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What do parents of children with autism spectrum disorder think about their quality of life? A qualitative study

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Abstract:

BACKGROUND: Living with children with autism spectrum disorder (ASD) can affect different aspects of parents' physical and mental health and quality of life. This study aimed to identify parents' perceptions of their quality of life and factors influencing such perceptions and investigate how they cope with difficulties in their daily lives.

MATERIALS AND METHODS: This study was conducted using a qualitative research design to gain insight into how children with ASD may influence their parents' quality of life. A total of 31 parents and school counselors were selected by the snowball sampling method in autism schools in Tehran in the academic year 2018–2019. Semi-structured interviews were used to collect the data. Each interview was held based on a preprepared guideline by the researchers. In-depth questions were also asked as needed. Finally, the data were analyzed using the content analysis approach.

RESULTS: The participants reported a variety of difficulties and crises to cope with in their daily lives. The factors reported to decrease the quality of life were categorized into six main themes and 20 subthemes. The main themes included "family interactions," "parenting," "daily living," "health," "financial issues," and "community-related."

CONCLUSIONS: Due to the diversity and multilevel factors affecting the quality of life of parents having children with ASD, it is essential to adopt a comprehensive approach with the participation of all stakeholders in the development, design, and implementation of future interventions.

Keywords:

Autism spectrum disorder, caregivers, child, daily living, parents, qualitative research, quality of life

Introduction

The term autism is used for a wide range of problems related to social skills, repetitive behaviors, speech challenges, and nonverbal communication.^[1] Studies on the prevalence of this disorder in recent years show an upward trend.^[2-5] Regardless of the reasons behind this increasing trend (expanding diagnostic criteria, raising awareness about the disorder, and better diagnosis) being diagnosed with autism spectrum disorder (ASD) can have several negative effects on different aspects of the life of a person with ASD and their family and community.^[6-8]

On the other hand, in recent years, the family-centered care approach, which involves parents and caregivers in planning and providing services, has been emphasized increasingly. Although such an approach reduces costs and conflicts in medical systems and increases the effectiveness of programs, it seems necessary to pay attention to its adverse consequences such as increasing stress, reducing attention to self-care, and thus reducing the quality of parents' lives.^[9]

According to the definition of the World Health Organization, quality of life is a unique perception of one's position in life

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in terms of culture, value context, and individual goals. From this perspective, quality of life can be subjective or objective. As an objective concept, quality of life refers to income, level of education and health, and in general the objective circumstance within a given cultural context. In contrast, subjective quality of life includes subjective dimensions such as feelings of happiness, stability, and intimacy in the individual.^[10]

Caring for a child with ASD can affect the quality of life of the parents both objectively and subjectively.

For example, given that ASD is a lifelong condition, it can be argued that it is associated with a wide range of direct and indirect economic costs.^[11,12] Many parents face serious job problems arising from their children's problems. In particular, most mothers are forced to leave their jobs to stay home and take care of their children.^[13] In addition to the financial burden of care, studies in various parts of the world have shown that having a child with ASD is often associated with poor quality of life in social, psychological, and physical dimensions as well as reduced happiness.^[14,15] The results of previous studies show that parents of children with ASD consistently experience higher levels of stress than parents of normal children and even parents of children with other psychiatric and developmental disorders (for example, Down syndrome, fragile X syndrome, and cerebral palsy).^[16] Sleep disorders, physical problems, lack of social interaction, marital conflict, financial problems, insufficient time to spend on health issues, and chronic stress are the challenges that parents of autistic children face.^[17-19] In other words, having a child with ASD generally changes the normal routine life of parents and other family members. These changes can be positive or negative. However, in most cases, the child with ASD is at the center of the family structure and activity, and therefore, other family members' needs may be neglected.^[20] Such conditions can lead to a vicious cycle that puts extra stress on the parents of such children.^[21-22]

Furthermore, caring for children with ASD and its consequences on the quality of life of parents cannot be considered separately from the cultural context of society. In addition to problems with looking after their autistic children, many parents face other problems, such as social isolation.^[23] In fact, social attitudes toward disability, processes, and facilities can affect their quality of life.^[10] Therefore, considering the importance of family-oriented approaches in planning for ASD, it is necessary to pay more attention to sociocultural contexts and use qualitative methods in this regard.

