

Original article / Araştırma

The stigma perceived by parents of intellectual disability children: an interpretative phenomenological analysis study

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ABSTRACT

Objective: The aim of this is to put forth perceptions of the stigma that parents of intellectual disabled individuals feel and the parents' experiences associated with the stigma. **Methods:** This research, which is made as qualitative research is carried out with 19 parents in Balıkesir between the dates April 2015-August 2016. A questionnaire and a semi structured interview form for parents and their disabled children have been used to collect the data. The interviews were held in rehabilitation centers. Face-to-face interviews that are realized via using the technique of in-depth interviews have been recorded on audio tape recorder. The audio recordings that were obtained from the interviews were transcribed and data were coded according to the themes and put into report form by interpreting. **Results:** As a result of the study, it was detected that parents who have intellectual disabled individuals do not receive sufficient support from family members, circle of friends and the society and feel stigmatized. **Conclusions:** It is considered as necessary to give psychological counseling and guidance to these parents who have the handicapped individuals and to educate and raise awareness of the society about the issue. (*Anatolian Journal of Psychiatry* 2018; 19(4):390-396)

Keywords: intellectual disability, family, discrimination, stigma, labeling

Zihinsel engelli bireylerin anne-babalarının algıladığı damgalanma: Yorumlayıcı bir fenomenolojik analiz çalışması

ÖZ

Amaç: Bu çalışmanın amacı, zihinsel engelli bireye sahip anne-babaların algıladıkları damgalanmayı ve bununla ilişkili deneyimlerini ortaya koymaktır. **Yöntem:** Nitel araştırma modeli ile yapılan bu araştırma, Nisan 2015-Eylül 2016 tarihleri arasında, Balıkesir'de 19 zihinsel engelli bireyin anne-babası ile yapılmıştır. Verilerin toplanmasında, anne-babaya ve çocuğa yönelik soru formu ile yarı yapılandırılmış görüşme formu kullanılmıştır. Görüşmeler rehabilitasyon merkezlerinde yapılmıştır. Derinlemesine görüşme tekniği kullanılarak yüz yüze yapılan görüşmeler ses kayıt aygıtına kaydedilmiştir. Görüşmelerden elde edilen ses kayıtları yazılı döküm haline getirilmiş, veriler kodlanıp temalara göre sınıflandırılmış, yorumlanarak rapor haline getirilmiştir. **Bulgular:** Çalışmada zihinsel engelli bireye sahip anne-babaların aile üyelerinden, arkadaş çevresinden ve toplumdan yeterli desteği almadığı ve damgalanma hissettiği saptanmıştır. **Sonuç:** Bu bireylere ruhsal danışmanlık ve rehberlik hizmetinin sunulması ve toplumun da bu konuda eğitilmesi, bilinçlendirilmesi gerektiği düşünülmektedir. (*Anadolu Psikiyatri Derg* 2018; 19:384-390)

Anahtar sözcükler: Zihinsel engel, aile, ayrımcılık, damgalanma, etiketlemek

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INTRODUCTION

Stigmatization is defined as a process in which individuals who are seen as 'unwanted differences' in society are labelled and lose their dignity and status because of stereotyping, discrimination, social exclusion, and negative emotional reactions displayed by the vast majority of people.¹

Stigmatization, an important public health problem, may be regarded as exclusion of or discrimination against a group of people who are different from the majority owing to their characteristics, such as HIV/AIDS, leprosy, mental illnesses,² or intellectual disability.³ The vast majority of people often have negative thoughts and even hostile and stigmatizing attitudes towards children with disabilities and their families.^{4,5} Families with disabled children are obliged to cope with insulting, hostile, or rude behavior from the community while struggling with the challenges of their children's disability.¹ Surveys show that these experiences have a negative impact on their quality of life.⁶ Many parents of children with disabilities prefer not to go out in public because they are afraid that their neighbors, relatives, or acquaintances will make ruthless statements about their children. This situation can sometimes lead these parents to feel lonely and guilty about their past, and unable to get support from their family, relatives, and neighbors.⁷ The expectation and opinions of society lead families of children with disabilities to feel of excluded or that they are bad parents.⁸ These families limit themselves and do not want to receive public support.⁴ Furthermore, fear of stigmatization may prevent these individuals from accessing support.⁹ Stigmatized families experience emotional distress and social isolation.^{6,10} Given that stigmatization can lead parents to get more emotionally and spiritually distressed, become isolated, and unable to meet their own children's needs, this problem must be urgently addressed and intervened.

