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The experiences of families raising autistic children: A phenomenological study

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Abstract:

BACKGROUND: Conditions and needs of autistic children have impacts on both the children and the family members who have crucial roles in raising the child. The prevalence of autism is increasing, and this fact makes it necessary to focus more on experiences of parents who have children with autism spectrum disorder (ASD). Hence, this study aimed to reflect the experiences of parents who have autistic children.

MATERIALS AND METHODS: The present study was a qualitative research with phenomenology approach which was conducted using content analysis approach. Participants were 14 parents with ASD children in Ahvaz, and they were included based on purposive sampling method. To gather the required data, semi-structured interviews were formed. Data analysis was performed by Colaizzi's seven-step method.

RESULTS: Fifty-four conceptual codes were extracted from interviews of ASD children parents. Parents of these children had two main experiences: first family related and second education and treatment problems. Family problems included three categories (financial, psychological, and family relationships). Education and treatment was categorized into three (schooling, transporting, and quality in facilities).

CONCLUSIONS: Problems mentioned by parents of autistic children highlight the need for providing training and counseling services as well as emotional supports from both society and government. Planning and implementing supportive plans empower parents to strategically face problems and eventually improve their life quality and mutual understanding.

Keywords:

Autism spectrum disorder, parents, qualitative research

Introduction

Autism spectrum disorders (ASDs) are a group of pervasive developmental disabilities known as the most prevalent, serious, and yet unknown disorders during childhood.^[1,2] Children with ASD are identified by a range of problems in their emotional, physical, and interactional skills, daily routines and playing, language development and natural speech, as well as imitative ability.^[3] ASD symptoms typically are apparent within the 1st year of age;

however, certain clinical diagnosis does not happen before age three.^[4] Although there is little information about the certain cause of ASD,^[5] some studies have found that ASD etiology is not just characterized by a unique factor instead environmental and genetic risk factors, or a combination of both factors, play roles in ASD etiology, however, just recently it is agreed that ASD is mostly caused by genetic factors.^[6]

In the last two decades, the prevalence of ASD has remarkably increased.^[7] It is estimated that ASD prevalence in 2014 was 2.24% which showed three times more than

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2000 estimation.^[8] In Iran, ASD prevalence among 5-year olds is estimated at 6.26 in 10,000.^[9]

ASD can be seen among all races, ethnics and across all socioeconomic groups. The prevalence of ASD among boys is four times higher than girls,^[10] but in girls, ADS is more comorbid with some diseases like epilepsy.^[11] Increasing prevalence of autism requires more focus on experiences of these children's parents.^[12] Special needs and conditions of autistic children influence not only the child but also family members who play roles in child development.^[13] Families with ASD children are facing a wide range of stressful and challenging conditions such as unexpected disabilities, child's harmful behaviors, and behavioral disorders, difficulty in getting services, dilemmas in finding an effective treatment, and finally, restricted and dull interaction with other members of the society.^[14]

The most stressful factor that parents with autistic children have experienced is limited acceptance of autistic behavior by society members and failure to receive social support.^[15] Lack of such supports increases parents' stress level.^[16] A fairly large number of studies confirm that mothers of autistic children face more challenges than mothers of other children with special needs, and have lower cognitive well-being^[17,18] as well as suffer from more stress.^[19]

A child with ASD may lead to several negative effects; parents feeling guilty, mothers quitting jobs to take care of the child, a low marital life quality, parents' depression and isolation feelings due to lack of time to spend for their personal needs.^[20] In addition, these disorders also insert financial burden on families to cure and rehabilitate children.^[21] In Asian countries, the cost of treatment and care for such children is about 70% of an officeholder.^[22] It is obvious, without instructing and supporting families, their resources (money, energy, time, and spirit) may decrease day by day.^[14]

Based on what went on, identifying ASD parents' problems and needs is crucial due to the impacts of ASD on children and their families, increasing prevalence of the disease, and the fact that autism is a lifetime disorder. Furthermore, Khuzestan province and its capital city, Ahvaz, is one of the autism centers in Iran, yet no comprehensive study has been done on these issues. Therefore, this study was conducted for the first time in Khuzestan province, although it was previously conducted in some other provinces of Iran. Considering multicultural context of this province, high prevalence of ASD, and scattered ASD centers, this study aimed to reflect the Experiences of families with ASD children in Ahvaz.