In other words, caring for people with ASD has wide and varied consequences due to the nature and adverse prognosis of this disorder. In addition, the quality of life,

well-being, and health of caregivers, especially parents, can interact with the quality of care and well-being of autistic people. Therefore, more attention is needed to identify factors affecting the quality of parents' lives, as a prerequisite for more efficient and effective planning.

Thus, this study was conducted with a qualitative approach to identify factors influencing the quality of life of parents having children with ASD in Tehran.

Materials and Methods

Study design and setting:

This research was a qualitative study using content analysis approach aiming at identifying the determinants of quality of life of parents having children with ASD from the perspective of parents and the counselors of public autism schools working at the Exceptional Education Organization in Tehran, Iran.

Study participants and sampling:

The participants of this study comprised 31 parents and counselors from seven autism schools in Tehran who were selected by the snowball sampling method which continued until data saturation. Furthermore, to achieve maximum diversity in the studied samples, sampling was done from all public autism schools. In the snowball sampling method, future members of the sample are selected through the former members of the sample, and the sample becomes larger and larger like a snowball. In other words, in this method, the researcher, by establishing a personal relationship with those who are interested in participating in the study, asks them to introduce other people who have the characteristics of the research and want to participate in the study. The researcher can preferably select samples that belong to different fields in terms of contextual variables and other characteristics. Therefore, due to the nature of the subject, and the stigma caused by having a child with ASD, and the need to build more trust with the samples in the present study, the snowball sampling method was adopted.

Inclusion criteria for parents were having at least one child with ASD under 13 years of age who was a student in autism schools and willingness to participate in the study. The inclusion criterion for school counselors was having at least 4 years of experience as a counselor in autism schools.

Data collection tool and technique

In this study, semistructured interviews were carried out to collect the data. A total of 34 interviews were conducted with 31 people, and the interview time varied from 30 to 60 min based on the response time of the participants. The interviews were held individually in a suitable place

in the school where the participants felt comfortable. Each interview started with the warm-up phase, and then, the participants were asked questions about their age, age of the child with ASD, age of diagnosis, etc. An interview guide was used to address the main questions, but there was a possibility for some new issues. In other words, general questions were designed as interview guides with open and interpretive answers, and individuals' answers guided the process [Table 1]. At each stage, exploratory questions were asked based on the participants' answers to deepen the data and clarify the concepts. The interviewees' reactions were also recorded (upset, nervousness, crying, etc.).

The data were analyzed in MAXQDA 2018 software. After analyzing each interview, the next interview was conducted. For data analysis, the contractual qualitative content analysis method was used using the Lundman and Graneheim method. In contractual content analysis, classes are extracted directly from texts. Content analysis is something beyond the extraction of objective content derived from text data; by so doing it is possible to reveal hidden themes and patterns from within the content of the data of the participants in the study. Guba and Lincoln's methods and four criteria of validity, verifiability, reliability, and portability were used to evaluate the accuracy and reliability of the data. For this purpose, the researchers had a long-term relationship

with the research sites, which helped to gain participants' trust and also to understand the study environment. Participant review was also used to verify the data and codes. The researchers tried to include participants with maximum diversity in terms of age, occupation, gender, and level of education. In addition, the coding of the interviews was done by the research team. Thus, a number of interviews were coded separately by the study team in terms of code similarity. In disputed cases, a consensus was reached eventually. Moreover, the transcripts of the interviews were reviewed by observers. Furthermore, an external observer familiar with qualitative studies was used to examine the data. In addition to determining the confirmation of the findings, all activities performed were recorded (how to conduct the study and obtain findings), and a work process report was used.

Ethical consideration

In terms of ethics, the present study was approved by the ethics committee of Tehran University of Medical Sciences with the code IR.TUMS.SPH.REC.1396.4130. Participants were also reassured about the confidentiality of their information (publication of study results in general form) and the use of the results solely for research purposes. Before the interview, the purpose and nature of the study were explained to the participants, and they were given the necessary assurance about the confidentiality of the information. Besides, after obtaining participants' informed consent to participate in the study and record the conversations, interviews were carried out.

