

Family Resilience Status and Characteristics in Families of Children with Autism: A Mixed-Methods Study

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Abstract

Objective: To analyze the status and experiences of family resilience among caregivers of children with autism, and to provide a basis for developing interventions to enhance family resilience. **Methods:** A mixed-methods study was conducted. Two hundred and sixty-one caregivers of children undergoing rehabilitation in the pediatric rehabilitation department were surveyed using a general information questionnaire and the Chinese version of the Family Resilience Assessment Scale (FRAS-C). Nine caregivers were selected for in-depth qualitative interviews. **Results:** The total family resilience score of caregivers was (71.26 ± 15.03) , indicating a medium-low level. Interview data summarized three themes: The formation of an inclusive and resilient mindset, multidimensional ability improvement, and family collaboration and resilience. **Conclusion:** The family resilience level of families with autistic children needs improvement. Despite the challenges, caregivers reported positive parenting growth experiences during caregiving.

Keywords: Autis, Caregivers, Psychological Resilience, Family, Mixed-Methods Research

1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by core features of social communication impairments, repetitive behaviors, and restricted interests[1]. The global prevalence is approximately 1%–2%, while the prevalence among Chinese children is about 0.7%, showing an increasing trend over the years, which may be related to improved diagnostic awareness and the widespread adoption of screening[2]. As most children with ASD experience cognitive and adaptive functioning impairments, their families often need to assume long-term or even lifelong caregiving responsibilities. They face significant pressures in terms of medical interventions, educational support, and daily life management, which can easily lead to increased caregiving burden and negatively affect family functioning and quality of life[3]. Family resilience refers to the ability of families to achieve adaptive adjustments through resources when facing adversity. Factors such as family structure and social support influence the level of resilience, and higher resilience is associated with better quality of life[4]. Enhancing resilience is of great significance for alleviating caregivers' pressure and maintaining their physical and mental health[3]. Therefore, this study employs a mixed-methods approach to systematically investigate the current status, influencing factors, and mechanisms of family resilience in families of children with ASD, aiming to provide empirical evidence and theoretical support for developing scientific and targeted family support intervention strategies.

2. Objects and Methods

2.1 Research Objects

2.1.1 Survey Participants

Convenience sampling was used to select children with ASD and their primary caregivers receiving rehabilitation training at the Longgang District Maternal and Child Health Hospital in Shenzhen from January 2024 to June 2025. Inclusion criteria were: children aged 0-14 meeting the diagnostic criteria for ASD[5]; being the primary caregiver; cohabiting with the child for ≥ 1 year; and providing informed consent. Exclusion criteria were: the child or caregiver having a physical illness that hindered communication; a history of mental illness; or voluntary withdrawal from the study. Based on Kendall's sample size estimation principle (5-20 times the number of

variables, plus 20% for potential attrition, with a minimum of 100), and considering 14 variables, 200 questionnaires were deemed necessary[6]. Ultimately, 270 were distributed to enhance reliability.

2.1.2 Interview Participants

Based on the quantitative results, caregivers with relatively higher resilience scores were purposively selected. Twelve mothers (P1-P12) were initially planned for interviews, which continued until data saturation was reached with nine participants. The study was approved by the hospital's ethics committee (Approval No.: LGFYKYXMLL-2024-19). All caregivers provided informed consent.

2.2 Methods

2.2.1 Research Tools

2.2.1.1 General Information Questionnaire

Covered the child's age, gender, duration of illness, monthly rehabilitation cost, and payment method; and the caregiver's relationship to the child, age, gender, occupation, education level, duration of care, family income, and place of residence.

2.2.1.2 Chinese Version of the Family Resilience Assessment Scale (FRAS-C)

Originally developed by Sixbey[7], translated and revised by Li et al[8]. It contains 32 items across 3 dimensions: family communication and problem-solving, utilizing social resources, and maintaining a positive attitude. A 4-point Likert scale is used. The total score ranges from 32 to 128, with higher scores indicating higher resilience. In this study, the Cronbach's α was 0.873.

