Original Article

Stigmatization among parents of autism spectrum disorder children in Riyadh, Saudi Arabia

Kahlid Alshaigi*, Reema Albraheem, Khalid Alsaleem, Moneer Zakaria, Aman Jobeir, Hesham Aldhalaan

King Faisal Specialist Hospital & Research Centre (KFSH & RC), Saudi Arabia

ABSTRACT

Background: Children diagnosed with autism spectrum disorder (ASD) have social and cognitive disabilities. For parents, these behaviors can lead to humiliation, social exclusion, and isolation. Stigma is a problem that not only may affect the individual with high functioning autism, but has the potential to extend to their family as well. Indeed, research indicates that the parents of children with disabilities (including ASD) commonly experience stigmatizing reactions from others.

Aim of work: To determine the prevalence of self and enacted stigma among parents of ASD children from Riyadh, Saudi Arabia, and recognize possible risk factors and causes of stigmatization.

Material and methods: An observational cross-sectional study involving the parents of ASD children from Riyadh, Saudi Arabia. About 163 participants were included from the Centre for Autism Research (CFAR) at King Faisal Specialist Hospital & Research Centre (KFSH & RC) in Riyadh. The primary material used for data collection was a five-point scale questionnaire developed by the investigator. The questionnaire consisted of closed ended questions related to the participants’ demographic data, autistic child, family life, resources, and social experiences as a parent. The collected data were analyzed using descriptive statistics and appropriate statistical analysis, using Statistical package for the social sciences (SPSS), version 22. The level of significance was P value < .05.

Results: The findings of this work indicated that 55 (33.7%) of the parents scored more than 3 in answering questions related to felt stigma; 82 (50.3%) were fathers. On the other hand, 108 (66.3%) did not feel stigmatized being a parent of autistic child. Forty-two (25.8%) of the parents scored more than 3 in answering questions related to enacted stigma, whereas 121 (74.2%) did not face enacted stigmatization being a parent of autistic child. There was a strong tendency for mothers (41, 75%) to feel more self- and enacted stigmatized than fathers (P < .05). Moreover, the gender of the autistic child, consanguinity, severity of the ASD, and the monthly income of the family showed no significant difference in the parents who scored more than 3 for felt- or enacted stigmatization (P > .05).

Conclusion: Among participated parents of children with ASD in Riyadh, Saudi Arabia, 33.7% of them experienced stigmatization, and mothers felt more self- and enacted stigmatized when compared to fathers. Public awareness among people in Saudi Arabia has been increased and, thus, negative stigmatization has decreased among parents in the country. A high level of felt stigma suggests the need for psychological intervention for the family to help cope with this new situation. A higher level of enacted stigma suggests the need for their rights (individuals with ASD) and increased awareness in the society. It is recommended that further research is needed in different centers in Riyadh and other regions of Saudi Arabia to investigate the prevalence of stigma in parents of autistic children.

© 2019 Publishing services provided by Elsevier B.V. on behalf of King Faisal Specialist Hospital & Research Centre (General Organization), Saudi Arabia. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).
1. Introduction

The autism spectrum disorder (ASD) affects the cognitive and social capabilities in diagnosed children as well as their families. ASD is usually diagnosed in the early years of childhood and illustrates a variety of developmental disorders [1]. According to the Centers for Disease Control and Prevention (CDC) in the U.S., about 1 in 68 American children has ASD [2]. According to statistics from the King Abdulaziz City for Science and Technology, about 1 in every 180 children in Saudi Arabia is diagnosed with ASD [3].

Children with ASD have difficulties in language and may display antisocial behaviors such as aggression, withdrawal, or even seek self-stimulation, sometimes in response to stress or changes in routine. It becomes difficult for the parents to handle their children with ASD because of the social consequences. For parents, these behaviors can lead to social exclusion, disgrace, and isolation [4].

Some of the children with ASD have a normal IQ, widespread vocal abilities, as well as frequently attend normal schools. However, the potential impact of ASD is severe [5]. Common experiences among children with ASD include obsession, impairment of social relationships, irregular levels of cognitive and intellectual functioning, and abnormalities in language and performance [6–8].

Stigma is considered one of the major problems experienced by parents of autistic children. Stigma not only affects children with high functioning autism but can extend to their parents as well. Studies indicate that the parents of children with ASD commonly experience stigmatizing reactions from others [9,10].

The theory of social stigma was developed by Goffman [11] in 1963 and consequently has been applied to a variety of adult sickness and cognitive conditions [12–15]. There are no much studies regarding perceived stigma in parents of children with mental disabilities; however, there are a few research studies regarding the impact of stigma in this case [16,17].

