Parents´ Perceptions of the Oral Health-related Quality of Life of their Autistic Children in Iran

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Objectives: The aim of this study was to evaluate parents' perception of the oral health-related quality of life (OHRQoL) of autistic children in Iran, and to determine the quality of life of their families in relation to child' oral health status. Study design: 70 families with at least one child with autism, and 70 families with normal children were enrolled. Parents' perceptions of the OHRQoL of children were assessed using pre-validated PedsQL oral health scale questionnaire. PedsQL Family Impact Module questionnaire was also used to evaluate the impact of having an autistic child on the quality of life of their families. Both of the questionnaires were filled by parents. Parents of children with autism spectrum filled a separate questionnaire for the sibling of the autistic child. In the control families, child-reported PedsQL oral health scale questionnaire was also filled by the child himself/herself. Mann- Whitney U-test, and chi-square were used for statistical analysis. Results: There was a significant difference in the mean total score of PedsQL oral health scale questionnaire between autistics and controls. Parents of normal children reported more oral problems ($p<0.001$). There was not a significant difference in the mean total score of PedsQL Family Impact Module questionnaire between the families of autistics and controls in the last 7 and 30 days. Conclusion: According to parents' point of view, oral health-related quality of life of autistic children was better than normal children. However, parents of autistic children had more problems in the social and communication issues.

Key words: Autism, Quality of life, Oral health

INTRODUCTION

Autism is a neurodevelopmental problem of childhood.[1] Patients usually have impaired social communication, interaction and restricted or stereotyped behavior[2]. Approximately 1 in 68 children has been identified with autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. ASD is about 4.5 times more common among boys (1 in 42) [3]. Genetics and autoimmune factors have been known as its etiologic factors. Potential motor, sensory, and intellectual disabilities of autistic children usually have negative impact on their oral health performance.

Tongue thrust, bruxism, and lip biting are also more commonly seen in autistic children [1]. In addition, some studies have reported higher prevalence of caries experience; gingivitis and unmet needs of autistic children [4]. Poor oral health can lead to eating and speech difficulties, oral pain, sleep disturbances, and decreased self-esteem. These will ultimately result in poor quality of life (QoL).

Health–related quality of life of autistic children has been studied extensively[1,5], whereas there is little data available on the oral health status of the children with ASD. On the other hand, these studies have contradictory results [4,6]. Moreover, to the best of our knowledge, no study has been done on the oral health-related quality of life of autistic children in Iran.

Parents have been used as judges of OHRQoL of autistic children in previous studies[7-10]. Considering the parents as the apt proxies of children with chronic diseases, their role in caring for autistic children becomes even more vital. The aim of the present study was to evaluate parents' perceptions of the oral health-related quality of life of their autistic children in Mashhad (Iran). Moreover, the impact of having an autistic child on the quality of life of their families is investigated.

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MATERIALS AND METHOD

This cross-sectional study was performed in Mashhad, Iran in 2014. Ethical approval was obtained from the regional ethical committee of the Mashhad University of Medical Sciences. A written informed consent form was signed by all participants or their guardians. A total of 70 families who had at least one child with autism spectrum were enrolled in the study. All the autistic children were in the mixed dentition stage. Children with autism suffered from other diseases that influenced dental caries, and also patients with a history of oral prophylaxis in the last 6 months were excluded from the study. The diagnosis of autism was initially done by a psychiatrist.

70 families with healthy child/children in the same age range served as control. Individuals who had undergone antibiotic or anti-inflammatory therapy in the last 6 months were excluded. Children with diagnosed systemic diseases or syndromes were also excluded from the study.

Demographic data including patients' age, sex, and parents' level of education were recorded. Parental perceptions of the oral health-related quality of life of children were assessed using pre-validated PedsQL oral health scale questionnaire. In addition, PedsQL Family Impact Module questionnaire was used to evaluate the impact of having an autistic child on the quality of life of their families. Both of the questionnaires were standardized for 8-12 year old children. The two questionnaires were administered in local language and validated using Mapi [11] method. Initially, two independent translations of the original questionnaires were produced by two professional translators, who were native speakers of the Persian language and fluent in the English language. Then a reconciled language version of the questionnaire was produced on the basis of the two forward translations. Then, a native speaker of English language who was fluent in Farsi produced a backward translation of the questionnaire. The produced questionnaire was compared with the original one. In case of discrepancies, changes were made in the reconciled translation in the Persian language. Subsequently, Persian language version of the questionnaire was produced. Finally, the questionnaires were reviewed by 6 orthodontists and one psychologist for getting feedback.

PedsQL oral health scale questionnaire included 5 domains: Oral symptoms, toothache, gingival pain, gingival bleeding during tooth brushing, esthetics, and functional limitations. Parents rated the items on the 5-point Likert scale ranging from zero (never) to four (every day or nearly every day). The score of the questionnaires ranged from 0 to 500 for PedsQL oral health scale questionnaire.