Results

In the present study, the factors affecting the quality of life from the perspective of parents and counselors of autism schools in Tehran were investigated. A total of 28 parents participated in the study; 75% of parents reported that their child was diagnosed with autism by the age of three, which is a golden time to diagnose and initiate early intervention [Table 2].

Based on the findings of this study, the factors affecting the quality of life of parents were classified into six main themes and 20 subthemes. The main themes included family interactions, parenting, daily living, health, financial issues, and community-related factors. For a more comprehensive explanation, the main themes and their subthemes are presented in Table 3.

Family interactions

Subthemes covered in this theme included marital conflicts, conflicts between parents and other children, and problems interacting with others. The following are some views by the interviewees in this regard:

Table 1: Semi-structured interview guide

Study questions for parents:

Please introduce yourself. How old are you? And tell me about your education status?

Please tell me how old your child (autistic child) is now?

Please explain the severity of the disorder in your autistic child, and the age at which he or she was diagnosed with the disorder?

Do you have another child? Healthy or autistic?

What is your definition of life?

What factors increase the quality of life? What factors do you think reduce the quality of life?

What challenges do you face as a parent of an autistic child?

How does having a child with autism spectrum affect your life?

What suggestions do you have for

improving your quality of life as a parent of an autistic child?

Study question for school counselors:

Please introduce yourself and tell me how long you have been working as a counselor in autism schools?

What is your general view of the quality of life of parents having autistic children?

What are the current challenges facing parents of autistic children?

Did you have any experience with the challenges of parents of autistic children? Please explain it

What are the most important factors that increase the quality of life of parents having children with autism?

What factors reduce the quality of life of parents of autistic children?

What suggestions do you have for improving the quality of life for parents of autistic children?

Table 2: Demographic characteristics of study participants

Participant demographics	n=28
Age of the parents (years)	40.39±7.50
Gender of the parents	
Male	6
Female	22
Educational status, n (%)	
High school	2 (7.14)
Diploma	11 (39.28)
Associate's degree	4 (14.28)
Bachelor's degree	9 (32.14)
Postgraduate	2 (7.14)
The age of the affected child (years)	10.17±2.31
The diagnosis age (years)	3.03±2
Having another child, n (%)	
Yes	9 (32.14)
No	19 (67.86)
Healthy child age (years)	11±6.28

Table 3: Factors affecting the quality of life of parents of children with autism spectrum disorder based on theme and subtheme

Theme	Subtheme
Family interactions	Marital conflicts
	Conflicts between parents and other children
	Problems interacting with others (neighbors, family, friends)
Parenting	Issues related to the care of an autistic child
	Issues related to the education of the autistic child
	Problems of treatment and rehabilitation of an autistic child
Daily living	Time constraints on daily tasks
	Lack of sleep
	Restrictions on participation in social events
Health	Restrictions on entertainment
	Physical health problems
	Mental health problems
	Restrictions on self-care
Financial issues	Issues related to spirituality and spiritual health
	Medical costs
	Nonmedical costs
Community-related actors	Legal issues and problems
	Factors related to programs and policies
	Lack of public awareness about ASD
	Social stigma

ASD=Autism spectrum disorder

“It is important to be able to have a good emotional relationship with your spouse because there are many who do not have an appropriate emotional relationship, and this makes their life much harder” P11.

“In my opinion, good marital relationships have a very good effect. Finally, many other things may happen to men, such as looking for another woman or a bad friend” P16. “ I can’t communicate with other people at all. It has also had a great

impact on our marital relationship. It has affected our behavior, our morals, and my behavior with my daughter. Many people tell me that it is good that you have a healthy child, but I say really not. Your situation is much better than mine. My daughter is also upset because of our problems” P23. “We had a neighbor who once told me that this child is screaming a lot and is sick, and you should hospitalize him and.... It affected my mind a lot why some people support but some do not understand” P5.