Stigmatization of the family with ASD children was one of the concerns when studying the social effects of autism. When the parents were asked about the way people treat them or their children due to his/her disability, they expressed that they may internalize community stigma as self-stigma. The component of self-stigma includes two magnitudes: the content and the process. Both of these two self-stigma dimensions greatly affect the parents’ mental health [18].

As a form of chronic disease, ASD represents a serious challenge not only to the afflicted person but also to the concerned family. Because autism, for several reasons, is extremely difficult to manage or treat, it poses a great risk to the family. Even when autism is diagnosed, the medication available for its treatment is inadequate. The provision of particular social and medical services for autistics individuals in KSA started from the mid 1990s; several non-governmental organizations independently developed programs for the management of autistic children [19]. The Government of Saudi Arabia grants funds to support these programs.

At present, the health authorities in the country offer a wide range of services for the treatment and education of autistic children and support their families [20]. As a disabling disease, the prognosis for autism is limited, and there is no actual cure. Only few afflicted persons will be able to work or live independently away from their families other than in a place for the mentally handicapped [21].

2. Aim of work

The aim of the study is to determine the prevalence of self and enacted stigma among parents of ASD children from Riyadh, Saudi Arabia and investigate the possible risk factors and causes of stigmatization. Also, this study aims to determine whether caring for children with ASD is associated with the quality of life among Saudi Arabian families and to recognize what kinds of support parents feel they need.

3. Research significance

The significance of this research is that it can contribute to the knowledge and understanding to parents regarding the care required for children with ASD and provide support and develop different approaches for the parents to help reduce the effect of stigma among them.

4. Material and methods

The present research is an observational cross-sectional study involving the parents of ASD children from Riyadh, Saudi Arabia. This study was conducted in Riyadh during January 2017–March 2018.

Two hundred parents of children diagnosed with ASD participated in the study. The diagnosis of ASD was done using DSM-IV-TR criteria [22].

The participants were collected from the Centre for Autism Research (CFAR) at King Faisal Specialist Hospital & Research Centre (KFSH & RC) in Riyadh and from a private autism centre. About 172 participants were included in the study. However, 9 participants were excluded because they are not parents (5 sisters and 4 aunts). Of the 163 included participants, 87 were mothers (53%) and 76 were fathers (47%). The ASD children comprised 129 boys (79%) and 34 girls (21%).

The inclusion criteria were: Male and female parents of children diagnosed with ASD, children with autism aged between 1 and 14 years, children of both sex (males and females), and free from chronic physical disease or other neurological disorder or handicapped. The parents of children with autism must give direct care to the child and should not have another child with other form of disabilities. The exclusion criteria were: Other relatives providing care to children with ASD and autistic child older than 14 years.

This study divided the stigma scale into two types: felt stigma (internal stigma or self-stigmatization) and enacted stigma (external stigma or discrimination). Felt stigma refers to the family’s embarrassment associated with the condition and the expectation of discrimination that prevents parents from talking about their experiences and seeking assist. Enacted stigma refers to the experience of unfair treatment by others.

5. Data collection

The primary material used for data collection was a questionnaire developed by the investigator. The questionnaire was based on the Beach Centre Family Quality of Life Scale [23] and Self-stigmatizing Thinking’s Automaticity and Repetition Scale (STARS) [18] modified for Saudi Arabia. The questionnaire comprised closed-ended questions concerning the participants’ demographic data, autistic child, family life, resources, and social experiences as a parent.

The questionnaire was a five-point scale (scale 1 for strongly disagreed and 5 for strongly agreed) and consisted of three sections. The first section was about the demographic data of the participants: age, gender, educational status, marital status, severity of ASD, income, and type of any service intervention to the child.

The second section was to measure the self-stigma and consisted of questions such as: I feel that my life will be better without a child with autism, I feel embarrassed of my child’s behaviors in public, I avoid participation in activities related to autism, I fear...
society’s perception if they discovered that my child has ASD, etc.

The third section was to measure enacted stigma and consisted of questions such as: My family feels ashamed of my child’s behaviors during social gatherings, my children avoid going out with my ASD child in public, others call my ASD child with names such as weird, impolite, mentally retarded, etc., others feel pity for me, or think less of me when they know I have a child with autism, my child experiences discrimination in school, etc.

Data were recorded via taking notes during interviews and collected through semi-structured interviews. All of the parents who were approached agreed to participate in the study. The main researcher himself conducted the interviews, and a relationship between him and participants was not established before the interview. All interviews were conducted in an office in CFAR while ensuring a private and secure environment. Interview lasted for a minimum of 20 min and a maximum of 30 min. The questions in the questionnaire were explained to the parents whenever clarification was needed.