2.2.1.3 Interview Outline

Prior to the formal interviews, the researcher developed an interview outline based on the research objectives and a resilience model within the Chinese cultural context[9]. The outline included the following: ① Please describe your specific feelings from the time you learned about your child's autism diagnosis to the present. What changes have occurred in your personality and abilities? What psychological changes have you experienced? How has your attitude toward life changed? Please explain the reasons behind these changes. ② What difficulties have you encountered while caring for your child? ③ What challenges have you faced while implementing interventions for your child?

2.2.2 Data Collection Methods

2.2.2.1 Questionnaire Survey

During the children's rehabilitation training sessions at the hospital, the researchers, after obtaining consent from their mothers, guided them in completing the Family Resilience Assessment Scale. The questionnaires were collected on-site immediately after completion.

2.2.2.2 Qualitative Interviews

Face-to-face, semi-structured interviews were conducted. The researcher explained the purpose of the interview to the participants and obtained their informed consent. The timing and format of the interviews were mutually agreed upon, with each interview lasting 40–60 minutes. After each interview, the data were anonymized, and participants were coded sequentially as P1–P9. Within 24 hours, the audio recordings were transcribed into Word documents. The transcripts were cross-checked against notes and repeatedly reviewed against the recordings by two researchers to ensure accuracy before being used for data extraction.

2.2.3 Statistical Methods

Statistical analysis was performed using the SPSS 27.0 software package. Measurement data conforming to a normal distribution are described using mean and standard deviation, with group comparisons conducted using t-tests and F-tests. Non-normally distributed data are described using medians. Categorical variables are described using frequency and percentage. Interview data were managed and analyzed using MAXQDA2020 software. Non-parametric statistical methods were employed for analysis. The descriptive data for themes were initially coded, and frequently occurring statements were categorized based on similar phrases, emotions, experiences, and values to identify themes.

3. Results

3.1 Quantitative Survey Results

3.1.1 General Characteristics of ASD Children and Their Caregivers

A total of 270 questionnaires were distributed, with 261 valid responses collected, yielding a valid response rate of 96.66%. Among the children with autism, 210 were male and 51 were female, with the majority (159 cases) aged 3–5 years. The caregivers were predominantly female (236 individuals), with the majority (132 individuals) aged 30–39 years. Details are presented in Table 1.

Table 1. Single factor analysis of FRAS-C scores in 261 ASD children

Item	n (%)	FRAS-C	t/F	P
Child's Gender				
Male	210 (80.45)	70.25 ± 14.65	2.54	<0.001
Female	51 (19.55)	75.22 ± 12.29		
Child's Age (years)			3.56	<0.001
<3	19 (7.27)	63.67 ± 14.88		
3-5	159 (60.91)	68.56 ± 12.65		
6-8	65 (24.90)	73.75 ± 17.23		
≥9	18 (6.92)	82.32 ± 12.36		
Illness Duration (years)			-2.77	<0.001
<3	112 (42.91)	68.78 ± 11.29		
≥3	149 (57.09)	73.26 ± 14.56		
Payment Method			3.68	<0.001
Out-of-pocket	21 (8.04)	63.08 ± 13.96		
Medical Insurance	136 (52.10)	70.36 ± 12.89		
Insurance + Disability Subsidy	104 (39.86)	75.63 ± 14.21		
Relationship to Child			1.08	0.436
Parent	236 (90.42)	75.36 ± 9.63		
Grandparent	25 (9.58)	71.23 ± 14.53		
Caregiver's Age (years)			1.63	0.213
20-29	55 (21.07)	70.52 ± 10.21		
30-39	132 (50.57)	69.63 ± 15.32		
40-49	43 (16.47)	78.23 ± 19.36		
50-59	15 (5.74)	70.89 ± 11.12		
≥60	16 (6.15)	69.32 ± 6.63		
Care Duration (years)			2.56	<0.001
<3	122 (46.74)	63.56 ± 12.36		
3-6	120 (45.97)	70.52 ± 13.85		
>6	19 (7.29)	76.32 ± 15.36		
Caregiver's Gender				
Male	25 (9.57)	72.36 ± 10.56	1.79	0.007
Female	236 (90.43)	74.03 ± 11.23		

3.1.2 Family Resilience Scores of Families with Autistic Children

The total FRAS-C score for the families of children with autism was (71.26± 15.03), with a mean item score of (2.24 ±0.56). The scores and mean item scores for each dimension of the FRAS-C are presented in Table 2.