Parenting:

Subthemes of this theme include:

Issues related to the care of an autistic child, issues related to the education of the autistic child, and problems of treatment and rehabilitation of an autistic child. The following are some of the comments of the interviewees:

“Repeating everything hundreds of times, such as greeting, washing hands, or going to the toilet, makes you feel like you’re just wasting time and not living” P2. “We always had to go to different places to rehabilitate my son. Although we were looking to find the best, not all rehabilitation centers were close to our house ... Well, in the end, it is hard to stay in traffic all the time and always have the stress that I will arrive on time” P18. “Our children are not all the same, so there is no way to teach and rehabilitate them” P28. “School entrance exam is a problem for parents. When my son took the school entrance exam, it was like I had a university entrance exam myself. In other words, my whole life would be affected if my child did not go to school” P1.

Daily living

The subthemes of restrictions on daily tasks, lack of sleep, and restrictions on participation in social events and entertainment are included in the theme. The following are some of the statements made by the interviewees in this regard:

“My son cannot sleep more than an hour without medicine, but he only takes three medicines for his sleep” P11. “ I was awake for two consecutive days and my son had a fever. I even remember calling my husband and saying: Come home; I can’t keep my eyes open for even a second. He left work and came home quickly” P6. “We are invited to a wedding this week. We must first think about babysitting. Because the noise bothers him, and he gets confused. Because of this, we do not go to very crowded places ... We can’t take our children to the park. he can’t stand in a line; everyone looks down on our children” P1.

Health

Physical and mental health problems, limitations in self-care, and issues related to spiritual health and spirituality were among the subthemes obtained in the main theme of health. The following are some of the interviewees’ opinions related to this theme:

"I can't take care of myself or exercise like a normal mother" P15. "When my son was diagnosed with autism, I cried for almost a year and nothing could calm me down, which harmed my eyes" P9. "We need time for ourselves. For example, I was a swimming coach, but for many years I have wanted to go swimming for an hour, but I can't because of my son" P26. "In fact, we are very far from God ... Sometimes we think why me?... I have never solved this for myself ... why I was chosen to have such a child?" P17. "What has happened to me is that God has always given me the best. I think even this child is a blessing that God has given me. I had good friends wherever I went, I had good colleagues, I have good family, these have helped me" P20. "Last year, my lungs became infected, and I got bronchitis. Because I did not go to the doctor until my lungs became involved. I thought if I go to the doctor, who will take care of my son? My condition will get better on its own ... And now I say that if I had cared more for myself, I would not have to go to the hospital" P2.

Financial issues

Based on the findings, medical and nonmedical costs were subthemes of financial issues. In this theme, expenses related to medicine, doctor, and rehabilitation were included in the subtheme of medical costs, but nonmedical costs actually referred to expenses such as education, childcare, equipment destruction, and transportation. The following are some of the views of the interviewees in this regard:

"The cost of children with ASD is very high, and it affects the quality of life 100%. With the money you spend for the treatment, you have to avoid many expenses" P13. "I spend all my income on medicine and rehabilitation for my son, and we give up entertainment, travel, and many other things" P1. "Our financial situation has become so bad that we have to live in the same unit with my mother-in-law" P24. "The parents of these children have to pay for anesthesia for dental services, which is very expensive" P31.

Community-related factors

Legal issues, factors related to programs and policies, social stigma, and lack of public awareness about ASD were the subtheme of this theme. The following statements are some views by the interviewees on the theme of community-related factors:

"In general, our doctors are not very familiar with autism. For example, my child had a cold two years ago, and his lungs were very involved. The doctor said he should be hospitalized. I said that my child is autistic and could not be hospitalized. The doctor was not very familiar with autism and its treatment conditions" P1. "We do not have the right culture, not only for children with autism but also for all people with disabilities. Maybe I would have been the same if I had not had an autistic child and seen someone with these conditions" P27. "The community, the municipalities must help. We still do not have

a billboard about autism, for example, what is autism and..." "Our children can't go to the theater, cinema, or parks, while experts say that they should not be born. While our children are automatically separated, so these facilities should be given to our children separately" P1. "School books are not suitable at all. My child does not understand science. My autistic child has to see objectively to understand" P1. "We have several boys' schools, but we do not have enough girls' autism schools. Because they do not take their daughters out, they have problems with their hijab because their appearance changes quickly" P29. "I think the nature of the spectrum of our children is also problematic ... none of them are alike. We have a lot of problems legally. When the baby's father dies, there are steps for the mother to take custody. A mother who becomes the head of the family should report to the guardianship office once or twice a year ... Very good, but it should be a little easier" P1. "We have a screening process to diagnose autism, but what should we do for the mother and father? Should they be confused between psychiatric and rehabilitation services?" P7.