This research occupies an important position in determining the experiences, problems and coping methods of the families. This study deals with the important gaps in the current researches and makes contribution to the understanding of the needs and experiences of these families. This study was carried out to determine the stigma experienced by parents with intellectual disabled individuals.

METHODS

Participants

Required permission has been taken from National Education Directorate to conduct the study. Consent form has been obtained from every research participants who were coded as A1 and A2 to keep the privacy. This study supported by the project Department of Balıkesir University. This study was performed in three center, which are affiliated with the Ministry of National Education and located in Balıkesir province.

In qualitative studies, it is not necessary to test the entire universe because the primary purpose is to understand facts in depth rather than to generalize them.¹¹ The research group constituted 19 people.

Data collection tools

Questionnaire for Parent and Child: The data collection form, developed by the researcher, includes questions on the socio-demographic characteristics of the parents with intellectually disabled children and the age and disability of the child in question.

Semi-structured Interview Form: In this section, there are eight questions overlapping with the literature. These questions were designed to carry out in-depth interviews with the support of the literature to reveal the exclusion experiences of parents with intellectually disabled children. The questions were open-ended.

Data analysis

The aim of data analysis in phenomenological studies is to reveal experiences and meanings. In this context, preliminary reading of the data was done as preparation for the data analysis. At later stages, coding of qualitative data, fitting to the theme, organizing data, interpretation, and reporting of qualitative results were performed. Participants were provided with codes such as A1 and A2 for reasons of privacy.

RESULTS

Of the participant parents, 89% were female and 79% were married, 62.7% were primary school graduates, 89.4% were unemployed, and 58% had two children. Of their children, 79% (15 children) were female and 74% (14 children) were diagnosed with moderate intellectual disability.

Table 1. Parents' introductory characteristics

Characteristics	n	%
Gender		
Female	17	89.0
Male	2	11.0
Marital status		
Married	15	79.0
Single	4	21.0
Educational status		
Illiterate	2	11.0
Primary school graduate	12	62.7
High school graduate	4	21.0
Associate degree	1	5.3
Occupation		
Unemployed	17	89.4
Public official	1	5.3
Self-employed	1	5.3
Number of children		
1	4	21.0
2	11	58.0
3	4	21.0

Parents' life changing experiences

Experiences of emotional distress: Some of the parents indicated that having an intellectually disabled child is a major challenge (A4, A10, A15, A16, A17). Some parents expressed the difficulties they have experienced as follows: "My life has turned upside down. In the beginning, I never accepted it. That is to say, both me and my husband got exhausted materially and spiritually, we were ruined" (A4).

Problems in marriage relations: Some of the participants stated that they had a negative relationship with their spouses (A1, A2, A7), and expressed their situations as follows: "After the diagnosis of our child, I had troubles with my spouse. For example, we wanted to divorce; we had many debates. Therefore, it is difficult for us. If he were a healthy child, perhaps these troubles would not happen. But we've had a lot of problems..." (A1).

Decrease in communication with the local com-

Table 2. Interview questions, themes, and subthemes

Interview questions	Themes	Subthemes
Can you tell me about your experience after having a child with intellectual disability?	Parents' life changing experiences after having a child with intellectual disability	Experiences of emotional distress Problems in marriage relations Decrease in communication with the local community
How was the attitude of your family members toward the diagnosis of your child?	Attitudes of family members towards the child's diagnosis	Positive attitude Negative attitude
How did the diagnosis of your child affect the social life of your other children (if any)?	The effects of having a intellectually disabled sibling	Jealous of the sibling Love/support for the sibling
Did you experience any change in your social life and friendships as a result of your child's diagnosis? Can you explain?	Parental involvement in society	Restrict social relationships
Did your friends change their behavior towards you owing to the diagnosis of your child? Can you explain?	Changes in parents' friend relationships	Decrease interview Support
What are the points that you have difficulty in explaining regarding your child's condition?	Cases where parents experience difficulty/stress explaining their children's Situation	A lack of sympathy/understanding in society
Do you think that the society has a negative attitude towards people with disabilities?	Society's approach to individuals with disabilities	Negative approach Exclusion Pity Positive approach
What is your method of coping with negative attitudes/behaviors towards your child? Can you explain?	Parents' experiences of coping with negative attitudes/behaviors	Escape/away from Fight

munity: Some of the participants said that after having a disabled child, their communication with the local community decreased (A8, A11): *"We do not go outside at night anymore, then it is also difficult to go outside on weekends. That is to say, our social life is now limited to the surroundings of our own family and relatives. Or if we go, we leave my son"* (A8).