PedsQL Family Impact module questionnaire included six items in overall health, five items in emotional well-being, four items in social well-being, five items in cognitive health, three items in communicational health, five items in family concerns about their children, three items in activities, and five items in familial issues about their children. The items of this questionnaire evaluate the occurrence of some situations in the last 7 and 30 days. The score of the questionnaire ranged from 0 to 3600. The higher the score of the questionnaire, the better the oral health-related quality of life is.

The score of each question was reversed according to the original English version, such that 100 represented never, and 0 represented for nearly every day. Mean score of each domain was calculated and compared between the two groups.

The two questionnaires were filled by parents of children in both groups. Parents of children with autism spectrum filled a separate questionnaire for the sister/brother of the autistic child. In the control families, child-reported PedsQL oral health scale questionnaire was also filled by the child himself/herself.

Total score of PedsQL oral health scale questionnaire was compared between autistic children and their normal counterparts (control), and autistic children and their normal siblings.

Child-reported vs parent reported scale was also compared. Total score of PedsQL family Impact Module was also compared between the families with autistic children and control group.

Statistical analysis was performed by using SPSS version 16.0 (SPSS Inc., Chicago, USA).Correlation between the parents' educational level and each domain of the questionnaires was also evaluated. Mann- Whitney U-test, chi-square, and spearman correlation tests were used for statistical analysis. $P<0.05$ was set as significant.

RESULTS

70 families with an autistic child and 70 families with healthy child/children filled the questionnaires in this study. Table 1, shows the demographic characteristics of participants. Mann-Whitney test did not reveal a significant difference between the two groups regarding age of patients. However; chi-Square analysis showed a significant difference in gender of the two groups ($P= 0.002$).

Contrary to mothers' educational level, there was a significant difference in fathers' educational level ($P< 0.001$) between the two groups.

Table 1. Demographic characteristics of the participants and their parents' educational level

	Normal children	Autistic children	P-value
Age			
8-10 years	(9.82%)58	(7.75%)53	0.35
11-12 years	(1.17%)12	(24.3%)17	
Total mean	091.±45.9	36.1±9.7	
Sex			
Girls	(44.3%)31	(20%)14	0.002
Boys	(755.%)39	(80%)56	
Fathers education level			
illiterate	(1.4%)1	(41.%)1	P<0.001
Primary	(24.3%)17	(68.%)6	
Intermediate	(628.%)20	(618.%)13	
Diploma	(137.%)26	(40%)28	
Above Diploma	(7.1%)5	(31.4%)22	
Mothers educational level			
illiterate	(1.4%)1	(41.%)1	0.051
Primary	(117.%)12	(14.3%)10	
Intermediate	(725.%)18	(117.%)12	
Diploma	(50%)35	(147.%)33	
Above Diploma	(75.%)4	(20%)14	

Mean score of PedsQL oral health scale questionnaire of the two groups is shown in table 2. There was a significant difference in the total score of PedsQL oral health scale questionnaire between the autistic and normal children. (P< 0.001). Table 3, demonstrates the scores of PedsQL family Impact Modules questionnaire of the two groups for the last 7 and 30 days. Autistic children had significantly more problem in social (P= 0.027) and communication (P= 0.004) domains compared to normal controls.

There was not a significant correlation between the parents' level of education and total score of the PedsQL Family Impact Module questionnaire of the autistic children for the last week (P=0.43 for fathers, P=0.29 for mothers) and month (P=0.57 for fathers, P=0.68 for mothers). Moreover, significant correlation was not found between the total score of the PedsQL Family Impact Module questionnaire of the autistic children and patients sex (P=0.42 for the last week, P=0.27 for the last month), or age (P=0.49 for the last week, P=0.43 for the last month).

13 siblings of autistic children with a mean age of 9 years old participated in the study (8 sisters, 5 brothers).Mann-Whitney test did not reveal a significant difference in the oral health-related problems of autistic children and their healthy siblings according to their parents report (Table 4). Parents of healthy children reported more oral-related problems than their own healthy children (Table 5).

Table 2. Comparison of the mean score of the PedsQL questionnaire between the normal and autistic children

	Normal children Median(IQR)	Autistic children Median(IQR)	P-value*
I have tooth pain	50(25)	100(50)	0010.>
I have tooth pain when I eat or drink something hot, cold, or sweet	50(50)	100(50)	0010.
I have teeth that are dark in color	100(50)	100(31.25)	320.0
I have gum pain	100(25)	100(0.00)	0480.
I have blood on my toothbrush after brushing my teeth	75(50)	100(50)	134.0
Total score	375(56.25)	425(125)	001.0>

*Mann-Whitney test

IQR: Interquartile range

Higher scores indicate better HRQoL.

Table 3. Comparison of the scores of PedsQL family Impact Modules questionnaire of the two groups for the last 7 and 30 days.