Materials and Methods

This study was a qualitative research with phenomenology approach which was conducted using content analysis approach.

Participants

Participants were 14 parents with ASD children in Ahvaz. Participants were included based on purposive sampling method, and they were added until data saturation point was obtained. Inclusion criteria were: living autistic child with family, the ability to speak Persian, and consent to participate in the study. Exclusion criteria also included: The family has another autistic child and the child has another physical or mental illness.

Data collection

To gather the required data, semi-structured interviews were formed. Participants answered questions such as: "Do you have financial problems because of your child's illness?" "Do have affected care of your child on marital status?" or "Do you have depressing during in this time?". The time and place of the interviews were confirmed by the participants; in average, each interview lasted for 90 min ranging 60–120 min regarding each participant's condition. They were informed about the aims of the study, and participants' consent forms were collected. All the interviews were recorded and completed during 3 months (September 22 to December 20, 2018).

Data analysis

All the interviews were transcribed by two of the researchers; the data were analyzed through seven-step Colaizzi's method. (1) Manuscripts of interviews were read several times by research team, (2) Significant statements which were directly related to research subjects were identified, (3) Relevant meanings were extracted and formulated from significant statements, (4) Identified meanings were clustered into categories and themes, (5) An exhaustive description was developed about experiences of families with autism children (6) Fundamental structure of the studied phenomenon was produced, and (7) Fundamental structure verification was sought through asking participants about final categorizations.^[23]

In addition to check the trustworthiness of the data Lincoln and Guba's four-criteria (credibility, dependability, confirmability, and transferability) was used.^[24] The validity of findings increased by means of Investigator Triangulation.

Ethical issues

When the study received ethics code (IR.AJUMS.REC.1397.591) from the Research Ethics Committee of

Ahvaz Jundishapur University of Medical Sciences, the researchers were introduced to associated places (ASD care centers, clinics, and households of children with ASD). The participants were informed about the aims of the study and confidentiality of interviews.

Results

The following sections present information related to participants' related demography as well as main themes and sub-themes.

Participants' demographic information

Participants' ages ranged from 20 to 40. They all had office jobs. Half of the parents had two or three kids. Most of them had average and above-average financial status.

Themes

In this study, six subthemes were extracted from two main themes based on parents views and included family problems (financial problems and resulting obstacles, parents' psychological and mental problems, marital problems and siblings' relationships), ASD

children's education and treatment (problems related to autistic children's education, parents and children transportation problems, and clinic-related problems). Codes (conceptual units) related to each theme are presented in the following table.

Family problems

Totally, parents of children with ASDs mentioned 27 problems which were classified into three subthemes of financial problems and resulting obstacles, parents' psychological and mental problems, marital problems, and siblings' relationships [Table 1].

Most parents mentioned high treatment prices as the most serious problem. Sometimes treatment process was negatively influenced because they could not afford to pay it. Some complain of the costs and insurance policies: "Costs are absolutely pressing us, insurances just cover some parts of the treatment cost" (Participant 3). Other parent mentions a point: "The costs are too high. We have to cut off our other costs to pay for the treatment. We do not spend any more for ourselves; we cannot" (Participant 6)! Another parent limits services as much as possible: "To tell the truth, I cannot afford

Table 1: Family problems in experienced life of Autism spectrum disorder children parents