Attitudes of family members towards the child's diagnosis

Some of the parents encountered a 'positive attitude' from their family members but some other parents were faced with a 'negative attitude' from their family members towards their children's diagnosis. Parents who encountered positive attitudes indicated that they were faced with attitudes such as mercy, pity, and material and spiritual support (A4, A8, A9, A12, A18), while the parents who encountered negative attitudes indicated that they were faced with attitudes such as dispiritedness, sadness, nervousness, and maltreatment (A1, A5, A6, A7, A17, A19). A17, who indicated that she received no support from her family, said: *"So where can a person go when he/she's too bored/stressed? The simplest is to go to his/her mother, right? When we went to my mother's home, I felt that they were uncomfortable, and then we got de-moralized, so each time I returned to my home. They do not understand our situation. So the best thing to do is to stay at home."*

The effects of having an intellectually disabled sibling

The sub-themes for the question of how the social lives of children with intellectually disabled siblings are influenced by this situation constitute exclusion of/being jealous of the sibling (A4, A5, A8, A17, A18) and love/support for the sibling (A10, A12, A16). One of the children who excluded his/her disabled sibling stated: *"Mother, I wish you did not give birth to him"* (A4).

Parental involvement in society

Most of the parents who participated in the study stated that they restricted their social interactions (A1, A2, A5, A6, A7, A9, A14). Some parents' explanations are listed below: *"Now, I do not know what to do with him, I cannot take him anywhere with me. Because he is so active and always touches everything near to him. He does not understand he should not do so. He always plays and tinkers with the things around him. We cannot even go to our neighbors; we cannot do anything outside or anywhere. I cannot move from house"* (A14).

Changes in parents' friend relationships

The themes of support (A1, A8, A10, A15) and exclusion/criticism (A3, A19) are located under the experiences related to the changes in the friendships of the parents with intellectually disabled children. A19 said: *"The people around us frustrated us too much. I do not know. They said he is disabled, handicapped. They also said that I should not have given birth to him. A lot of things happened."*

Cases where parents have trouble/stress explaining their children's situation

Parents (A1, A5, A6, A7, A12) reported a lack of sympathy/understanding in society, particularly that they experience difficulty/stress explaining their children's situation. A6 said: *"Some people did not know he was ill/disabled, and slapped him. When I warned those people they barely understood the situation, and did not do any such thing anymore. As a father, I do not want to extend such problems, so I always try to settle such matters amicably, stating my son's illness."*

Society's approach to individuals with disabilities

When the parents were asked about society's approach to individuals with disabilities, the majority of them stated that it was a negative approach, but only one of them indicated that it was a positive approach.

A6, one of the participants (A4, A6, A7, A13) who experienced society's negative attitudes in the form of exclusion of disabled individuals, mentioned: *"Society excludes, constantly excludes them. I say I am healthy, but the other says, no! You are not healthy. So the others exclude me. In short, people with disabilities are being excluded. Your health is good, your beauty is good. My child is not beautiful, he is sick, ill. You see the situation, but you do not approve it. That is it..."*

Furthermore, A9, one of the participants who replied that society takes pity on disabled individuals, mentioned: *"People behave like they feel sorry for us. For instance, people around me say what a pity! How bizarre the child is!"*

Parents' experiences of coping with negative attitudes/behaviors

Some parents with intellectually disabled children stated that they had moved away from places where other people display negative attitudes towards their children and do not deal with those individuals (A1, A5, A11, A16). In this re-

gard, A5 said: *"We do not respond to them, but I cry."*

Furthermore, some parents (A2, A7, A9, A10) stated that they fought against this kind of situation when they encountered negative attitudes towards their children.