The questionnaire included: (1) Parents’ knowledge related to their awareness about their children’s autism as speech and language therapy, appropriate school and educational services, and social skills training and (2) parents’ stigma stress scale to evaluate the amount of pressure and burden on the parents’ caring for autistic children.

5.1 Tool validity and reliability

A pilot study was performed on 23 parents (not included in the final results of the study), which included 16 mothers and 7 fathers, to attain the validity and reliability of the questionnaire, test clarity, ensure arrangement of content and applicability of items, and determine the time required to fill in the constructed questionnaire of the research. The reliability statistics showed that Cronbach’s alpha based on standardized items was 0.777. Parents participated in the pilot study were not included in the main study sample.

6. Ethical consideration

The necessary official approval for this research ethics was obtained from King Faisal Specialist Hospital and Research Centre (KFSH & RC) Riyadh, Saudi Arabia, (Ref. No. 2171045). Also, polices and guidelines of the Research Advisory Council of KFSH & RC and the laws of Saudi Arabia were considered and followed strictly.

In this study, the data were collected based on questionnaires distributed to parents of the patients. The study did not pose more than minimal risk to the research subjects; therefore, the benefit/risk ratio was considered to be favourable, and a waiver of informed consent was requested. Informed consents were obtained from the participants to share after explaining the nature, purpose, and benefits of the current study. Participation was voluntary, and subjects were allowed to choose not to participate. The identity of the selected parent or child in the study was kept confidential. The participants were assured that their or child’s identifying information will not be declared and cannot be traced by any mean clarifying that all the study data will be used only for scientific research.

7. Statistical analysis

In the current study, the collected data were analyzed using descriptive statistics and appropriate statistical analysis, using Statistical package for the social sciences (SPSS), version 22. Statistical tests were performed to calculate the percentages, mean, and standard deviation for the general characteristics of the parents and child with autism. Chi-square and p-value for the relation between factors affecting stigma among parents of children with autism were done. The level of significance was P value <.05.

8. Limitations of the study

The study was limited by the inadequate local literature about stigma in parents caring for children with mental or social disabilities. Few researches in different regions of Saudi Arabia have been performed on the stigmatizations among parents of autistic children. Moreover, not all ASD centers in Riyadh or other centers in the kingdom were included in the study.

9. Results

The demographic data of the ASD children and the parents caring for them are shown in Tables 1 and 2. Among the 163 ASD child cared by parents included in this study, 129 (79.1%) were males and 34 (20.9%) were female children. Most ASD cases (92, 56%) were aged between 6 and 12 years. The birth order of 78 (47.9%) children was fourth or more. Only 11 (6.7%) were in a normal school, whereas 25 (15.3%) were in school of special needs and 40 (24.5%) were not sent to school. The severity of the ASD was mild in 73 children (44.8%), moderate in 78 (47.9%), and severe in 12 cases (7.3%). About 122 (74.8%) parents agreed that they receive concerning social and medical services (Table 1).

About 163 respondents participated in this study, of which 87 (53.4%) were mothers 76 (46.6%) were fathers. About 83 (50.9%) parents were in the age of 36–45 years and 98 (60.2%) had a university degree. In 117 (72%) cases, there was consanguinity between the parents and 146 (89.6%) were married (Table 2).

Most of the participants (59, 36.2%) had their original residence in Riyadh, 48 (29.5%) were from Makkah, and 26(16%) from the eastern province region (Table 3).

