

A QUALITATIVE STUDY INQUIRING PERCEIVED STIGMA OF PARENTS HAVING CHILDREN WITH AUTISM ATTENDING A REHABILITATION CENTER IN İSTANBUL, TURKEY

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ABSTRACT

Objective: Decreasing discrimination and stigmatization, creating a sense of responsibility among citizens on children and their families and increasing public awareness towards children having autism can be very important in the early diagnosis and treatment of autism since the most important treatments of autism can be accomplished in social settings. The aim of this qualitative study, carried out in İstanbul was to evaluate the perceptions of social stigma of a group of parents who have children with autism.

Material and Method: In this qualitative study, data was collected via in-depth interviews with ten parents who have children with autism. Thematic content analysis was used subjective interpretation of textual data through the process of coding and the identification of themes.

Results: Five themes were identified: 1) Stigmatization in the big family; 2) stigmatization in the community; 3) stigmatization in school/preschool period; 4) stigmatization in healthcare settings; and 5) coping with stigmatization. The community does not only label the child having autism but also his family members. It has been determined that one of the main problems in relation to teaching children with autism is that mainstream schools do not accept children with autism on excuses of various reasons.

Conclusion: The parents of children with autism experienced exclusion, discrimination and stigmatization both in the families and in the community. Children were mostly discriminated during school period. Stigmatization existed not only by the community but also in the healthcare settings. To this end, parents felt isolated in the community.

Keywords: Qualitative research, stigmatization, autism, discrimination

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İSTANBUL'DA BİR REHABİLİTASYON MERKEZİNDE OTİZMLİ ÇOCUĞU OLAN EBEVEYNLERDE ALGILANAN STİGMA ÜZERİNE NİTELİKSEL BİR ÇALIŞMA

ÖZET

Amaç: Ayrımcılığın ve stigmatizasyonun (damgalamanın) azaltılması, çocuklar ve aileleri için insanlarda sorumluluk duygusu oluşturulması ve otizmlili çocuklara yönelik toplum farkındalığının artırılması gibi eylemler; en başarılı otizm tedavilerinin sosyal ortamlarda gerçekleşebildiği düşünüldüğünde, otizmin erken tanısı ve tedavisinde önemli yere sahip olabilirler. İstanbul ilinde yapılan bu niteliksel çalışmanın amacı, otizmlili çocuğu olan bir grup ebeveynin sosyal stigma algılarını değerlendirmektir.

Materyal ve Metot: Bu niteliksel çalışmada veriler otizmlili çocuk sahibi olan on ebeveynle yapılan derinlemesine görüşmeler yoluyla toplanmıştır. Kodlama ve temaların oluşturulması sürecinde, metne aktarılan verinin öznel yorumlanması için tematik içerik analizi uygulanmıştır.

Bulgular: Çalışmada beş tema belirlenmiştir: 1) Akrabalar arasında stigmatizasyon; 2) toplumda stigmatizasyon; 3) okulda / okul öncesi dönemde stigmatizasyon; 4) sağlık kurumlarında stigmatizasyon ve 5) stigmatizasyon ile başa çıkma yolları. Toplumda yalnızca otizmlili çocuklar değil aynı zamanda aile üyeleri de etiketlenmektedir. Otizmlili çocuğun eğitimiyle ilgili en önemli sorunlardan birinin; okulların, çeşitli mazeretleri öne sürerek otizmlili çocuğu kabul etmemeleri olduğu tespit edilmiştir.

Sonuç: Otizmlili çocukları olan ebeveynler hem akrabalar arasında hem de toplumda dışlanma, ayrımcılık ve stigmatizasyon deneyimlemişlerdir. Çocuklar çoğunlukla okul döneminde ayrımcılığa uğramışlardır. Stigmatizasyon yalnızca toplumda değil, zaman zaman sağlık kurumlarında da gerçekleşmektedir. Tüm bunların neticesinde aileler kendilerine toplumdan izole hissetmektedirler.