DISCUSSION

It is stated in the literature that families with intellectually disabled children experience grief related to their sadness and guilt.^{12,13} In this study, the participants expressed that they were very sad when they learned that their children were disabled. Parents who burst into tears during the interview had experienced very intense emotional difficulties. Similar to the results of the present study results, Top asked families about changes in their perspectives on life and found that they were pessimistic, desperate, and sensitive, but got used to their children's situation and learned how to be strong and patient against it.¹⁴ Aslan and Şeker stated that all the parents reported that they were sad and depressed when they had children with disabilities and could not accept the situation.¹⁵ It is recommended to arrange psychoeducation programs for those parents and provide support systems that reduce their burden.

Participants, particularly mothers, declared that they did not receive adequate support from their spouses and that they frequently argued with their spouses because of their intellectually disabled children. Ergün and Ertem found that 54.8% of mothers were blamed by their husbands for their intellectually disabled children.¹⁶ Ntswane and Rhyn reported that most of the fathers refused to stay with their wives and intellectually disabled children and decided not to do anything for them.¹⁷ It is thought that it may be beneficial for those families, particularly the husbands, to receive training programs on duty sharing, aiming to reduce the mothers' burden of child care and family order.

In this study, some of the parents stated that after the birth of the child, they completely stopped communication with their community and locked themselves in their house. It is thought that the cause of this may be the negative reactions received and the emotional difficulties they have experienced. It is thought that the support systems for these families should be increased.

In this study, parents who experienced a negative attitude from their families stated that their relatives blamed them for the situation and be-

haved differently towards the child. The relatives' perception of the situation of families with an intellectually disabled child as a negative and desperate case causes them to have similar feelings. Erdoğan found that 21.7% of parents were blamed for their child's disability and determined that 46.2% of the accusing persons were relatives, 38.5% were neighbors, and 15.3% were their spouses.¹⁸ Parents are also expected to be trained to support these families, and the families should have professional support to cope with their emotional difficulties.

When parents were asked about their social involvement, some of them stated that they had restricted their social relations. Tamer found that the limitation of their social life for mothers of children with intellectual disabilities was the second most important source of stress.¹⁹ To do so, it is believed that awareness of social support systems and using them should be encouraged in parents.

When parents were asked about changes in their friendships, it was determined that they included the themes of 'support', 'reduction in seeing each other', 'exclusion', and 'criticism'. In the literature, it has been stated that these families restricted their friendships or made very few friendships with other caregivers and had little time to spend with others.²⁰ Farrugia found that families with autistic children changed their social environment as a result of stigmatization and lost almost half of their friends.²¹ In this study, it is thought that the reason for parents isolating themselves may be disapproval/exclusion by their friends. It is important to educate the community in this respect. It is important that all parents receive support from their friends and that their friends motivate them, and it is thought that maintaining this support is important in this regard.

In this study, parents stated that they expected society to be sympathetic and thoughtful towards them. Similar to the present study results, all of the families in Top's study also wanted people to be sympathetic and concerned about them and their children.¹⁴ It is thought that there is a need for a wide range of activities to educate society, and appropriate media could facilitate this process.

In this study, parents who reported that society had a negative approach towards disabled individuals stated that society excluded them and took pity on them. Aslan and Şeker found that the social perception for intellectually disabled individuals is extremely negative and prejudiced,

so that intellectually disabled individuals and their parents feel excluded from society and parents with disabled children prefer not to go into society as much as possible.¹⁵ Education and information are effective ways of changing society's attitudes towards people with disabilities.²² In this present study, some of the participants stated that the community should be educated and they expect the community to be more tolerant of them. Therefore, it is clear that training and awareness-raising activities for the society are needed.

In the present study, the themes of moving away/ evasion were observed as the methods of parents with intellectually disabled children of

coping with society's negative attitudes/behaviors. Şengül and Baykan also found that mothers with intellectually disabled children used more denial and apathy as coping methods than healthy mothers.²³ It is thought that it may be useful to teach these parents proper coping methods to deal with their problems.

CONCLUSION

The results of this research showed that most of the participants restricted their social relations after having a child with disability, and that society has a negative attitude towards individuals with disabilities and their families.

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