

## RESEARCH ARTICLE

## QUALITATIVE RESEARCH ON LIVING STATUS OF OLDER AUTISTIC FAMILIES IN JIAXING CITY, CHINA

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## ARTICLE DETAILS

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## ABSTRACT

**Objective:** It aimed to learn the living status of older autistic children and to put forward countermeasures and suggestions to improve the quality of life of older autistic children and family members. **Methods:** Literature analysis method was used to understand the related research and policy of older autism in China. Deep interview was conducted with older autistic families. The contents of the interviews were recorded after informed consent, and the recordings were transformed into text materials. Text analysis was carried out. One family was given a six-month psychological intervention. **Results:** All the 6 cases cannot go out independently and seek emergency help. Only 1 case has self-care ability. The main psychological stress of family member is worrying about children's future. 5 cases pointed out that adolescent emotional and behavioral problems are urgent problems for parents. **Conclusion:** It is necessary to apply psychological lectures and counseling for emotional and behavioral management to autism family members. It is important to develop employment policy and caring services. Which are helpful to improve the living status of older autism and family members.

## KEYWORDS

Older Autism, Life Status, Qualitative Research.

## 1. INTRODUCTION

Autism is a subtype of generalized developmental disorder. In 2014, Autism research center of Family Education Committee of the Chinese Educational Society released a Report. Which is about the Autism Child Development in China. It shows that there will be more than 10 million autistic people in China (Development Report of Autistic Children in China, 2014). Autism spectrum disorder is a lifelong, incurable neurodevelopmental disorder, and most autistic children require lifelong parental caring. In recent years, the autism children in China have been paid more and more attention by the government and society. There is great progress in diagnosis, treatment, rehabilitation training, support of national welfare policy and so on.

In 1982, the first case of autism children was diagnosed in China. With the increase of the incidence of autism, more and more children were diagnosed with autism. More and more autism children entered youth and adulthood, while their parents entered the middle and old age and gradually lost their ability to take care of autism children. Older autism spectrum disorders have become a large group. At present, many policy support and rehabilitation training are aimed at younger autism children. The living status and future placement of older autism is a social problem that cannot be ignored.

This study conducted deep interviews to understand the current situation

of older autism and family members in Jiaxing, China. It provided suggestions and data for policy formulation to improve the quality of life of older autism families.

## 2. RESEARCH METHODS AND DESIGN

## 2.1 Subjects

The subjects of this study were older autism family members, and the entry criteria were as follows:

- 1) Diagnosed with autism spectrum disorder.
- 2) Over 12 years.
- 3) Main family members living together with older autism.

## 2.2 Research design

Through literature analysis and professional discussion, a deputy senior college teacher and a deputy senior pediatrician engaged in the study of autism children worked out a semi-structured interview outline, as detailed in Table 1. Face to face interview was conducted after informed consent. The interview content was recorded and converted into a text material. The text content is analyzed. Before the interview, group screening was carried out to collect basic information such as age, sex, parental education and so on.

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**Table 1:** Outline of Semi-Structured Interviews for Older Autism

Serial number	Content
1	Hello, can you tell me about the child?
2	How did the child find the problem?
3	After finding the problem, how do you help your child to recover?
4	Has anyone or agency ever helped you?
5	Does anyone at home help you with the children?
6	When do you think is the hardest time?
7	Can family members support each other?
8	What is your current work and life?
9	What is the financial burden of children's rehabilitation training to families? Is there any funding?
10	What are the plans after the children's special school? What do children do after special school?

### 2.3 Quality control

Before conducting the interview study, the research team organized a group birthday, roller skating, color mud and other activities for autism children to establish a good interaction with family members. All the interviewed families are aware of the interview content and research purpose, willing to accept interviews to ensure the quality of interviews.

Unified interview guidance, unclear or ambiguous content linked to the family, supplementary collection.

## 3. ANALYSIS OF THE MAIN POINTS OF INTERVIEW

### 3.1 Basic information of the family interviewed

**Table 2:** Basic family interviews

Item and Family Number	N 1	N 2	N 3	N 4	N 5	N 6
Parenting	Parents and grandparents	Mother alone	Both parents	Both parents	Parents and grandparents	Both parents
Father's degree	College or above	College or above	High school	College or above	College or above	College or above
Mother's degree	College or above	College or above	Primary	College or above	College or above	High school
Child sex	boy	boy	boy	girl	Boy	Male
Age	13	12	15	21	12	14
Time of diagnosis	4 years	2 years	5 years	27 months	4 years	4 years
Annual training costs	40,000 RMB	Trained by mother	40,000 RMB	No training	20,000-40,000RMB	20,000-30,000RMB
Can the child take care of himself?	No	No	No	No	No	Yes (with parents behind)
Does the child go out independently	No	No	No	No	No	No
Does the child have the ability to ask for help	No	No	No	No	No	No
Is there a problem of emotional irritability, behavioral impulses	Yes	Yes	Yes	Yes	Yes	Yes

### 3.2 Self-care ability of older autism

Self-care ability is the necessary life skill of survival and the key factor to determine the quality of family life. The results of the interview showed that only one autism of the six families could live on their own, and the prerequisite was the situation of parents around them. In the case of leaving parents, children cannot live independently even if the necessary life items are prepared. Parents say that even with this ability, parents are not sure to leave their children alone at home, for example, worried about safety issues of household appliances using. In the interview, each family has a similar expression: "Autism children like our child must not be able to do these things. Perhaps many blows in the process of upbringing, parents generally have no confidence in their children's ability.