Anahtar kelimeler: Niteliksel araştırma, stigmatizasyon, otizm, ayrımcılık

INTRODUCTION

Autism being first defined by Kanner can be considered as a neurodevelopmental condition interfering with the person's ability to communicate and relate to others.^{1,2} It appears to be one of the fastest growing disabilities in children.³⁻⁵ Due to increasing prevalence, autism is widely considered to be an emerging public health problem.⁶ Signs begin to manifest in early childhood.⁶⁻⁸ Many studies show that early diagnosis enables prompt initiation of appropriate therapy, early behavioral and social intervention aiding in their development and improving their communication and social skills.⁹⁻¹⁴ Most of the time after behavioral and social training conducted at early ages, the symptoms might often be easy to manipulate.^{11-13,15,16} Early and intensive intellectual, behavioral and social intervention programs in young children having autism are largely recommended in the cure of autism.¹⁰⁻¹⁷ However, the length of time from parent's first notice of symptoms to the time of diagnosis is relatively long, leading to delayed diagnosis and intervention.¹⁴⁻¹⁸ One of the reasons for the parents' consulting appropriate health authorities for timely diagnosis can be because of insufficient public awareness of autism or because of the embarrassment of possible stigmatization of children with autism in the community.¹⁹⁻²¹ Furthermore, the parents of children with autism frequently encounter hostile or insensitive reactions from the public when their children behave inappropriately.²⁰ The parents

might be subjected to stigma due to the public's misconception of their lack of control or discipline over their children with autism.¹⁹ Stigmatizing public reactions can have an effect on the individual's sense of full participation in social life of the community.²⁰ To this end, decreasing discrimination and stigmatization and creating a sense of responsibility among citizens on children and their families and increasing public awareness towards children having autism can be very crucial in the early diagnosis and treatment of autism since the most important treatments of autism can be accomplished in social settings.²¹ Therefore, the aim of this qualitative study carried out in Istanbul was to evaluate the perceptions of social stigma among a group of parents who have children with autism and their ways of coping with autism.

MATERIAL AND METHOD

Participants

Our study was conducted at a Rehabilitation Center in Istanbul Province of Turkey. Ten parents who have their 5-23 years old children with autism and who have brought their children to this center for rehabilitation formed our study group.

Data Collection

Data was collected via in-depth interviews with the parents. The interview guide had two parts: a narrative section in which participants were asked to tell their

Table 1. The sociodemographic characteristics of the participants.

Participant	Mother/Father (name and sex of the child with autism)	Age	Education	Occupation	Number of children (birth order of child with autism)
A.	Father (D.- male)	28	University	White-collared worker	1 (first child has autism)
Z.	Mother (E.- male)	39	High-school	White-collared worker	2 (first child has autism)
Ş.	Mother (U.-male)	35	High-school	White-collared worker	2 (second child has autism)
B.	Mother (S.-female, S.-male and S.-male)	41	High-school	Housewife	3 (three children having autism)
G.	Mother (D.- male)	33	Secondary-school	Housewife	1 (first child has autism)
N.	Mother (A.-male and E.- male)	29	High-school	Housewife	2 (two children having autism)
R.	Mother (Ö.- male)	41	Primary-school	Housewife	4 (fourth child has autism)
D.	Mother (M.- male)	51	Primary-school	Housewife	4 (fourth child has autism)
S.	Mother (B.- male)	34	Primary-school	Housewife	1 (first child has autism)
H.	Mother (Y.- male)	28	Illiterate	Housewife	3 (second child has autism)

stories; and then a semi-structured section in which the perceptions of social stigma of a group of parents of children having autism and their ways of coping were explored in depth. The semi-structured section was developed after extensive literature review and used as the study tool. The first draft of the interview guide was discussed among the researchers and was modified after discussion.

The questions were open-ended. Probing questions were used where necessary, and participants were given freedom to express their views at the end of the interview session. Each interview lasted approximately 45 to 60 minutes. Informed written consent was sought for tape-recording and for fully transcribing all the interviews. Each interview was transcribed verbatim on the same day of the interview. A total of 52 pages made-up the full transcription. Transcribed interviews underwent to thematic content analysis, and the transcripts were analyzed for relevant content to identify the emerging themes.