The findings of this work indicated that 55 (33.7%) of the parents

| Table 1 | Number and percentage of children with autism according to their characteristics. |
|---------|---------------------------------------------------------------|
| Item                | No. | %   | P value |
| Children’s age (years) |     |     |        |
| 2–5 years old       | 56  | 34.4| >.05   |
| 6–12 years old      | 92  | 56.4|        |
| 13–17 years old     | 8   | 4.9 |        |
| 18–28 years old     | 7   | 4.3 |        |
| Gender              |     |     |        |
| Male                | 129 | 79.1| <.05   |
| Female              | 34  | 20.9|        |
| Birth order         |     |     |        |
| First               | 23  | 14  | >.05   |
| Second              | 27  | 16.6|        |
| Third               | 35  | 21.5|        |
| Fourth and more     | 78  | 47.9|        |
| Level of education  |     |     |        |
| School of special needs | 25 | 15.3| >.05   |
| Normal school       | 11  | 6.7 |        |
| Not attached to school | 40 | 24.5|        |
| N/A                 | 87  | 53.3|        |
| Onset and duration of autism | | | |
| 6–12 months         | 38  | 23.3| >.05   |
| 12 months—3 years   | 62  | 38.1|        |
| 3–9 years           | 47  | 28.8|        |
| >9 years            | 16  | 9.8 |        |
| Severity of the disease |   |   | >.05   |
| Mild                | 73  | 44.8|        |
| Moderate            | 78  | 47.9|        |
| Severe              | 12  | 7.3 |        |
| Receiving services  |     |     |        |
| Yes                 | 122 | 74.8| <.05   |
| No                  | 41  | 25.2|        |
The results showed that 42 (25.8%) of the parents scored more than 3 in answering questions related to felt stigma; 82 (50.3%) were fathers. On the other hand, 108 (66.3%) did not feel stigmatized being a parent of autistic child; 47 (28.8%) were male child. The chi-square value was 2.0043, which was statistically nonsignificant ($P > .05$). The feeling of self-stigmatized was found to be more among mothers (41, 75%) compared to fathers ($P < .05$). Moreover, the gender of the autistic child, consanguinity, severity of the ASD, and the monthly income of the family showed no significant difference in parents who scored more than 3 for enacted stigmatization ($P > .05$) (Table 4).

The response of parents to the questions about felt stigma is shown in Table 5. There were only 2 questions that scored more than 50% agreement to the item of felt stigma. About 64.9% agreed to the question “I believe that our society does not understand children with ASD’s situation”. Moreover, 50.3% agreed to “My child with autism has affected our vacations.”

The response of parents to the questions that might indicate enacted stigmatization is shown in Table 6. There was only one question that scored more than 50% agreement to the item of enacted stigma. About 55% of the parents agreed to the question “Others feel pity for me, or think less of me when they know I have a child with autism.”

### Table 2
Number and percentage of parents of children with autism according to their socio-demographic characteristics.

| Item                     | No. | %   | P value |
|--------------------------|-----|-----|---------|
| Gender                   |     |     |         |
| Mothers                  | 87  | 53.4| >.05    |
| Fathers                  | 76  | 46.6|         |
| Age (years)              |     |     |         |
| 26–35 years old          | 55  | 33.7| >.05    |
| 36–45 years old          | 83  | 50.9|         |
| 45 + years old           | 25  | 15.4|         |
| Educational level        |     |     |         |
| Primary Education        | 43  | 26.4| >.05    |
| University Degree        | 98  | 60.2|         |
| Higher Education         | 22  | 13.5|         |
| Residence                |     |     |         |
| North Riyadh             | 32  | 20  | >.05    |
| East Riyadh              | 47  | 29  |         |
| West Riyadh              | 36  | 22  |         |
| South and centre Riyadh  | 48  | 29  |         |
| Monthly income           |     |     |         |
| 5000 SAR or Less         | 28  | 17.1| >.05    |
| 5000–10,000 SAR           | 44  | 27  |         |
| 10,000–20,000 SAR         | 63  | 38.7|         |
| 20,000 SAR or more       | 28  | 17.2|         |
| Consanguinity            |     |     |         |
| Yes                      | 117 | 72  | <.05    |
| No                       | 46  | 28  |         |
| Marital status           |     |     |         |
| Married                  | 146 | 89.6| <.05    |
| Divorced                 | 7   | 4.3 |         |
| Separated                | 7   | 4.3 |         |
| Widowed                  | 3   | 1.8 |         |

### Table 3
Original residence of the families of children with autism.

| Region of Residence | Frequency | Percent | Cumulative Frequency | Cumulative Percent |
|---------------------|-----------|---------|----------------------|-------------------|
| Riyadh Region       | 59        | 36.2    | 59                   | 36.2              |
| Qassim Region       | 4         | 2.5     | 63                   | 38.7              |
| Hail Region         | 3         | 1.8     | 66                   | 40.5              |
| Makkah Region       | 48        | 28.5    | 114                  | 70                |
| Madinah Region      | 5         | 3.1     | 119                  | 73.1              |
| Tabuk Region        | 2         | 1.2     | 121                  | 74.3              |
| Jawf Region         | 2         | 1.2     | 123                  | 75.5              |
| Asir Region         | 7         | 4.3     | 130                  | 79.8              |
| Jizan Region        | 3         | 1.8     | 133                  | 81.6              |
| Najran Region       | 4         | 2.4     | 137                  | 84                |
| Eastern Province Region | 26    | 16      | 163                  | 100               |

### Table 4
Felt stigma among parents of children with autism.

| Felt Stigma Score | Frequency | Percent | P value |
|-------------------|-----------|---------|---------|
| <3                | 108       | 66.3    | >.05    |
| Male              | 82        | 50.3    |         |
| Female            | 26        | 16      |         |
| => 3              | 55        | 33.7    |         |
| Male              | 47        | 28.8    |         |
| Female            | 8         | 4.9     |         |

who scored more than 3 for enacted stigmatization ($P > .05$) (Table 5).