Theme	Categories	Codes
Family problems	Financial problems and consequential challenges	High costs of different treatment classes needed by child (especially severe autism cases) Insurance policies do not completely cover ADS treatment programs The cost of transportation to other cities for some treatment classes Relying on inside-home practices due to high cost of training classes and transportation Unwillingness to have another pregnancy due to financial problems Lack of social support resulting from financial inability to travel to parents' hometown
	Parents' mental and psychological problems	Parents' depressive feelings about the child with ASD Parents' suicide intentions resulting from severe depression levels Parents' Resisting against accepting their child's disease Rage Feeling because of slow progress of treatment Feeling disability in continuing child's treatment program and disappointing in effective treatment Parents' doubts resulting from lack of knowledge about the disease Feeling unhappy due to worries about the child's condition Being worried about nursing of the child in their absence Feeling guilty about not doing enough to prevent the disease Feeling guilty about not doing enough in treatment process Not visiting a psychologist due to their limited time Not visiting a psychologist due to their friends' negative experiences after sedative tablets Unwillingness to have a second pregnancy due to their fear of giving birth to another disabled child Not caring about spouse due to losing concentration or increasing stress of taking care of the child
	Marital problems and siblings' relations	Marital conflicts because of fatigue related to taking care of the child Intention to separation and divorce resulting from child's disorder and lack of social support for the family Intention to separate because husband is accusing mom as responsible for the child's disorders Ignoring typically developing child because of rigorous and excessive care for the child with ASD A typically developing child's jealousy toward the child with ASD who receives more attention Child's aggressive behavior because the child with ASD receives more attention Unwillingness of the typically developing child to play with the child with ASDs

ASD=Autism spectrum disorder

to send him to speech therapy class; I do the training at home" (Participant 2).

All participants had experienced stress and anxiety feelings. Some of them believed they cannot be happy anymore due to current concerns. Such depressions affected some parents so deeply that they could not pass denial phase. In addition, suicide intention was mentioned by some other interviewees. Some parent feels he even does not have time for himself: "Most of the time I feel depressed but I never had time to visit a psychologist" (Participant 3). Other one remembers: "It is difficult for his mother to accept her child's disease. When our son was two, she was under treatment for her depression" (Participant 7). One of interviewees basically denies problem in public while worries for his wife as well as himself: "I hate the name autism. Wherever I go they say it's autism. I say no. My child has delay in language. My wife is depressed. She says "I want to kill myself." If I had not stopped her, she could have killed herself. One of my colleagues had a sick child. She went to a psychologist. She got pills. After a while her hands had tremors. I got scared. If I go to a psychologist, I will be affected to" (Participant 5).

Respondents believed child's disorders ended in emotional distance between parents and problems in marital life. Most mothers said they spend all their time and energy for their child with ASD and they have nothing more to spend for the typically growing child such as: "Most of my time is for this child (the autistic one), I have no time to play with the other one" (Participant 3). Some forget about their simple daily jobs: "Anyway, when I am doing my child's daily routines, I lose concentration. Well, for example, after a while you cannot iron your husband's clothes" (Participant 1), While they cannot take a break: "My husband says leave one of the children with me, and you and the other one go to your mom's home for a month, but I am scared to do it" (Participant 5).

Education and treatment problems

Twenty-seven problems were identified as education and treatment problems of children with ASD including problems related to autistic children's education, parents and children transportation problems, and clinic-related problems [Table 2].

As children with ASD have certain stereotypes, and their learning requires more time compared to typically developed children, parents reported problems related to ASD children's education. Although some parents mentioned the need of having a school for ASD children, some parents believed that such schools prevent children from learning social communication skills. A participant says: "I registered him in a private school.

After 20 day teachers asked me to go to school. They said your son does not sit on his chair in the class and distracts other students. If he has problems take him to a psychologist" (Participant 5). Other parent recalls: "Once I took him to the kindergarten, the staff didn't let him in. They said your child has stereotypical behaviors. Other children may learn negative behaviors from him. In case of other families notice this, they will not bring their children to this kindergarten; as a result, we have to close the kindergarten" (Participant 3). A mother does not believe in special schools: "In an autism school, it is not possible for children to learn how to communicate with others because all of them are autistic children. Moreover, my child will learn other negative stereotypical behaviour like screaming" (Participant 1). Finally, we can hear from some other parent: "I do not allow my child go to a school where autistic children go. I will pay more money if I have to but I take him to an ordinary private school, because public schools do not register them at all" (Participant 7).