Interviews were carried out with nine mothers and a father present. Therefore, nine interviews were conducted with the mother and one interview with the father. The interviews were carried out in a separate and comfortable room where the participants could feel at ease. The names of the participants were not asked for confidentiality, only a nickname stated by the participants was used in addressing them. The content of the interviews was considered to be saturated when no new content was gained from participants. Therefore, the data was analyzed after ten interviews have been completed. At the end of the interviews, the advantages of having a child with autism, early intervention options were mentioned, and some coping up strategies were recommended for encouraging the parents.

Data Analysis

Thematic content analysis was used for the subjective interpretation of the content of textual data through the process of coding and the identification of themes.

All the researchers who conducted the interviews had participated in the process of data analysis: first, each researcher analyzed the transcription of the interview individually and after that they shared it with other researchers. After consecutive discussions, the researchers confirmed the contents and produced themes. Data analysis was performed by repeatedly reading all data, line by line. Codes were created from the data and were sorted into categories and subcategories based on the level of abstractness and how different codes were related. Relationships were identified through a comparison of the similarities and differences between the categories and subcategories.

Ethical Approval

Ethical approval for our study was granted by the Ethical Committee of Marmara University School of Medicine (Protocol Code: 09.2016.486). Oral informed consent was obtained from the study participants. All data were analyzed anonymously. All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and national research committee and with the declaration of Helsinki as revised in 2000.

RESULTS

Nine mothers and one father agreed to participate in this qualitative study. Table 1 presents the sociodemographic characteristics of the participants.

The age of the parents differed between 28-51 years. One of them was university graduate, four were high-school graduates, one secondary and one primary school graduates, in addition one was illiterate. One mother stated that she had two children having autism. Furthermore, one mother stated that she had three children having autism.

In our study as presented in Table 2, there were five themes namely; stigmatization in the big family, stigmatization in the community, stigmatization in school/ preschool period, stigmatization in healthcare settings and coping with stigmatization.

Stigmatization In The Big Family

Parents feel the need to hide the diagnosis from their relatives because after the recognition of autism, they might behave the child in a bad manner, or they just look at the child with a pity and not help the parents. The child is stigmatized and discriminated by the relatives. This caused most parents to isolate themselves from the big family:

“...I told the diagnosis to some of my relatives. He is a different child, true; whether they accept him as he is or not does not interest me. He is my child and I love him. I did not mind not to see my own family for three years after the diagnosis.”

(N., A. and E.'s mother, 29, high school graduate, housewife, 2 children have autism).

Exclusion does not only prevent the child's mother from seeing her family, but also prevents her sister from seeing her family, too:

“...My sister (the aunt of the child having autism) kept her own children away. She had to keep them away; because one day when we went to see her baby, she was told by her mother-in-law not to accept us because my child with autism could harm the baby.”

(D., M. 's mother, 51, primary school graduate, housewife).

We understand that even a relative is able to make fun of the child having autism; this in turn hurts the parents.

“...I witnessed that his uncle's brother was laughing at him, laughing at his childlike behavior. I felt so sorry for that.”

(Z., E. 's mother, 39, high school graduate, white-collared worker).