The response of parents to the questions about felt stigma is shown in Table 5. There were only 2 questions that scored more than 50% agreement to the item of felt stigma. About 64.9% agreed to the question “I believe that our society does not understand children with ASD’s situation”. Moreover, 50.3% agreed to “My child with autism has affected our vacations.”

The response of parents to the questions that might indicate enacted stigmatization is shown in Table 6. There was only one question that scored more than 50% agreement to the item of enacted stigma. About 55% of the parents agreed to the question “Others feel pity for me, or think less of me when they know I have a child with autism.”

### 10. Discussion
Samadi and McConkey [24] reported that further research about stigmatization among parents of children with ASD in developing countries is required to recognize different difficulties experienced by them. They identified that stigma research is mostly limited to parents of autistic children in developed Western countries. This indicated to the researchers of developing countries, including KSA, about the gap in the literature on studies exploring stigma among parents of children with ASD particularly in KSA. Therefore, the goal of this study was to identify the prevalence and possible risk factors...
of self and enacted stigma among families of ASD children from Riyadh, Saudi Arabia [25].

Parents of children with ASD in KSA face multiple challenges and difficulties caring for their children because of the burden of disease on the child in the Saudi society and the conservative cultural issues associated with their people and developing social life. However, the present results demonstrated that only 33.7% of the parents scored more than 3 in answering questions related to felt stigma, whereas 66.3% did not feel stigmatized being a parent of autistic child. Moreover, there was no statistical significant difference between parents caring for male or female ASD child.

However, the findings of the current work illustrated that the feeling of self and enacted stigmatization were statistically more significant among mothers compared to the fathers of ASD children. This might be due to some psychological or social factors affecting Saudi mothers rather than the fathers. This was in accordance with previous studies indicating that parents’ abilities to successfully respond to their autistic children’s problem could be significantly different due to certain psychosocial factors. Some parents of ASD children experienced mental problem and stigmatization to certain extent, whereas some others experienced a lesser amount of psychosocial problems such as stigmatization [26,27].

This finding was in agreement with the study of Al Towairqi et al. [28], in Taif region, Saudi Arabia, who demonstrated that Saudi mothers caring for ASD child were facing more depression compared to a group of mothers caring for normally developing children. They stressed that Saudi mothers of ASD children must be provided with definite psychological support and social interventions from both the government and private society to reduce the possibility of maternal depression. Moreover, Al Eitban et al. [29] explored the existence and amount of mood problems among Saudi mothers caring for disabled children. They concluded that Saudi mothers with disabled children demonstrated high amounts of depression and anxiety and obtained an increased score in total Hospital Anxiety and Depression Scale (HADS). They suggested that further awareness should be raised to support and protect the psychological health of mothers with disabled children.

However, this finding was in agreement with that reported by Dehnavi et al. [30], in Isfahan, Iran, who showed that 25% of mothers of autistic children had self-stigmatization, which significant affected their mental health. They also indicated in their investigation that about 60% of the Iranian mothers caring for children with ASD were at greater risk for decline in their level of mental health compared to mothers caring for normal child. They concluded that self-stigmatization was a psychosocial process that begins with labeling and could lead to complete social withdrawal.

### Table 5

| Enacted Stigma Score | Frequency | Percent | P value |
|----------------------|-----------|---------|---------|
| <3                   | 121       | 74.2    | >.05    |
| Male:                | 99        | 60.7    |         |
| Female:              | 22        | 13.5    |         |
| → 3                  | 42        | 25.8    |         |
| Male:                | 30        | 18.4    |         |
| Female:              | 12        | 7.4     |         |

→ 3 according to:

| Gender of parents | Frequency | Percent | P value |
|-------------------|-----------|---------|---------|
| Mother            | 31        | 74      | <.05    |
| Father            | 11        | 26      |         |

| Consanguinity     | Frequency | Percent | P value |
|-------------------|-----------|---------|---------|
| Yes               | 32        | 76      | >.05    |
| No                | 10        | 24      |         |

| Severity of the disease | Frequency | Percent | P value |
|-------------------------|-----------|---------|---------|
| Mild                    | 17        | 40      | >.05    |
| Moderate                | 21        | 50      |         |
| Severe                  | 4         | 10      |         |

| Monthly income         | Frequency | Percent | P value |
|------------------------|-----------|---------|---------|
| 5000 SAR or Less       | 7         | 17      | >.05    |
| 5000–10,000 SAR        | 12        | 29      |         |
| 10,000–20,000 SAR      | 14        | 33      |         |
| 20,000 SAR or more     | 9         | 21      |         |