### 3.3 Emotional Management of Autism at puberty becomes the Major Dilemma of Family Life

All six families interviewed indicated that emotional problems in adolescence were the most important family problems. After the diagnosis of the child, the family learns the rehabilitation training method of autism through various ways, but knows little about the emotional and behavioral problems. Compared with the normal children, the adolescent emotional and behavioral problems of autism are more prominent and changeable.

Family members are described as follows:

Family N3: The emotional problems of adolescence are so common. He come out at intervals. Sometimes he just throws his hand over and hits us. When there is no things wrong, he also lost his temper. We only turned around and looked at him. Nothing we can do.

Family N5: The child has a little temper recently. He used to like sports, but now he does not like sports. He likes to lie at home, likes reading, tearing books. The emotional individual time is bigger. Sometimes he can do what he like, sometimes he has a slight attack behavior, such as pinching the little sister's face, sometimes he can cry and hit people

Family N6: He is very annoying now. No one wants to reason. He was born in 2006, normal child puberty also arrived. You will never be not satisfied with the temper.

### 3.4 The most important stress in the family is the confusion of children's future

For the source of family stress, six families agreed to worry about the future of their children. Although there are also economic, work, life and other aspects of pressure, they believe that if the autism child can support themselves in the future, or can take care of themselves, all other problems

can be solved. The oldest child is 21 years old, but parents still keep her in special education schools. Because if she left school, she can only stay at home. The parents are more overwhelmed.

Jiaxing special education school has carried out pilot work, aiming at the aspect of employment ability, such as horticulture, noodle, housekeeping and so on, to cultivate students' skill and help students obtain employment. Because of the particularity of autism, these employment directions are not completely consistent with the employment skills and employability of people with physical disabilities. In this study, six families have not received employment skills training, parents are very looking forward to the autistic employment support policy. Even if they cannot be making money, but they need not stay at home all day. One parent sighed many times during the interview: "We don't expect him to be able to do anything, we just hope that there is a place to go. So we can have a rest".

In this study, the mental health status of parents was evaluated by 0-10 points, only 1 family rated as 8 points, the other 5 families were less than 5 points, the average score was 2.7 points. In deep interviews, the interviewer found that parents even had the idea of committing suicide or taking their children together. The economic support of community and other organizations and the mutual spiritual support between autism parents are important channels for families to relieve their stress.

#### 4. DISCUSSION AND RECOMMENDATIONS

This study found that the self-care ability of older autism is not optimistic, which is related to parents' awareness of children and parents' parenting style. The interview found that parents thought that children could not be independent of life, so they adopted an arranged parenting style. Some parents have tried to train their children, but give up because the progress is too slow. The only child who can take care of himself in this study just under the supervision of his parents. The whole family has a sense of consciousness and patience, for example, folding quilts for half a year. Chinese scholars have found that 60 percent of adult autism people need help in their own lives. One of the causes is that the parents say they are not at ease even if autism children are basically independent (Hongqin, 2017). At present, the training for autistic parents is mainly focused on rehabilitation training. Parents should also pay attention to the learning of children's knowledge, and there is a lot of room for improvement in the awareness and methods of children's ability to live independently.

At present, the policy and economic support of our country is mainly aimed at the young autistic children aged 0-6 years old. They can carry out rehabilitation training in the government or social rehabilitation education center. After 7 years of age, they can go into ordinary primary schools to follow the class. Learning is very difficult based on social incomprehension and intolerance of autism (Jinfa, 2014). The vast majority of students attend special education schools, which are often left with nowhere to go after graduation. In this study, 21-year-old autism, her parents even chose to let her go to special education schools repeatedly. They did not want their child to come back and stay at home. Older autism's future confusion is the main source of pressure for parents. More than 94 percent of parents are worried about their children's future life, employment and placement, according to the survey (Shenzhen Autism

Research Association, 2013). Another survey of 67 families in 13 provinces China, municipalities such as Beijing and Guangzhou, it was found that the employment rate of autism over the age of 18 was only 9 percent (Wanjie, 2016). The absence of rehabilitation from school has become the norm status for older autism.

This study found that parents with older autism, based on years of assessment of their child's development, are highly expected to earn their own living, but many of them already know that the possibility is very low. More parents expect older autism to have a Care-Center to be "entrusted", when parents can take care of them, they can be temporarily hosted, parents can have time to rest. When parents do not have the ability to take care of them or their parents died. There are room for autism in this Care-Center. Therefore, at this stage, the resettlement needs of older autism is the most important need.

To sum up, the rehabilitation of autism is a continuous lifelong process. In the family-centered rehabilitation model in China, the support of the government and society is very needed. The first thing to be solved is to establish the autism rehabilitation institution connecting the special education school, which can effectively ensure that the effect of the early rehabilitation training can be maintained and developed, rather than the retrogression caused by the interruption of rehabilitation. Secondly, the rehabilitation training of older autism should take "maintenance" as the main body and combine with the compound mode of "employment" education, which is more suitable for the present situation of older autism. Finally, the guidance of family education for older autism should increase the guidance of adolescent emotion and behavior management to help families and older autism through their adolescence.

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