*	n	%
Anxiety about the future	147	91.9
Thinking that this is an act of God	99	61.9
Desperation	84	52.5
Bewilderment	77	48.1
Disappointment	62	38.8
Shock	50	31.3
Depression	45	28.1
Anger	27	16.9
Towards oneself	15	9.4
Towards one's spouse	3	1.9
Towards the doctor	6	3.8
Towards the hospital	3	1.9
Guilt	23	14.4
External blame	21	13.1
Suicidal attempts or thoughts	20	12.5
Rejection/non-acceptance	15	9.4
Fear	14	8.8
Wishing for child's death, then feeling guilty	3	1.9

*More than one choice was marked.

Table 4. Behavior of healthy siblings toward disabled child

Behavior	n	%
Behaves in warm, close, protective ways	92	57.5
Plays with the child	64	40.0
Supportive toward the child, participates in the child's care	62	38.8
Jealous of the child	25	15.6
Says that he or she is sick and tired of the child	22	13.8
Acts nervous and angry towards the child	19	11.9
Exhibits developmental regression	14	8.8
Feels lonely	12	7.5
Feels embarrassed	11	6.9
Shies away from, is afraid of the child	10	6.3
Introverted	10	6.3

*More than one choice was marked.

Discussion

Disability in children is a tremendous stressor, not only for the child but also for the families that have to deal with the host of additional physical, emotional, social, and economic issues accompanying care of a disabled child.^[17] Caregiving mothers in particular have been shown to experience a greater physical, emotional, and social burden.^[17-19] A significant finding given that the current research indicates that the mother is typically the primary, and sometimes the sole, caregiver of an intellectually disabled child. This burden may, however, be somewhat

Table 5. Families' seeking information and support from health professionals

	n	%
Families' seeking information and support		
Yes	49	30.6
Sometimes	59	36.9
No	52	32.5
Families' need for receiving consultancy		
Yes	108	67.5
No	52	32.5

Table 6. Interpersonal relations between family members and their environment

	n	%
Interpersonal problems between family members		
Yes	105	65.6
No	73	45.6
Spending sufficient time with other children		
Yes	70	43.8
No	90	56.3
Giving birth to another child to help look after the child		
Yes	75	46.9
No	85	53.1
In contact with other families with disabled children		
Yes	127	79.4
No	33	20.6
Association with related associations/ organizations		
Yes	20	12.5
No	140	87.5

Table 7. Scores of families with intellectual disability children on the FBAS

Total FBAS scores	n	%
Score of 97 and below	12	7.5
Over 97	148	92.5
Total	160	100

FBAS: Family Burden Assessment Scale.

alleviated if other members of the family support the mother in this role.^[8]

The presence of an intellectually disabled child in the family brings with it many emotional problems. Many families experience difficulty in disclosing the child's disability to family and friends,^[17] and prior research has shown that families typically experience disappointment,^[17] guilt,^[2,15,17,20,21] anxiety about the future,^[14,20-22] embarrassment,^[20,21] and serious anxiety over

society's acceptance of the child.^[14,20,21] Studies report that families feel more positive by accepting their child's condition and acting in the direction of religious beliefs.^[23] The current research findings indicated that mothers often viewed the situation as an act of God.

Due to the irreversibility and irreparability of intellectual disability, families experience differing degrees of burden that affect them in a variety of ways.^[6,23] It has been reported that while some siblings exhibit a positive outlook that is conducive to providing physical and emotional care to the disabled child, others feel anxiety about the future and isolation, exhibit behavioral disorders, and experience other problems such as poor academic performance.^[12,14] As (Sari et al. 2006) further observed, healthy children typically do not want to be seen in public with their disabled siblings, but may, however, become protective and helpful when faced with negative events in the course of their sibling's illness.^[24] The current research found that healthy children had more positive feelings toward their disabled siblings and had warm, close, and protective relationships with them.

Parents with mentally or physically disabled children often exhibit a need for psychosocial support. Nurses are effective in reducing family burden by using interventions designed to increase the general level of wellness of the disabled child^[6,7] and in alleviating depression among family members by helping them to cope with stress.^[2,22] In addition to these activities, it has been suggested that nurses should take a more effective role in educating and supporting families with intellectually disabled children.^[5] The current research found that the majority of parents sought the support of health professionals either sometimes or not at all. Furthermore, the fact that the families reported a pronounced need for professional advice suggests that the required help is not being delivered. Health professionals are in position to provide this assistance, and nurses in particular may be best placed to act as a bridge between special educational units and guidance centers to ensure that intellectually disabled children and their families receive the help they need.^[5]

Literature reports that marital relations are often affected following the birth of an intellectually disabled child, but there are also examples where good relationships between spouses have been maintained.^[7,9] Families with intellectually disabled children generally isolate themselves and are therefore less likely to have an active social life. Studies have shown that stress caused by this introversion of families often leads to an increased number of marital problems.^[25,26] In the present research, it was reported that the majority of families had marital problems and that parents were not able to dedicate enough time to their healthy children. These results are consistent with those of other studies. Moreover, it is important to note that about half of the families reported that they had purposely conceived another child so that the sibling would be able to help in the future care of their disabled child. Such an approach places a great burden upon the new

sibling as the healthy child is made to suffer the burden of becoming a caregiver. Families should be counseled to not place this responsibility on healthy children. In addition, the government should establish policies to support families with disabled children.

The findings of the current research also revealed that most families are in contact with other families with disabled children, but that they have no connection with any relevant support organization. Research indicates the positive effects of bringing together families with similar problems, professional support services for families reduce stress of parents and increase their well-being.^[2,27] Sharing their experiences and becoming acquainted with other parents that have to cope with similar chronic health problems may provide some relief to families with disabled children, but it is likely that they would benefit further through membership of organizations that are experienced at reducing the burden imposed by intellectually disabled children.

Living with and caring for an intellectually disabled child has been shown to place a significant burden on family members.^[16] Most of the mothers in this research scored above 97 on the FBAS. Caliskan and Bayat's^[8] study (2016) has determined that the family burden score of mothers with children with mental disability was over 97 points. This represents a high degree of burden and thus supports the findings of previous research. Sivrikaya and Çiftci Tekinarslan's^[19] study (2013) showed there was a significant negative linear relation among social support levels and its dimensions, satisfaction from support types, and stress and burden. In other words, as the mothers' perceived social support increased, family stress and caregiver burden decreased. Oh and Lee^[18] (2009) have stated that the overall family burden will be reduced when mothers, who spend long hours looking after their children, receive home care services. Family burden is a psychological burden associated with the way in which negative physical, emotional, social, and financial consequences of care are perceived and interpreted. Similarly, other studies have suggested that the presence of children with disability in families increases the burden.^[6,28] Nurses need to diagnose the burdens on these families and plan appropriate initiatives.^[16]

Conclusion

Families with intellectually disabled children experience a tremendous burden characterized by physical, emotional, social, and economic troubles. This burden causes parents to experience anxiety about the future of the disabled child, and many parents expect more support from health professionals than they are currently receiving. As a result of previous research and the results of this research, it is recommended that these families be given psychological advisory services to help them cope, provided with pertinent education, and afforded the opportunity to contact related associations that may be able to provide additional support.

Limitations of the Research

Collection of data only from mothers is a limitation of research. Asking the questions to the father and comparing the data could make a difference in the results. For this reason, it is recommended to investigate family stress, social support and family burden of fathers as well as mothers in further research. In addition, research should be conducted to reveal how the life of siblings of the children with intellectual disability will be affected.

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