Table 2. Themes and Subthemes Driven from the Collected Data.	
Themes	Subthemes
Stigmatization in the Big Family	<ol style="list-style-type: none"> 1. People looking with eyes full of pity 2. Because they did not want a normally developing child to play with a child having autism in the big family 3. Because they behaved bad towards the child having autism and made fun of him 4. Parents isolate themselves from the big family - disruption of family ties: <ul style="list-style-type: none"> - in order to prevent their labelling of the child - in order not to disrupt the child's daily life
Stigmatization in the Community	<ol style="list-style-type: none"> 1. Stigmatization at work 2. Not able to establish empathy 3. Labelling the 'bad' mother 4. Stigmatization of the child with autism is provoked by the family of the normally developing child 5. The attitude towards the child changes depending on their awareness about autism 6. The community cannot tolerate the 'naughty' child having autism. All 'naughty' behaviors are attributed to autism
Stigmatization in School / Preschool Period	<ol style="list-style-type: none"> 1. Insufficient attention and discrimination of teachers 2. The teachers' misunderstanding the child having autism and stigmatizing him 3. A child having autism is not assisted in socializing with his peers 4. Most schools are unwilling to accept the child having autism 5. Parents of other children try to isolate them from the child having autism
Stigmatization in Healthcare Settings	<ol style="list-style-type: none"> 1. Do not have enough knowledge about autism 2. Unable to guide parents 3. The attitudes of doctors also tended to stigmatize the child
Coping with Stigmatization	<ol style="list-style-type: none"> 1. Don't mind the situation 2. Getting professional psychological support 3. Decrease relations with other people

Stigmatization In The Community

Labeling The Child

The Community; varying according to their level of knowledge on autism, most of the time did not empathize with the parents. Sometimes the community might make a mistake even when trying to sympathize with the child having autism.

“...A lady said 'Wow! I have watched the film 'rain man'. People with autism are very intelligent. Can you multiple 30 with 60?'. How can you explain her?”

(D., M.'s mother, 51, primary school graduate, housewife).

Labeling The Parents

The Community does not only label the child having autism but also his parents. A father was stigmatized in the workplace as 'the father of an autistic child'; furthermore, a mother was labelled as 'bad mother' while trying to educate the child in discipline as a 'misbehaving mother'.

"...when I showed my colleagues his diagnosis report of autism, they said: 'Your child will not be accepted even for military task in the future.' That was a very painful reaction."

(A., D.'s father, 28, university graduate, White-collared worker).

Stigmatization In School / Preschool Period

Stigmatization In The Preschool Period

It was stated that the youngsters were discriminating the child having autism and they were thought to have learnt to discriminate from the adults.

"(... talking about another mother) ... her daughter also came: 'E. drank water from my cup! I do not want to drink water from that cup!' 'Why?' her mother asked. 'Because he is sick!' told the normally developing child ... But my son E. has only autism, he is not sick! A 5-year-old child cannot know this, unless she is taught by her mother!"

(N., A.'s and E.'s mother, 29, high school graduate, housewife).

Stigmatization In School Period

Schools are among the places where the child having autism were frequently stigmatized. This was due to the child's having hard time while communicating with his peers during their school years. It has been determined that one of the main problems at school was that the school does not accept the child having autism although legally he has the right to be integrated as a mainstream student. While the main role in his integration belongs to teachers, many teachers were reported to be insufficient in his education, and they usually do not include him in classroom activities:

"... They do not accept, for example, many nursery schools do not accept him. They said that they cannot take such a child. Although I thought I was going to register my son E. to the best teacher of the school, the teacher never cared about E. My neighbor took care of my son E. and taught my son E. how to read and write. E.'s teacher was never aware that E. learnt to read and write."

(Z., E.'s mother, 39, high school graduate, white-collared worker).

Normally developing children at school do not understand why the child having autism behaves like that, therefore they stigmatize him.

"...Other children at school react to Ö. They say: 'Ö. does not speak. Stay away from him! He is mad!"

(R., Ö.'s mother, 41, primary school graduate, housewife).

In fact, the dimension of social discrimination was so serious that even a participating mother confessed that she did not want a 'severely autistic' child at school; whereas her son was also 'mild autistic'.

"...But now they have brought another child to school. It affected me. I felt sorry. He's very sick. He is completely away from other students. I thought of talking to the Director of school that they should send him out. I will wait for some more days. The family insists to bring him to this school. I told his family, too, ' He cannot learn anything here, he is not appropriate for this school.' Certainly, the child does not know anything. They go out to the garden at breaks the bell rings, he knows none of them. He always stands still in the same place, and check out the bell, he makes odd movements. ...I will wait for one week, if the family insists to bring him to school, I will go and talk to the Director about him."

