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## ARTICLE

# INVESTIGATION AND STUDY ON THE INFLUENCING FACTORS OF THE QUALITY OF LIFE IN OLDER AUTISTIC FAMILIES

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## ARTICLE DETAILS

## ABSTRACT

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**Objective:** It aimed to understand the living situation of older autistic children and to propose countermeasures and suggestions to improve the quality of life of older autism and family members. **Methods:** The questionnaire method was used to understand the living situation of older autistic families. The literature analysis method was adopted to understand the relevant research and policies of older autism in China, conduct in-depth interviews with older families with autism, record the interview content with informed consent, and transform the recording into text data for text analysis. A psychological intervention was conducted in one family for six months. **Results:** The risk of 10 interviews, only 1 case of older autism can take care of themselves, 10 cannot go out and emergency help; 10 families think children as the main source of psychological pressure, 7 families pointed out that adolescent emotional and behavior problems are urgent guidance. **Conclusion:** The joint training mode of "policy + skills training + enterprise docking" is carried out for older autistic employment which helps to improve the living status of older autism and family members.

**KEY WORDS**

Older Autism, Quality of Life, Influence Factor.

**1. INTRODUCTION**

Older autistic patients refers to the age of more than 14 years old, was diagnosed with autism, is a part of autism cannot be ignored. With the expansion of older autism groups, the domestic rescue policy for this group is still stay in the almost blank stage. Chinese researchers in Beijing and Guangzhou of 13 provinces and municipalities of 67 families in autism adult care survey, found that the employment rate of more than 18 years of autism is only 9%<sup>[1]</sup>. The placement and life of older autism is a social problem that we must pay attention to. Through social practice, in-depth interviews and case consultation, this research aims to have a deeper understanding of the living situation of older autistic patients, promote the role of social support in autistic patients and their family services, and promote the socialization process of older autistic patients, so as to improve the family and social burden of autistic patients.

**2. RESEARCH METHODS AND DESIGN****2.1 Subjects**

In the early stage, the autistic families of Jiaying City were surveyed through the members of the research group, and 10 older autistic families who met the entry criteria were selected. The subjects were older families with autism, with four entry criteria:

- 1) Diagnosed with autism spectrum disorder.
- 2) Over 12 years.

- 3) Main family members living together with older autism.

- 4) No schizophrenia or severe organic mental illness and physical illness.

**2.2 Research method**

This study collected general information through compiled questionnaires and used the Social Support Assessment Scale (SSRS), the Quality-of-Life Scale (SF-36) to understand the social support of older autistic families and the quality of life.

**(1) General information**

General information includes the respondent's family structure, child training, and family economics.

**(2) Social Support Assessment Scale (SSRS)**

The social support assessment scale has ten entries, including objective support (3), subjective support (4), and the utilization of social support (3). The questionnaire design is basically reasonable, the entries are easily understood without ambiguity, the total table a coefficient is 0.69. Among them, a coefficient is 0.825, a coefficient is 0.849, and a coefficient is 0.833. It can be seen that the internal consistency confidence coefficient of each component table is relatively high. The correlation coefficient of the questionnaire is 0.724-0.835, indicating the high validity of the scale. The correlation coefficient between the component scales is 0.462-0.664, below the correlation with the total

**Table 1:** Semi structured interviews with older autistic caregivers.

Serial number	Content
1	Hello, can you tell you about the child’s situation?
2	How did the children find out the problems?
3	How do you help your child recover after you find the problem?
4	Has anyone or agency ever helped you?
5	Does anyone at home help you take care of your children together?
6	When do you think that the most difficult time is when?
7	Can the family members support each other?
8	Is your current work and life situation?
9	Is the financial burden of children’s rehabilitation training to the family? Is there any funding?
10	How does the child plan after graduating from a special school? / What do the children mainly do after graduation from a special school?

table, indicating a higher structural validity of the scale<sup>[2]</sup>.

**(3) Quality of Life Scale (S F-36)**

The quality-of-life scale comprehensively summarizes the quality of survival from eight aspects, including physiological function, physical function, physical pain, general health status, energy, social function, emotional function and mental health. In addition to SF dimension, the Cronbach’s a coefficient of each dimension is greater than 0.70, indicating that the internal consistency of the scale is very good and can be used for group evaluation of quality of life. In the validity analysis, except the RE dimension, the other dimensions set validity and differentiation validity have good reliability and validity<sup>[3]</sup>. In each dimension, the higher the score, the better the respondent’s health.

**2.3 Parent interview**

A deputy senior college teacher engaged in the research of autistic children and a deputy senior child protection doctor jointly compiled a semi-structured interview outline through literature analysis and professional discussion. See Table 1 for details. Record the 1 to 1 interview with informed consent. Turn the recording into text material for text content analysis.

**(1) Quality control**

Before the interview and research, the research team had organized many activities, such as autistic children’s collective birthdays, roller skating and color mud, to establish a good interactive relationship with autistic families. All families know the content and purpose of the study and were willing to accept interviews to ensure the quality of the interview. Unified interview guidance, unclear or ambiguous content to contact the family, for a supplementary collection.