Discussion

The concept of quality of life is defined as how people measure "goodness" in various aspects of their life.^[24] Because this concept can be also used as an acceptable framework for assessing the living conditions of different communities and evaluating interventions, it has become an important concept among decision-makers.^[25] Furthermore, the issue of improving the quality of life, along with other factors, has been emphasized in the general policies and 20-year vision of the country.^[26]

But the quality of life is a dynamic issue and based on the results of various studies, the presence of a child with special needs has a great impact on the functioning and needs of the family, especially their parents. On the other hand, reducing the quality of life of primary caregivers can reduce the quality of care for the child. Therefore, identifying factors affecting the quality of life of such parents is important for planning and implementing future interventions.^[27]

This study aimed to identify factors affecting the quality of life of parents having children with ASD.

Family interactions

According to the results of the study, one of the factors affecting the quality of life of the parents was family interactions.

These results are supported by the findings of Gua's quantitative study conducted on 151 Taiwanese families with at least one autistic child and 113 families with healthy children. The results showed that marital satisfaction and family cohesion in parents of children with ASD, especially mothers, were significantly lower

than in parents of healthy children.^[18] The findings of the Keyvanara's study also support the results of the present study.^[25]

Parenting

Based on the findings of this study, parenting and its related factors were other factors affecting the quality of life of parents having children with ASD. These findings are in agreement with the findings of Khorramabadi's study on the application of parenting education programs to 24 mothers of autistic children. The Findings of Khorramabadi's study showed that using parenting-based educational approaches, improving parents' perception of difficult behaviors of these children, and empowering them to cope with parenting tasks leads to positive health consequences for parents.^[28] The findings of the present study also agree with Özgür's study conducted on 161 patients with ASD and their parents, reporting that the quality of life of parents decreased significantly as children's problems deteriorated in certain areas.^[29] In this respect, the results of our study are consistent with the results of a survey conducted by Schlebusch in South Africa on 180 families with young children with ASD.^[30] Other studies in this regard also support the present study, including studies by Soltanifar in Iran and Riany.^[31-32]

Daily living

According to the findings of this study, caring for a child with ASD can affect the daily activities of parents and even the whole family and is another factor affecting the quality of life of the parents of such children. Such parents often face limitations in normal life routines such as sleeping. Various studies have shown that in families with children with ASD, most of the daily activities are centered on these children, and the needs of other family members may be neglected. For example, in a systematic review by Mirzaie *et al.*, the results showed that some daily routines, such as bedtime or eating, can be affected by caring for a child with ASD.^[20] Such results are consistent with the findings of this study. On the other hand, the results of other studies demonstrate that problems with sleeping and waking up, bedtime, and mornings can turn into a stressful time for such parents.^[33-35] Other studies have also shown an association between sleep problems and quality of life.^[36-38]

Health

Another major theme of the study was parental health. In fact, lifelong and continuous care has adverse effects on parents' health. Moreover, the focus of activities and family structure on the child with ASD can lead to neglecting the needs of other family members. These findings are consistent with previous studies showing that parents of children with ASD are more stressed than other parents and even parents of children with other conditions.^[39]

In a study carried out by Kuhlthau, the results showed that 55.6% of the parents of autistic children reported physical problems caused by care. In addition, 57.7% had experienced mental health problems.^[17]

In fact, paying attention to the physical health dimension is very important because of its importance in the quality of life. Previous research demonstrates that many parents of these children experience multiple physical and psychological problems, such as high blood pressure, and weight changes, and fatigue, which ultimately have negative effects on their quality of life.^[40-41]

In terms of spirituality issues, obtained as one of the subthemes of the present study, several studies have examined the relationship between quality of life and spiritual health.^[42-44] Hodge, for example, reported a significant relationship between spirituality and the well-being of patient caregivers.^[45]