(B., S., S. and S.'s mother, 41, high school graduate, housewife, three children have autism).

Stigmatization In Healthcare Settings

When parents first suspect the difference in the child having autism, they take him to a pediatrician or an otorhinolaryngologist. Parents thought that the doctors working in the above-mentioned two specialities do not have enough knowledge about autism and also, they were frequently unable to guide parents to a child psychiatrist. Parents are often referred to several inappropriate health personnel before the diagnosis.

"...We take him to a doctor, he examines his ear, he inspects brain MR. We are surprised that he says there's nothing wrong with him. We started to take him to doctors at the age of four. We took him to doctors for one year. He is at the age of five now, but he cannot speak yet. He was diagnosed at the age of 5. ... for example, I went to the hospital this morning to give his report to the pediatrician; even the pediatrician does not know what autism means. 'What is autistic?' she said, ' He does not talk...' I said."

(R., Ö.'s mother, 41, primary school graduate, housewife)

The current status of early diagnosed children was reported to be much better than the status of late diagnosed children. The parents mentioned how important early recognition was in autism and that the health personnel had so much responsibility. They also emphasized that every parent had the right to taste the feeling of hearing the first words of their child:

“...I have never heard a voice of my baby until he first called me ‘Daddy!’. I felt strange at that moment! At that moment, I felt like I have been reborn.”

(A., D.'s father, 28, university graduate, white-collared worker).

The attitudes of some health personnel could also tend to stigmatize the child.

“...He said: ‘This boy will not give a reaction at all (He moves his hand gesturing ‘no reaction’) Even if you educate him, this child is closed. This boy can give hardly a reaction.”

(A., D.'s father, 28, university graduate, white-collared worker).

“... The health personnel told us that he will be a child like a weed. ‘Weed is the meaning of ‘autistic’ he said to us... He can never be treated, he cannot be like a normal child!”

(B., S., S. and S.'s mother, 41, high school graduate, housewife, three children have autism).

Coping With Stigmatization

It has been determined that parents can hardly bear the behavior of others towards their child having autism due to their stigmatization/exclusion/discrimination and labeling. Besides; community attributes every inappropriate behavior to the autistic traits of this child. The community labels the child as 'sick' or 'disabled'.

“...We are pushed out of the community with our children. So, we decreased our relations with other people. Can you go to a place where they don't want you and your child?”

(D., M.'s mother, 51, primary school graduate, housewife).

DISCUSSION

The aim of this qualitative study was to evaluate the perceptions of social stigma among a group of parents of children having autism and their ways of coping with stigma.

We have found that, the children in our study were stigmatized and discriminated by the relatives. This caused most parents to isolate themselves from the big family. Based on the cognitive and emotional impacts of affiliate stigma, relatives especially in the extended family might react as not to have any relation with a stigmatized person.²²

The Community; varying according to their level of knowledge on autism, most of the time did not empathize with the family.¹⁹ In Gona's study in Kenya, parents experienced social isolation of their child and also public intolerance.²³ The insensitivity and unfavorable comments made by community members resulted in parents perceiving themselves as social outcasts.²³ In Selimoğlu's study in Turkey, parents stated rejection by the community and even by some family members as if they had some contagious disease.²⁴ In Greece study some mothers reported loneliness and isolation as a result of rejection by the social environment, an actual experience of social exclusion.²⁵ This social avoidance behavior influenced mother's mental health according to Dehnavi.²² In Boyd's literature review, it is noted that low levels of social support were the most powerful predictors of depression and anxiety in mothers.²⁶