	Parents of normal children Median(IQR) (7 days)	Parents of autistic children Median(IQR) (7 days)	P-value*	Parents of normal children Median(IQR) (30 days)	Parents of autistic Children Median(IQR) (30 days)	P-value*
Physical problems	512(181.25)	475(250)	804.0	475(200)	450(256.25)	963.0
Emotional problems	400(131.25)	375(256.25)	2290.	375(156.25)	362(225)	7290.
Social Problems	325(125)	325(181.25)	436.0	350(100)	300(175)	0270.
Cognitive Problems	400(200)	450(156.25)	1480.	400(150)	425(181.25)	4410.
Communication problems	250(125)	175(175)	145.0	225(106.25)	150(181.25)	0040.
Anxiety	300(181.25)	350(250)	3510.	275(162.5)	300(250)	7560.
Daily activities	175(75)	200(156.25)	4370.	175(100)	175(100)	9720.
Family relationships	400(156.25)	450(181.25)	0820.	400(156.25)	400(200)	398.0
Total	2812(918.75)	2600(1481)	9670.	2755(881.25)	2400(1181.25)	532.0

*Mann-Whitney test
IQR: Interquartile range
Higher scores indicate lower problems.

Table 4. Comparison of PedsQL oral health scale questionnaire score of the autistic child with their normal siblings

	Siblings of autistic child Median(IQR)	Autistic child Median(IQR)	P-value*
I have tooth pain	100(37.5)	100(50)	83.0
I have tooth pain when I eat or drink something hot, cold, or sweet	100(50)	100(50)	73.0
I have teeth that are dark in color	100(62.5)	100(31.25)	38.0
I have gum pain	100(0.00)	100(0.00)	96.0
I have blood on my toothbrush after brushing my teeth	50(50)	100(50)	18.0
Total score	425(137)	425(125)	0.43

*Mann-Whitney test
IQR: Interquartile range
Higher scores indicate better oral health status.

Table 5. Comparison of the scores of parent-reported vs child- reported PedsQL oral health scale questionnaire

	Normal children Median(IQR)	Parents of Normal children Median(IQR)	P value*
I have tooth pain	75/23±50.77	63/22±35.65	0020.
I have tooth pain when I eat or drink something hot, cold, or sweet	91/26±10.77	76/27±14.67	0340.
I have teeth that are dark in color	91/18±14.87	33/24±42.81	2390.
I have gum pain	80/20±57.83	73/25±71.85	141.0
I have blood on my toothbrush after brushing my teeth	69/23±00.75	49/30±21.73	8860.
Total score	64/62±31.400	67/70±86.372	0090.

*Mann-Whitney test
IQR: Interquartile range
Higher scores indicate better HRQoL.

DISCUSSION

The present study was designed to evaluate the parents' perceptions of the OHRQoL of autistic children. Moreover, family impact of an autistic child has been investigated in current study.

In present study, maternal education did not show a significant difference between the two groups, while fathers of autistic children had significantly higher educational level. Better socio-economic status of families with an autistic child had been reported in a previous study [12].

Parents of normal children reported more oral health-related problems compared to autistic patients. This finding was similar to some other studies [8,12]. This difference could be due to the either limited ability of autistic patients in describing their problems to their parents [13,14], or the business of the parents of autistic children and lack of the attention towards oral health problems of their affected child. It should also be reminded that autism spectrum of our patients was of low severity and this may contribute to the lower problems reported by their parents. Sheldrick et al [15] reported that parental perception of the oral health-related quality of life of the autistic children was different with their affected child. Therefore, parents' reports cannot reflect the exact quality of life of the autistic children.

Considering the impaired ability of autistic children in communication and reporting their own problems, regular dental visits are recommended for these patients.

In present study, parents of children with autism disorder reported more problems in social and communicatory domains in the last month compared to normal families. This shows that parents of autistic children had problems in communication with others or their social activities because of their child's oral -health related problems.

Tunali and Power [16] reported that many of the mothers of the autistic children had been taken time off the work. These mothers had less time for themselves and received less emotional support from their husbands. Considering these problems, more social support of the families of autistic children seems inevitable. Garrido et al [17] reported that the higher the verbal skills of the autistic children, the higher the quality of life of autistic children would be. Pani et al [8] showed that the parents of autistic children reported more problems in the fields of parental emotions and financial issues.

There was not a significant difference between the quality of life of the autistic children and normal siblings perceived by their parents. This was in contrast to the Pani et al´s results[8], who reported lower oral health-related quality of life of autistic children in comparison to their siblings. Considering the limited number of siblings of autistic children (13 individuals) in our study, the results of the present study should be interpreted cautiously.

Parents reported more problems in the oral health-related quality of life of their normal children compared to the children's own perception. This can be due to the limited ability of normal children in remembering their own oral health-related problems.

Considering the limited number of our studied groups, the results of the present study should be interpreted cautiously. In addition, it should be reminded that all the patients with autism spectrum were diagnosed to have a low- severity disorder in our study, which may influence the findings of the present investigation. Future studies with larger sample sizes in other nations on moderate to severe forms of the disease are strongly recommended.

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