**3. STUDY RESULTS**

**3.1 General information**

Of the ten families, six are parents raise their children, two families for parents and the elderly, and the remaining two are single-parent. All ten families have a junior high school degree or above, and four families have a junior college degree or above. There are two families with an annual income of 100,000 or more, the rest are below 100,000, and two families with an annual income of only 10,000-30,000. Except for two families whose children have no rehabilitation training, the other families spend money on child training ranging from 50,000-80,000,000 every year.

**3.2 Social support**

The ten families surveyed differ widely in objective support, with a highest score of 12, a minimum of only 3, and two families scoring three. For subjective support, the maximum score is 25 and a minimum of 11. In terms of social support utilization, the maximum score is 11 points, and the minimum score is 4 points. The three dimensions total 48, the

lowest 18 and an average score of 29. In this scale, the total score ≥ 20 is normal, and vice versa, less social support, and in 10 households, only one family receives a total score under 20 points. At the same time, the results show that the families with more objective support have also gained more subjective support and have a correspondingly higher utilization of the support.

**3.3 QUALITY OF LIFE**

Of the ten families surveyed were in good physiology, with a maximum score of 100, a minimum score of 70 and an average score of 85.5, indicating that their health conditions did not interfere with normal physiological activity.

In physiological functions, scores are significant differences in ten families, with 100,75 for two, 25 for two, and 0 for two.

In physical pain, ten families all scored over 72, with a highest score of 100.

The average scores of general health, energy, social and emotional functions were 49.6,49, 98.75, and 50. The highest and lowest scores are also far different in mental health.

Through the eight dimensions of the quality-of-life scale, it is concluded that the quality of life of different families varies greatly, but most older families with autism have low quality of life.

**3.4 Interview content analysis**

**(1) Coping with children’s emotional and behavioral problems**

Patients with autism lag behind their development than children of their same age, which can be classified into three categories: social interaction disorders, language communication disorders, and rigid behavior patterns. It is often accompanied by epilepsy, depression, anxiety, and attention deficit hyperactivity disorder. After interviews, children found that it is often difficult to control their emotions during adolescence, their temper is also cloudy or shine, and even fall things, self-harm, hurt others.

N3: The emotional problem in adolescence comes out at once in a while. Then inexplicably will lose a temper ah, that sent out, sometimes things

**Table 2:** Values of Social Support Assessment Scale (SSRS)

	Objective support	Subjective support	Support for utilization
Maximum score	12	25	11
Minimum score	3	11	4
Average score	6.2	16.6	6.2

**Table 3:** Values of quality-of-life scale (SF-36)

	Physiology and physical function (P F)	Phyphysiological function (R P)	Body pain (BP)	General health conditions (GH)	Energy (VT)	Social function (SF)	Emotional functions (RE)	Mental health (MH)
Maximum score	100	100	100	92	80	125	100	80
Minimum score	70	0	72	10	0	62.5	0	16
Average score	85.5	60	77.4	49.6	49	98.75	50	56

throw. Sometimes he would throw his hand over and hit us. When he lost, sometimes saying he was wrong, we turned around and he came.

N5: Children recently have a bigger temper, used to like sports, now not love sports, like to lie at home, like books, tear books, individual emotions are relatively big, sometimes do what they like, sometimes have a slight attack behavior, such as pinching the little sister's face, sometimes cry, will beat people.

When families initially found that children have autism, most choose to consult doctors, attend lectures and attend training classes. In the face of their children, the general parents choose to listen to their children's opinions, to meet the children's reasonable requirements. But when faced with their child's sudden emotional problems, parents usually change from initial patience education to solving "violence" with "violence". Some parents said: sometimes children will be irritable because of the parents and temper, and parents cannot control the children's temper will be more impatient, even beat and scold phenomenon, this is a vicious circle.

#### (2) Social attribution of children after adulthood

N1: What I hope now is to say that his career will face and cannot stay at school in two years, which is just a problem. I think more important is to help the family, because our nerves cannot always be tight, in case one day I get sick, how to do, so I think there is such an agency government money or we pay also can be such services, such as a month has two days of activities, parents don't have to look at him, let us also have time to relax, I think this need very much. Career, can target such a kind of person, there are such institutions to provide some simple work, salary how much is not the so-called, mainly to let him do something every day, it is very good.

N3: In fact, the most difficult time is two points, there is no free time, but for him he doesn't know, we are always nervous. The second point is his future, not despair, but little hope, even in the dark only beans big hope.

Children with autism vary different intellectual levels, with both deeply impaired and those with superior skills<sup>[3]</sup>. However, due to the label of autism, many bosses are afraid to hire these patients, so the adult social ownership of children is still a problem. Moreover, for the future of their children, the parents are very confused, and have a negative and pessimistic attitude. The future livelihood problem of young people with autism spectrum disorder is an imminent social problem<sup>[4]</sup>.