‘The Community does not only label the child having autism but also his family members’ was one of the common phrases mentioned in our study. In Boyd's review, one of the most stressful factors associated with parenting a child having autism was poor acceptance of autistic behaviors by other family members.²⁶ In Gray's paper, this condition was referred to as a courtesy stigma.¹⁹ By this they meant that the members of such families experience stigmatization due to their affiliation with the stigmatized individual rather than through any characteristic of their own.¹⁹ Most parents in Australia and in Kenya studies, perceived themselves as being stigmatized by their child's condition.^{19,23,27,28} Gray stated that most parents experienced stigma, where particularly mothers encountered avoidance, unsympathetic staring and rude comments from other people.²⁸ Mak discussed parents of children having autism being stigmatized and blamed by other people in the community, who blame them for causing their children's developmental disturbances.²⁹ In Gona's study in Kenya, shame was

experienced by some parents because of perceived.²³ In Farrugia's study in Australia, too, parents reported embarrassment caused by public enacted stigma.²⁷ In Fox's study parents also declared shame after the diagnosis and they had 'felt stigma'.³⁰ In Fox's study stigma forced parents' tendency to hide the child.³⁰ In Mak's study carried out in Hong Kong, China, parents felt internalized-stigma and self-blame.²⁹ Mak identified some parents feeling that 'it was my fault to let my child be 'stigmatized'.²⁹ Green stated in U.S.A. study that where mothers feel embarrassed by, guilty about or resentful of their type of mothering, well-being of other family members is likely to be affected as well.²⁰ According to Goffman who was the first person who applied stigma for explanation of a specific psychological-social phenomenon, at first, a person was stigmatized, then the stigmatized person's relatives were exposed to stigmatization.²² Affiliate stigmatization happens afterwards, in the way that people just because of having a relation to a stigma person are at the exposure of unfavorable behaviors.²²

As far as the pre-school period was concerned, the youngsters were discriminating the child having autism and they were thought to have learnt to discriminate from the adults.

In our study, schools were among the places where the child having autism was frequently stigmatized. Many of the children in Gray's study in Australia, experienced isolation and/or bullying at school, and relatively few had succeeded at establishing friendship with older children.²⁸ In other studies, it is stated that children with autism are at risk of being harmed, ignored or nagged in the classroom, for example they are more likely to be bullied.^{31,32} In our study, stigmatization and discrimination of child having autism was believed to be due to the child's having hard time while communicating with his peers during their school years.

'Normally developing children at school do not understand why the child having autism behaves like that, therefore they stigmatize him.' was one of the common ideas that can be drawn from our study. In Greece study, one mother's concern stood out in her narrative about whether the teacher would treat her child with dignity, whether his friends would laugh at him, whether the older kids would beat him up again.²⁵ However, in Humphrey's study the respondents felt that the key benefits mainstream pupils without autism would gain from a child having autism integrated into mainstream was increased

understanding and tolerance of people different to themselves.³¹

In our study it has been determined that one of the main problems at school was that the school does not accept the child having autism; although legally he has the right to be integrated as a mainstream student. However, upon acceptance to school, not only the mainstream children with autism benefit from inclusion but also their normally developing peers.¹³ Inclusive education started in Turkey in year 1983 with the regulation concerning children with special needs. In Turkey although there are legal obligations about special education services and inclusive education, there are not enough people trained to provide those services and there are not well-designed educational environments for inclusive education according to Yasar *et al.*¹⁶

In our study, while the main role in integration belongs to teachers, many teachers were reported to be insufficient in education of a child having autism, and they did not include him in classroom activities. The results of some other studies suggest that the stigmatization on autism is prevalent among teachers.³¹⁻³³ Similar inadequacy feelings of teachers about educating a child having autism existed in Liu's, McConkey's and Humphrey's studies whereas in Sweden pre-school teachers felt more secure about their approach to the children with autism in Andersson's study.^{12,13,17,31} In Selimoğlu's study in Turkey, majority of the participating parents complained of the inadequacy of primary school teachers about autism.²⁴ In Greece study, the mothers of children with autism expressed their concern about the existing schools because of the problems in both infrastructure and staffing and because of these problems, several children in the autistic spectrum were forced to remain at home without attending school.²⁵ In Greece study similar to our study, mothers stated that the child was rejected at school.²⁵ In Gray's study, relations with teachers and school administration was often cited as a problem.²⁸