Table 2. Total FRAS-C scores and dimensions of 261 ASD children (score, $\bar{x} \pm s$)

Dimension	Score (Mean ± SD)	Mean Item Score (Mean ± SD)
Family Communication and Problem-Solving	19.56 ± 11.23	2.18 ±0.65
Utilizing Social Resources	7.13 ± 1.62	2.41 ±0.25
Maintaining a Positive Attitude	13.63 ± 4.41	2.25 ± 0.66
Total Score	71.26± 15.03	2.24 ±0.56

3.2 Qualitative Interview Results

3.2.1 Characteristics of Interview Participants

Nine caregivers of children with ASD who demonstrated relatively high levels of family resilience participated in the interviews. Their detailed characteristics are presented in Table 3.

Table 3. Characteristics of Interviewees and Their Children (n=9)

Code	Caregiver Age (years)	Child Age (years)	Symptom Severity[8]	Illness Duration (years)
P1	37	3	①	18
P2	24	6	②	24
P3	41	3	②	12
P4	39	2.5	②	36
P5	38	6	①	20
P6	26	4	①	26
P7	38	5	②	48
P8	40	2.5	②	14
P9	33	5	①	32

3.2.2 Interview Results

3.2.2.1 Forming an Inclusive and Resilient Mindset

3.2.2.1.1 Patience

Interviewees reported becoming more patient with their children after recognizing the diagnosis, particularly in responding to the children's problematic behaviors during daily life and interventions with a more tolerant attitude. P3: "I used to be very impatient. Now I can control my temper better and be more patient."

3.2.2.1.2 Resilience

After their children were diagnosed with autism, some interviewees were able to face life's difficulties and setbacks with a more resilient and positive mindset. P7: "I myself have become stronger, and my ability to handle pressure has improved. For example, when encountering difficulties at work, I can adjust my mindset quite well."

3.2.2.1.3 Empathy

Through the process of caring for a child with autism, the interviewees experienced burden and pressure, which made them more empathetic towards other children and parents. P6: "When chatting with other parents in the group, I can really understand the feelings of parents when their children don't make progress at the beginning of intervention."

3.2.2.2 Multidimensional Ability Improvement

3.2.2.2.1 Learning and Communication Skills

Caregivers improved their learning and communication skills through interactions with other parents of children with autism. P6: "We discuss, learn, and share with each other, and then find suitable methods for our children to carry out interventions."

3.2.2.2.2 Parenting and Intervention Skills

Parents enhanced their parenting and intervention abilities by setting family training goals and mastering basic intervention techniques. P4: "I went to Beijing for three months to learn Applied Behavior Analysis... The combination of integration and family intervention has led to significant progress in my child."

3.2.2.2.3 Work Ability

Having gone through the process of seeking medical help and interventions for their children, parents enriched their life experiences. This allowed them to face setbacks at work with a better mindset and solve problems more effectively. P8: "Although this business trip to the north was very difficult, I succeeded. I feel that through these complex life experiences... my work ability has improved."

3.2.2.3 Family Collaboration and Resilience

3.2.2.3.1 Reshaping Self-Worth

Parents re-examined their own meaning and value and attempted to reshape their self-worth through different ways. P5: "I value myself more now. I didn't understand self-care before; all my time was spent on the family and the child... I feel life is short, and I should live a little for myself."