Financial issues

Raising a child with special needs can impose various financial problems on the family. Various studies have been conducted on the financial burden of caring for children with ASD.^[40] For example, in a meta-analysis by DePape and Lindsay, the results emphasized the importance of financial issues in the demands of the parents of these children. Spending too much time caring for a child imposes time constraints on the parents of these children to engage in economic activities. In addition, the additional costs associated with caregiving increase the financial burden on such parents.^[46]

In a study conducted by Mosadeghrad *et al.*^[11] examining the economic burden of ASD, the results were consistent with the present study. According to the results of their study, about 32% of the costs were related to direct medical costs. Parents also reported that more than half of the costs were nonmedical expenses such as medication supplements, transportation, and education. Among direct medical costs, most payments were related to the rehabilitation of these children. In addition, 70% of the indirect costs, which accounted for about 16% of the total costs, were related to the cost of production lost due to leaving work.^[11]

The relationship between financial issues and quality of life has been acknowledged in various studies.^[47-49] For instance, Kuhlthau's study supports the findings of the present study showing that 52.5% of parents suffered from financial problems caused by caring for their autistic child.^[17]

Community-related factors

In terms of issues and supports related to society, various studies have acknowledged the importance

and role of these factors and hence agree with the findings of the current study. For example, in a qualitative study by Shepherd, results showed that more attention should be paid to policies and some gaps between the views of parents and policymakers. The need to improve the relationship between policymakers and parents to determine their real needs in the care process and to pay attention to differences between their needs was also acknowledged. Shepherd's study, therefore, supports the findings of this study.^[50]

In another study carried out by Mohammadi to empower parents of autistic children with a qualitative approach on three parents, eight mothers, and five educators working in the ASD Children's Association, the subjects emphasized the importance of social support, which is consistent with the findings of the current study.^[51] Similarly, In the Kuru study, 51 biological mothers and fathers and 90 children with ASD were studied. The results showed that there was a statistically significant relationship between the quality of life of these parents and their perceived social support, in agreement with the findings of this study.^[52]

Limitation and recommendation

The strength of this study is to address the factors affecting the quality of life of parents from the perspective of both parents of children with autism (mothers and fathers) and school counselors. However, researchers faced limitations in the research process. Poor parental involvement, especially of fathers, and lack of cooperation from school principals were the two main limitations of this study. Therefore, the research team had to hold meetings with school principals and parents to justify the goals and importance of the study. Another limitation was the poor participation of parents of autistic girls. Due to the gender-dependent nature of the disorder and differences in the severity and clinical protests of the disorder in girls and cultural barriers, access to parents of autistic girls was often difficult. However, this limitation was partly overcome with the cooperation of school principals and the use of the snowball method in sampling. Nevertheless, it is suggested that more studies should be undertaken on fathers and autistic girls in the future studies.

Furthermore, the present study was conducted on parents of autistic children studying in public autism schools located in Tehran; thus, it is necessary to be careful in generalizing the results. Therefore, it is recommended that other similar studies should be carried out in other parts of the country and age groups to provide more comprehensive information for better and more effective policymaking.

Conclusions

The findings of this study showed that factors affecting the quality of life of parents having autistic children include a wide range of individual, interpersonal, and social aspects. Therefore, it can be argued that it seems necessary to pay attention to all levels of effective factors in the design and implementation of future interventions. In particular, the parents and all family members of these patients face special needs at each stage during the long period of care. Therefore, family-centered interventions should be given more attention in policymaking. On the other hand, perhaps the best strategies for improving ASD are strategies suggested by the World Health Organization because, in addition to empowerment, they emphasize the importance of supportive policies and environments and redirecting existing systems. In many societies, disability is seen as the punishment of a sin, and having a child with special needs will lead to stigma and social rejection, which will eventually lead to the further isolation of caregivers of such children. Thus, trying to inform communities and paying more attention to cultural sensitivities are necessary for future planning to increase the quality of life of such people and their families. Certainly, achieving positive results by applying such strategies is not possible without coordination and cooperation among all stakeholders.

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Conflicts of interest

There are no conflicts of interest.

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