In our study, when parents first suspect the difference in the child having autism, they take him to a pediatrician or an otorhinolaryngologist. In another study in Turkey, pediatrician was the first place of contact of the families.²⁴ In Selimoğlu's study similar findings appeared as to the incompetency of the health personnel, inconsistency between physicians as of the diagnosis, sometimes leading to delay of the diagnosis.²⁴ Furthermore, unconfidence towards the

health personnel led to rejection of the diagnosis by the families in Selimoğlu's study.²⁴ In Olivier's study, in South Africa, parents reported similar problems concerning the diagnosis process and the health personnel.³⁴ In UK study, some general practitioners whom parents first contacted referred the child straight-away for assessment leading to timely diagnosis; however, some were told that nothing was wrong with the child by their practitioner causing a delay of 6 months-5 years.³⁵ Lack of action or knowledge of health personnel in Ryan's study left parents feeling isolated.³⁵ In Latino study parents found the health-care providers' diagnosis and advices less trustworthy.³⁶

In our study it was understood that the doctors working in the specialities of pediatrics or otorhinolaryngology do not have enough knowledge about autism or they are frequently unable to guide parents to a child psychiatrist. In Selimoğlu's study, majority of the parents declared that they received unpleasurable attitude from the health personnel.²⁴ Parents of Latino children in Zuckerman's study experienced mixed concerns with the health care provider to whom they first applied for diagnosis.³⁶ Some thought the primary care provider helped them to obtain the autism diagnosis quickly; whereas others felt their concerns were ignored, resulting in delayed diagnosis, and some showed dismissive behaviors.³⁶

The attitudes of some health personnel who were competent enough to make the right diagnosis of autism could also tend to stigmatize the child was confessed by the parents of our study which ended up with the parents' feeling helpless. However, in his paper, Boyd recommends professionals having a responsibility to help especially mothers to better cope with an already difficult and potentially life-long situation.²⁶

In our study, it has been determined that parents can hardly bear the behavior of others towards their child having autism due to their stigmatization/exclusion/discrimination and labeling. In several studies, the parents who perceived themselves to be stigmatized stated that this was because of tantrums, destructive or socially inappropriate behaviors of the child in public places.^{19,23,27-29,36} Avoidance, unsympathetic staring, rude comments by others were explained in public places.²⁸ Sometimes parents attempted to defuse the condition by explaining the nature of autism to the person who made the comment.²⁸ Frequently this was successful; however sometimes, an explanation

made no difference causing the parents react with considerable anger of their own.²⁸ In our study, the parents also thought that community attributes every inappropriate behavior to the autistic traits of this child; furthermore, the community labels the child as 'sick' or 'disabled'. Therefore, the parents of our study chose to decrease their relations with other people. In Gona's paper, too, the coping strategies of parents were reported to be parents' withdrawal from social relations, but also, shifting expectations, working towards inclusion and greater acceptance of the child.²³ Olivier's advice is, parents should realize that their child does not have autism because of something which they did wrong.³⁴ Green recommends helping parents develop strategies for dealing with the stigmatized public reactions they expect; thus, increasing chances for contact between children with and without disabilities, potentially helping to break the self-perpetuating stigma.²⁰

Limitations

Since, interviews were made by taking audio recordings and at the same time explaining the difficulties the participants experienced to somebody whom they don't know could be quite challenging. The researchers observed that the participants sometimes could not act comfortably and could not answer every question in detail. These can be major limitations of our research. Furthermore, the findings of our study cannot generalize to the whole population since it was a qualitative study.

CONCLUSION

In this qualitative study, the parents of children with autism experienced exclusion, discrimination and stigmatization both in the families and in the community. Children were mostly discriminated during school period. Stigmatization existed not only by the community but also in healthcare settings. To this end, parents felt isolated in the community. This might have delayed the diagnosis and the therapeutic interventions and unfortunately prevented recovery. Therefore, creating awareness of community should start with training health personnel. This might reduce exclusion, discrimination and stigmatization in the community and facilitate the recovery of this children.

*The authors declare that there are no conflicts of interest.

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