One of the problems that parents of children with ASD suffer from is transportation. Parents were dissatisfied with school buses which are over full. Some other mentioned restlessness and disquiet of the child in the buses as the other problem. A parent mentions: "My child does not sit in the bus. He is restless. Other mothers ask me: what is wrong with your kid? I don't send my child to school by bus because I have seen how drivers are treating children, it is very improper. In addition, kids are piled in the bus about twice of its capacity. All of these kids are aggressive; and I cannot send my child with them, no way. As a result, I have to get a taxi; and it is expensive" (Participant 3). A mother has a point: "As long as his speech has not improved I won't send him with strangers, because they may mistreat him or hurt him and he cannot tell me. There are things in Tehran (the capital city) that you cannot find here. There are special advantages in parking places for parents of ASDs children. I was fined several times because of parking place" (Participant 6).

Another point that parents mentioned was improper conditions of the clinics. Almost all participants were dissatisfied with quality of services in the clinics. Some complained trainers: "His tutors shout at him, this causes the child suffer from personality problems in the future. You have to search a lot to find a good-tempered tutor" (Participant 2). And others were expecting more from related facilities: "I am not satisfied with the facilities, neither private nor public facilities provide appropriate services. They don't have dark rooms. For such children they should have at least one dark room" (Participant 3), or: "It is very crowded here and children have behavioral problems. Once I suggested them to provide a playing room. So we can stay over there with our kids, when kids are restless. As a result,

Table 2: Education and treatment problems in experienced life of autism spectrum disorder children parents

Theme	Categories	Codes
Education and treatment problems	Problems related to children's education	Lack of autism school in some cities
		High tuition of autism school
		Autistic children's unwillingness to interact in autism schools
Learning more stereotype behaviors (mostly inappropriate) from other children in autism schools		
Low educational quality of autism schools since children with different levels are placed in one class		
Low educational quality of autism schools since these schools just care about babysitting the children not training them		
Failure in learning for autism children who registered in autism schools		
Disturbance of autism children in ordinary preschools due to noise		
Not allowing autism children to register for some kindergartens and schools		
Non-professionally proper treatment of kindergarten and marking children as retarded		
Transportation problems for parents		Increase of stereotype behaviors among autistic children due to instructors' improper behavior
		Low speed of learning for children
		Far distance between autistic children schools and other children's schools
		Not using public transportation due to autistic children's stereotype behaviors and their restlessness
		Dissatisfaction with vehicles which are considered for taking autistic children to school
		Parents' stress for leaving children alone with driver in vehicles
		Drivers' refusal to take autistic children to clinics without their parents
Clinics problems		Lack of parking slots around clinics for vehicles taking autistic children
		Reduction of parents' resting time due to taking children to clinics and not using clinics' vehicles
		Signs of joints' pain and orthopedic problems in mothers due to moving children on the way to clinics and school
		Parents' dissatisfaction with provided services
		Crowded public clinics in addition to improper regulation and planning for classes
		Very short visit times in public clinics
		Improper behavior of some instructors in public clinics
Difference among clinicians' performance in public and private clinics		
Concentration of private clinics in metropolises and poor access to these centers for families living in other towns		
		training classes (such as speech therapy, Occupational therapy, ...) are scattered in different clinics

our children do not make noise and cause problems for other classes (and they did nothing)" (Participant 6). At last they try to compare it with other cities: "Compared to Tehran and other cities, Ahvaz facilities are in poor conditions. Hydrotherapy and play therapy places are very limited. The child's conditions do not improve in these contexts" (Participant 5).