#### (3) Financial pressure on the family

N7: Economic pressure must be a little, after all, such a child the expenses must be bigger than the average child, we certainly want to let him to learn a little more. For example, we live with grandparents, the elderly will help, the economic situation may be slightly better in the same type of families, those families who have no one to help to take care of their children, their will is actually greater financial pressure.

As direct caregivers and supporters of older autistic children, parents have suffered a lot of economic and spiritual pressure for a long time<sup>[5]</sup>. Three main causes of economic difficulties: first, people with autism affect the work and employment of caregivers, reduce family income;

second, autism is a lifelong disease, autistic families in autism care and rehabilitation; third, autistic families have to participate in rehabilitation institutions to get subsidies, many families cannot afford the subsidies, can only abandon subsidies<sup>[6]</sup>.

The interview found through the interview that 10 interviewed families, except one family training at home, one family currently has no training, the other 8 families spend 25,000-60,000 yuan per year. In addition to training costs, it also includes extra teachers and tutoring for children. With less income and increased spending, economic stress is a real problem for autistic families.

#### (4) Psychological pressure of the family members

Parents of autistic patients have a tendency of introverted and neurotic personality, with obvious psychological anxiety, depression, hostility and other aspects<sup>[7]</sup>. Due to the particularity of the disease, the parents need to accompany and care, thus have to give up normal social interaction. The possibility of children's emotional instability, unattainable social value and suffocating economic pressure, may make the caregivers appear depression, anxiety and other bad emotions. In addition, the surrounding-colored glasses for autistic families have increased the mental pressure on family members.

According to the survey results, autistic families believe that the main psychological pressure comes from concerns about their children's future, family economic reasons, and the low social understanding of autistic people.

#### (5) The impact of social support on autistic families

N2: Why do I say that the mentality is better, but I get more help from the society. One is that our community provides a lot of help. I often take my children to the community to play, they are like treating loved ones, very good to him, quite take care of all aspects.

Autism families because of the situation of children, often unwilling to communicate with the outside world, feel and normal children's family many contents have no way to understand, can get the social support resources are less, the existing social support, social assistance force is far from meet the actual needs, social security for the disabled, social support is weak. Social policy is a long-term mechanism, difficult to see obvious results in a short time, so it is very necessary for social workers to intervene in families with autism, in the field of autism has a lot of space for social workers to play their professional advantages, provide services for more autistic families, improve the social support of autistic patients and families, so as to reduce difficulties for more families and reduce pain<sup>[8]</sup>. The vast majority of the social support a family comes from social workers in various fields, these families with substantial social support, parents and children live better than families who do not receive social support.

## 4. DISCUSSION

At present, there are many social assistance policies for autistic children, but it is very difficult for older autistic patients to maintain a dignified and quality of living environment.

The results show that older families with autism receive relatively different social support and relatively different quality of life, and families with more social support generally have better quality of life. The emotional response problems of adolescent autistic children and the future attribution of their children are the current problems facing parents. In the face of children's emotional problems, parents need to think about their own education methods, improper ways are easy to hit children's self-esteem and confidence, is not conducive to the development of parent-child relationship, parents need to teach students according to their own situation, reasonable guidance, pay attention to the management of children's emotions.

Now for autistic children policy and economic support mainly focus on young autism groups, and for older autism policy, a 21-year-old autism parents once said, when the child left from the special school, she really doesn't know what children can do at home, before learning some skills will become more and more degenerate. In this interview, more than 60 percent of parents found their children's future hopeless. Therefore, children's future confusion has also become the main source of parents' psychological pressure. Thirteen cities, including Beijing and Guangzhou, have conducted research on 67 older autism care issues. On the result, the employment rate of autistic patients over the age of 18 is only 9%. Therefore, the lack of recovery of older autistic patients is a normal phenomenon in the society. Due to the particularity of autism groups, what older autistic groups need at this stage is the resettlement mode with maintenance as the main body, and the joint training mode of policy training of + skills and connect + enterprises.

This study found that social support has a positive impact on the quality of life of autistic families. In the existing social support, social assistance forces are far from meeting the actual needs, social security for the disabled is incomplete, and social support is weak. Social policy is a long-term mechanism, difficult to see obvious results in a short time, so it is very necessary for social workers to intervene in families with autism, in the field of autism has a lot of space for social workers to play their professional advantages, provide services for more autistic families, improve the social support of autistic patients and families, so as to reduce difficulties for more families and reduce pain<sup>[10]</sup>.

To sum up, the rehabilitation of autism is a long and long process, and the rehabilitation and care problem of older autistic patients' needs relevant support from the government and society. Rehabilitation institutions connecting special education schools will be established to ensure that the skills of autistic patients do not degenerate. The government has issued relevant assistance policies to reduce the economic pressure on older autism. The society helps parents learn the relevant knowledge of adolescent emotional management of autistic patients with educator role intervention, establishes the support network of the families of autistic patients, and takes the role of advocate intervention to improve the social security system of autistic families<sup>[11]</sup>. The Mental Health Association establishes a long-term model of mental health services, providing regular group psychological counseling and psychological

lectures on emotional management, to improve the mental health level of parents. Multi-party collaboration to help older autistic families jointly improve their quality of life.

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