### Table 6

| Question                                                                 | SD | D   | N   | A   | SA  |
|-------------------------------------------------------------------------|----|-----|-----|-----|-----|
| I feel embarrassed of my child’s behaviors in public                     | 21 | 36  | 32  | 54  | 18  |
| I avoid participation in activities related to autism                    | 13 | 22.4| 19.9| 33.5| 11.2|
| I fear society’s perception if they discovered that my child has ASD     | 40 | 52  | 42  | 12  | 9   |
| I prefer NOT to share my personal experience with other ASD families     | 25.8| 33.6| 27.1| 7.7 | 5.8 |
| I believe that our society does not understand children with ASD’s situation | 53 | 44  | 19  | 29  | 14  |
| I prefer to visit clinics for my child’s appointments during off-peak hours to avoid meeting someone I know | 33.3| 27.7| 11.9| 18.3| 8.8 |
| I take decisions regarding my child that might be wrong because I am afraid of our society’s perception      | 0.9| 10.8| 14.7| 33.7| 31.2|
| I hide my child’s diagnosis so it won’t affect my other children’s future | 0.8| 12.1| 8.3 |
| I feel that my life will be better without a child with autism            | 38.9| 24.8| 11.5| 15.3| 9.5 |
| After my child showed signs of autism, I hesitated to begin the diagnostic process, fearing to face the truth | 37 | 36  | 37  | 39  | 9   |
| My other children feel inequity because they have a sibling with autism  | 23.4| 22.8| 23.4| 24.7| 5.7 |
| My child with autism has affected our vacations                          | 34.8| 15.4| 6.2 |
| My child with autism reduced my chances in getting a job or continuing my education | 28.2| 20.5| 22.4| 13.4| 13.5|
| I feel that my personal/practical life has been affected after my child’s diagnosis | 15.2| 19.6| 16.5| 34.8| 13.9|
The current work might suggest that in other countries, parents caring for children with ASD experience challenges that may impair their psychological adjustments. Raising a child with ASD needs a lot of care, including more than thirty hours almost every week. Many mothers are forced to quit their jobs to take care of their ASD child; this issue takes a huge toll on the economic burden of the family and exposes them to an additional tense circumstance [31].

In most cases, this is not the situation. In Saudi community, social support from the family, relatives, friends, as well as the government plays an important role in decreasing the psychological problems, including stigmatization among parents of ASD children. Moreover, the evolving social perception of ASD among the people in Saudi Arabia was a great support to the parents caring for autistic child. In the U.S., Martin [32] detailed suggestions for the improvement of knowledge about ASDs, including enhanced research works, augmented cooperation in ASD specialists, and increasing general attention of the autistic child and their parents. The author demonstrated that due to the increase in public awareness of autism in the U.S., there was a significant decline in the negative stigmatization among ASD parents.

The results of the present study demonstrated that most of the participants reported that they have noticed some abnormalities in their child and experienced felt stigma even before actual diagnosis. After the diagnosis, the parents reported that the felt stigma disappeared or diminished greatly. About 64.9% of the participants agreed to the question “I believe that our society does not understand children with ASD’s situation.” This might indicate that more efforts are required in different fields to enhance the public understanding of ASD in Saudi Arabia.

This finding was supported by Phetrasuwan and Miles [33] who investigated the various source of stress in mothers raising a child with ASD and analyzed the relationship between parenting stresses and disturbances in the psychological status of the caring mothers. They indicated that the most important cause of parenting stress among ASD caring mothers was the child behavioral symptoms and not the characteristic of the autistic child itself. Moreover, when the caring mothers were facing parenting stress, they would suffer from more depressive symptoms, which impact their well-being. They concluded that their research results have indicated the need for certain intrusions with ASD caring mothers to assist them control the behavior of their autistic child and then have more time and power to reduce depressive symptoms and have a better well-being.

The present findings indicated that 25.8% of the parents scored more than 3 in answering questions related to enacted stigma, whereas 74.2% did not experience enacted stigmatization being a parent of autistic child. This was much lesser than what was reported in the study of Farrugia [34] in Australia. All parents who participated in their research reported that they lost about half of their close friends because of the social effects of enacted stigmatization. Moreover, the study of Farrugia [34] revealed that almost all of the parents participated in the study reported enacted stigmatization related to the socially improper behavior of their ASD child.