Discussion

The first problem that parents of ASD in this study suggested was financial problems. Studies have concluded expenses of families for children with ASD are up to three times more than typically developed kids as well as mentally and physically disabled children at the same age.^[25] For participants, treatment costs and lack of insurance support were the biggest financial challenges. Sharp argues in his study that even if insurance companies cover medical tests related to diagnosis, they never pay for therapies for behaviors.^[26]

It is suggested that financial supports from government and charities address such families, As Koohkan *et al.*

found in a qualitative study, the role of various charities is very significant in access to financial support for families of sick children.^[27]

In addition, providing a more comprehensive insurance coverage may reduce the total financial burdens of the families. Among all mental conditions that parents mentioned depression, anger, inability, suffer, and guilty feeling were the most repeated. The results of Poretamad *et al.* show that mothers with autistic children experience higher parental stress levels and this increases their anger.^[28] As a response, it is suggested that autism schools and clinics may help families of children with ASD to face their conditions via setting training courses for decreasing psychological pressures, training effective confrontation, training life skills, and at the end managing anger as well as stress.^[29] Dadipour *et al.* Also considered necessary the role of training courses and counseling for the mental health of families and their coping with the problems of the sick child.^[30]

One of the results of the present study about the marital conditions of parents was couples' intention to divorce.

Tensions of raising autistic children, and their behavior problems, increase the possibility of divorce.^[31]

In line with the results of this study, Hartley *et al.* found that divorce rate among parents with autistic children is twice as much as it is for parents with normal children.^[32] It seems provision of family consulting can help to restore and develop parents' relation.

Going to school can be considered as the beginning of a new kind of partnership between children with ASD and their parents to deal with special needs of family.^[33] The results of the present study revealed lack of enough autism schools and low educational quality in these schools are pressing problems for training autistic kids. According to Balance *et al.*, parents with ASD children are always concerned about lack of necessary educational and health services in autistic schools.^[34]

Another identified problem for parents in this study was using public transportation systems for autistic children and their presence in public. Although parents mostly pointed that conditions in other cities, namely Tehran, the capital, are better for children with ASD, the results of previous studies done in Tehran also suggested public transportation as one of the problems.^[15]

It seems that allocating school buses and experienced drivers for transporting these children would be effective if required standards were considered, so that both parents and children benefit from relatively peaceful environment in vehicle as well as safety and security of the conditions. Parents questioned the poor quality of the services presented by the clinics. Ahmadi *et al.* in 2011 compared the needs of families with ASD children in Iran and Canada. Based on their study, there were three most common needs in special children's families: continuous services, professional expertise, and professional understanding.^[35] These three and other needs in ASD remind us the crucial role of service quality in ASD children. It seems some comprehensive clinics need to be considered and established to provide a wide range of services for special children to meet their needs. Quality development programs may drive these facilities in delivering effective services along with other aspects of quality.

It is obvious that most of the identified problems and needs are not merely related to health field but address other sections; hence, health strategies do not solve the problem by itself. That is, problems, challenges, and meeting the identified needs and expectations of parents of children with ASD require multisector communications and cooperation.

Limitations of the study

Among the limitations of the present study was unwillingness of some families to mention their experience and problems. To encourage them to interview, the interviewers explained that their cooperation and participation may greatly help to identify their problems and try to solve them. In this way, they cooperated more consciously. Furthermore, this study was done in centers of Ahvaz; hence it needs to be cautious to generalize the results. Indeed, qualitative research may not be generalized. Similar research needs to be conducted in other provinces of Iran, then through a meta-analysis reveal the experience and general problems of these families for metropolitan and health policymakers.

Conclusions

Parents of ASD children had two main experiences: first family related and second education and treatment problems. Family problems included three categories (financial, psychological, and family relationships). Education and treatment was categorized into three (schooling, transporting, and quality in facilities). Health policymakers and other stakeholders need to support these families at least in three contact points: at home, school, and ASD facilities. Problems mentioned by parents of autistic children highlight the need for providing training and counseling services as well as emotional supports from both society and government. Planning and implementing supportive plans are necessary to empower parents to strategically face problems and eventually improve their life quality and mutual understanding. Considering the wide range needs of these families, it takes a multisector cooperation in order to provide them proper services and alleviate some of the burdens for families with ASD children.

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Conflicts of interest

There are no conflicts of interest.

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