3.2.2.3.2 Experiencing Life Satisfaction

Faced with the challenges of integrating their children with autism into kindergarten and society, parents gained satisfaction with life by adjusting their expectations for their children. P7: "Later, I gradually came to accept the situation. Anyway, life must go on. We just try our best to help the child master more life skills so he can live a normal life when he grows up. We are very satisfied with that."

3.2.2.3.3 Forming Positive Health Concepts

Some parents changed their views on money and personal value, placing greater importance on the health of both their children and themselves. P2: "Making money shouldn't be the most important thing; the child's health is the most important. If the child is not healthy, no amount of money is useful."

4. Discussion

This study found that the mean total Family Resilience Assessment Scale–Chinese version score among families of children with autism was 71.26 ± 15.03 , lower than resilience levels reported in families of stroke survivors[10] and breast cancer patients[11]. These findings suggest that family resilience in caregivers of autistic children is suboptimal and warrants targeted improvement. This may be attributed to autism spectrum disorder being a lifelong neurodevelopmental condition requiring intensive, costly, and often prolonged rehabilitation with uncertain outcomes. Such demands impose substantial physical and psychological burdens on caregivers, impairing family functioning and structural adaptability, and consequently diminishing resilience.

Research indicates that raising a child with autism presents unique challenges, including persistent concerns about prognosis and uncertainty throughout the rehabilitation process—factors that further compromise family resilience[12]. Nevertheless, this study also identified multifaceted resilience and posttraumatic growth among caregivers, manifested as increased psychological flexibility, enhanced coping capacities, and the reconstruction of personal and familial meaning. These observations align with posttraumatic growth theory[13], which posits that individuals may experience positive psychological transformation following adversity through reflective processing. In this context, caregivers demonstrated growing acceptance of their children's behaviors, cultivated empathy, and reported improved emotional well-being. Evidence confirms that adaptive cognition and effective coping strategies are key determinants of parental adjustment in families of children with autism[14]. Therefore, timely psychological support and training in evidence-based intervention techniques can facilitate the development of realistic, sustainable coping mechanisms, thereby promoting resilience enhancement and long-term growth.

External support emerged as a critical enabler of family resilience, bolstering caregivers' competence and confidence in managing interventions. However, findings differ partially from Xu Jiayi et al.[15], who reported increased psychological resilience and self-efficacy among parents of adolescents with mood disorders despite caregiving stress. This discrepancy may reflect the protracted course of autism and the typically slow, nonlinear progress in developmental outcomes. Even when caregivers acquire skills, their self-efficacy may fluctuate in response to recurring behavioral challenges or limited therapeutic gains[16].

Consistent with prior literature[17], this study found that parents often reconstruct life meaning amid caregiving demands, adopting a more open and reflective outlook on life and placing greater emphasis on personal and familial well-being. Resilience in this context evolves from passive endurance to active meaning-making. Key strategies—such as access to social support, psychological flexibility training, professional education, peer networks, emotional support, and cognitive behavioral therapy[18]—serve as vital pathways to strengthen caregivers' sense of purpose and meaning-making capacity.

5. Limitations of Existing Studies

This study was conducted solely in Shenzhen, which limits the geographical representativeness of the sample. Future research could employ multi-center surveys to enhance the generalizability of the findings. Furthermore, this study utilized a cross-sectional design with a single measurement point, which cannot capture the long-term dynamics of family resilience. Future studies should adopt longitudinal designs with multiple assessment points to comprehensively explore the dynamic changes in resilience over time.

6. Conclusion

The results indicate that the level of family resilience is at a medium-low level, with overall low scores in the dimensions of family communication and problem-solving, utilization of social resources, and maintaining a positive attitude. The study identified five core themes: an inclusive and resilient mindset, multidimensional ability improvement, and family members reconstructing self-worth and life meaning. These findings reflect the multidimensional experiences of caregivers during the caregiving process. Healthcare professionals should pay attention to parents' positive coping experiences, provide psychological support and professional care guidance, and help families cope with challenges to promote the healthy functioning of the family system.

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