Table 7
Response of parents to questions about enacted stigma.

| Question                                                                 | SD   | D    | N    | A    | SA   |
|-------------------------------------------------------------------------|------|------|------|------|------|
| My family feels ashamed of my child’s behaviors during social gatherings| 20   | 31   | 23   | 65   | 19   |
| My other children avoid going out with my child with autism in public    | 12.7%| 19.6%| 14.6%| 41.1%| 12%  |
| Others call my child with autism with names such as weird, impolite, mentally retarded, etc. | 37   | 44   | 25   | 32   | 6    |
| Others feel pity for me, or think less of me when they know I have a child with autism | 25.7%| 30.6%| 17.3%| 22.2%| 4.2% |
| Others feel pity for me, or think less of me when they know I have a child with autism | 36   | 28   | 28   | 47   | 17   |
| Others feel pity for me, or think less of me when they know I have a child with autism | 23.1%| 18%  | 18%  | 30%  | 10.9%|
| Others feel pity for me, or think less of me when they know I have a child with autism | 18   | 34   | 20   | 55   | 33   |
| Others feel pity for me, or think less of me when they know I have a child with autism | 11.3%| 21.2%| 12.5%| 34.4%| 20.6%|
| Others feel pity for me, or think less of me when they know I have a child with autism | 27   | 36   | 32   | 34   | 20   |
| Others feel pity for me, or think less of me when they know I have a child with autism | 18.1%| 24.2%| 21.5%| 22.8%| 13.4%|
| Others feel pity for me, or think less of me when they know I have a child with autism | 27   | 33   | 34   | 40   | 19   |
| Others feel pity for me, or think less of me when they know I have a child with autism | 17.7%| 21.6%| 22.2%| 26.1%| 12.4%|
| Others feel pity for me, or think less of me when they know I have a child with autism | 24.4%| 23.7%| 24.4 | 17.9%| 9.6% |
| Others feel pity for me, or think less of me when they know I have a child with autism | 63   | 40   | 31   | 14   | 6    |
| Others feel pity for me, or think less of me when they know I have a child with autism | 40.1%| 25.9%| 20.1%| 9.0% | 3.9% |
| Others feel pity for me, or think less of me when they know I have a child with autism | 29   | 44   | 34   | 28   | 15   |
| Others feel pity for me, or think less of me when they know I have a child with autism | 19.3%| 29.3%| 22.7%| 18.7%| 10%  |
| Others feel pity for me, or think less of me when they know I have a child with autism | 38   | 28   | 34   | 22   | 15   |
| Others feel pity for me, or think less of me when they know I have a child with autism | 27.5%| 21%  | 24.6%| 15.9%| 10.5% |
| Others feel pity for me, or think less of me when they know I have a child with autism | 32   | 36   | 38   | 28   | 19   |
| Others feel pity for me, or think less of me when they know I have a child with autism | 20.9%| 23.5%| 24.9%| 18.3%| 12.4%|
nature of ASD. A high level of felt stigma requires psychological intervention for the family to with this new situation. A higher level of enacted stigma suggests the need for their rights (individuals with ASD) and increased awareness in the society. It is recommended that further research is needed to be done in different centers in Riyadh and other regions of Saudi Arabia to investigate the prevalence of stigma in parents of autistic children.

Conflicts of interest statement

None.

Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijpam.2019.06.003.

References

[1] Levy SE, Mandell DS, Schultz RT. Autism. Lancet 2009;374:1627–38.
[2] Centers for Disease Control and Prevention, CDC Surveillance Summaries. MMWR Morb Mortal Wkly Rep 2007;56:1–28.
[3] Salman S. A study revealing the prevalence rate of autism in Saudi Arabia. In: Asharg Al-Awsat news; 2011.
[4] Baxter AJ, Brugha TS, Erskine HE, Scheurer RW, Vos T, Scott TG. The epidemiology and global burden of autism spectrum disorders. Psychol Med 2014;11:1–13.
[5] Johnson CP, Myers SM. American Academy of Pediatrics Council on children with Disabilities. Identification and evaluation of children with autism spectrum disorders. Pediatrics 2007;120:1183–215.
[6] Lincoln AJ, Courchesne E, Kilman BA, Elmasian R, Allen M. A study of intellectual abilities in high functioning people with autism. J Autism Dev Disord 1988;18:305–24.
[7] Szatmari P, Bartolucci G, Bremmer R, Bond S, Rich S. A follow-up study of high functioning autistic children. J Autism Dev Disord 1989;19:213–25.
[8] Gray D. Coping over time: the parents of children with autism. J Intell Disabil Res 2006;50(12):970–6.
[9] Baxter C. Investigating stigma as stress in social interactions of parents. J Ment Defic Res 1989;33:455–66.
[10] Volkmar FR, Chawarska K. Autism in infants: an update. World Psychiatry 2008;7:19–21.
[11] Goffman E. Stigma. Englewood Cliffs, New Jersey: Prentice-Hall Inc. USA; 1963.
[12] Becker G. Coping with stigma: lifelong adaptation of deaf people. Soc Sci Med 1981;15B(1):21–4.
[13] Hopper S. Diabetes as a stigmatizing condition: the case of low income clinic patients in the United States. Soc Sci Med 1981;15B:11–9.
[14] Jacoby A. Felt versus enacted stigma: a concept revisited. Soc Sci Med 1994;38:269–74.
[15] Nijhof G. Parkinson’s disease as a problem of shame in public appearances. Sociof Health Illn 1995;17(2):193–205.
[16] West P. The social meaning of epilepsy: stigma as a potential explanation for psychopathology in children. In: Whitman S, Hermann BP, editors. Psychopathology in epilepsy. New York: Oxford University Press; 1986.
[17] Gray DE. Perceptions of stigma: the parents of autistic children. Sociof Health Illn 1993;15(1):102–20.
[18] Chan KKS, Lam CB. Self-stigma among parents of children with autism spectrum disorder. Res Autism Spectr Disord 2018;48:44–52.
[19] Al-Saleh SM, Al-Hifthy EH, Ghazziuddin M. Autism in Saudi Arabia: presentation, clinical correlates and comorbidity. Transcult Psychiatry 2009;46:340–7.
[20] Salhia HO, Al-Nasser LA, Taher LS, Al-Khathami AM, El-Metwally AA. Systemic review of the epidemiology of autism in Arab Gulf countries. Neurosciences 2014;19(4):291–6.
[21] WHO. Mental health Mental health disorders. Available at: http://www.who.int/mental_health/management/depression/definition/en/. [Accessed 22 July 2012.]
[22] American Psychiatric Association. Diagnostic and statistical manual of mental disorders: Dsm-5. Amer Psychiatric Pub Incorporated; 2013.
[23] Park J, Hoffman L, Marquis J, Turnbull AP, Ponton D, Mannan H, Wang M, Nelson L. Toward assessing family outcomes of service delivery: validation of a family quality of life survey. J Intell Disabil Res 2003;47(4/5):367–84.
[24] Samadi SA, McConkey R. Autism in developing countries: lessons from Iran. Autism research and treatment 2011;4:14359–70.
[25] Alqahtani MM. Understanding autism in Saudi Arabia: a qualitative analysis of the community and cultural context. J Pediatr Neurol 2012;10(1):15–22.
[26] Benson P, Karlol KL, Superstein GN. Maternal involvement in the education of young children with autism spectrum disorders. Autism 2008;12(1):47–63.
[27] Lai WW, Goh TJ, Oei1 PST, Sung M. Coping and well-being in parents of children with autism spectrum disorders (ASD). J Autism Dev Disord 2015;45:2582–93.
[28] Al Towairqi W, Alosaimi W, Al Zaidi S, Helmy FF, Al Sherif E. Depression among mothers of autistic spectral disorder children. Int J Contemp Pediatr 2015;2(2):119–26.
[29] Al Eibat MH, Robert AA, Al Saeed AH. Mood problems of mothers with disabled children in Saudi Arabia. Saudi Med J 2010;31(10):1161–5.
[30] Dehnavi RS, Malekpour M, Faramarzi S, Talebi H. The share of internalized stigma and autism quotient in predicting the mental health of mothers with autism children in Iran. Int J Bus Sci Soc 2011;2(20):251–9.
[31] Dehnavi SR. Stigma in mothers with autism spectrum disorder. Exceptional Education 2015;7(135):72–83.
[32] Martin DM. The ever-changing social perception of autism spectrum disorder in the United States. Project completed in partial fulfillment for graduation from the honors college of East Carolina university. 2013. Available at: https://libres.uncg.edu/r/llisting.aspx?id=14091.
[33] Phetrasuwan S, Miles MS. Parenting stress in mothers of children with autism spectrum disorders. J Spec Pediatr Nurs (JSPN) 2009;14(3):157–65.
[34] Farrugia D. Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. Sociof Health Illn 2009;31(7):1011–27.
[35] Kinnear SH, Link BG, Ballan MS, Fischbach RL. Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families’ lives. J Autism Dev Disord 2016;46(3):942–53.