# Study on family quality of life in caregivers of children with ASD and its influencing factors

(scientific paper)

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***Abstract:*** *This study was aimed to identify quality of family life in caregivers of children with autism spectrum disorder (ASD) and its influencing factors. A total of 165 caregivers parenting a child with ASD from Sichuan province in China were investigated by the Chinese version of Beach Center Family Quality of Life Scale to assess five domains: family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support. Results indicated that the caregiver's satisfaction on quality of family life was at the medium level. Caregivers felt the most satisfied with family interaction and the least satisfied with family physical/material well-being. The multiple linear regression analysis revealed that quality of family life was affected by caregiver's employment status, place of residence, monthly income, and income and expenditure situation. The findings of the study highlight the need for social support to enhance quality of family life in caregivers of children with ASD, which would be finally benefit to children in the families.*

***Keywords:*** *caregivers of children with ASD, quality of family life, influencing factors*

## 1 Introduction

Autism spectrum disorder (ASD) was defined as neurodevelopmental disorder that is characterized by persistent impairment in reciprocal social communication and social interaction, and restricted, repetitive patterns of behavior, interests, or activities (APA, 2013). As a permanent developmental disorder, it will bring lifelong challenges to individuals (Hendricks, & Wehman, 2009). Families play a key role throughout the lifespan of individuals with ASD. However, families of children with ASD are more likely to suffer from depression than families of children with other disabilities, and they may also have a heritable vulnerability for depression (Tonge,

Brereton, Kiomall, et al., 2006). Consequently, families raising a child with ASD are under stress that may impact their quality of family life, which in turn make against to the development of children with ASD.

Researches about quality of family life originated from quality of individual life. With the deepening of people's understanding on the importance of family to children's physical and mental development, more attention has turned to quality of family life in recent years. Quality of family life is defined as occurring when the family's needs are met, family members enjoy their life together as a family, and family members have the opportunity to pursue and achieve outcomes that are important to their happiness and fulfillment (Turnbull, Turnbull, Poston, et al., 2004). Luo (2014) reported a middle and lower level of satisfaction on quality of family life after surveying 90 caregivers of children with autism from Chengdu in Sichuan province with a self-designed questionnaire. Li (2016) also reported a middle and lower level of satisfaction on quality of family life of 211 caregivers of children with ASD, as measured by the Chinese version of Beach Center Family Quality of Life Scale. She also found four influencing factors of quality of family life, namely family atmosphere, parents mentality, children's problem, and social support. While Ma (2014) found that quality of family life of parents of children with autism was at lower level, and was affected by children's gender, the time of illness, parents work or not, parents' educational level, income, and living condition. In addition, Bayat (2005) found a significant relationship between each variable: child's age, income, depression, perceptions of positive contributions of autism and the variable: family quality of life. Schlebusch, Dada, & Samuels (2017) conducted a survey with 180 families of children with ASD in South Africa with the Beach Center Family Quality of Life Scale and found that family income, family type, and the severity level of autism were significantly associated with how satisfied families felt about their quality of life. It can be found from these existing researches that families of children with ASD had lower level of quality of family life, and the quality of family life was associated with child's characteristics and family's characteristics.

Although research on quality of life of families of children with ASD has become more common, it remains underdeveloped in developing countries like China. Considering having a child with ASD places a number of burdens on the shoulders of the caregivers, more researches should be conducted to further examine the quality of life of families with children with ASD. The focus of the current study was to survey quality of family life of children with ASD and identify its influencing factors, hoping to help improving quality of family life of children with ASD, and then create a better family environment for the development of children with ASD.

## 2 Method

### 2.1 Participants

The study focused on quality of life of families raising a child with ASD. The study followed the age criteria set by UNCRC that defines children as the period from birth to 18 years old. So the families raising a child with ASD under 18 years old had been recruited in this study. Finally, 165 families of children with ASD from Chengdu, Mianyang, Deyang, Leshan, and Bazhong of Sichuan province were surveyed in this study. As reported in Table 1, the participating families have child mostly males (n = 110, 67.10%), and others are females (n = 54, 32.90%). The children ranged in age from 2 to 17 years (M = 9.77, SD = 2.969), and severity level from mild (n = 28, 17.10%), moderate (n = 59, 36.00%), severe (n = 65, 39.60%), to very severe (n = 12, 7.30%). The participants were largely married or living with a partner (n = 140, 85.40%), and the others were divorced, separated, or widowed (n = 24, 14.60%). Most participants were unemployed (n = 76, 46.60%), others had full time jobs (n = 59, 36.20%), part time jobs (n = 16, 9.80%), or were looking for jobs (n = 12, 7.40%). Most participants had received a primary school degree (n = 48, 29.00%), while others had a junior school (n = 32, 19.40%), senior high school (n = 28, 17.00%), junior college (n = 26, 15.80%), bachelor or above degree (n = 31, 18.80%). Most participants lived in cities (n = 82, 49.70%), others lived in towns (n = 35, 21.20%) and villages (n = 48, 29.10%). A majority of participants had income more than 2000 RMB per month (n = 119, 72.60%), others had below 2000 RMB (n = 45, 27.40%). Accordingly, most families had basic balance of income and expenditure (n = 69, 41.80%), and many families could not make ends meet (n = 64, 38.80%), while only a few families income exceeded expenditure (n = 32, 19.40%).

**Table 1:** *Participant Families Demographics (N = 165)*

| Variables | Category | Frequency | % |
|---|---|---|---|
| Child's gender | Male | 110 | 67.10 |
| | Female | 54 | 32.90 |
| Child's age | Aged 6 and under | 18 | 11.10 |
| | Aged 7~14 | 120 | 74.10 |
| | Aged 15~17 | 24 | 14.80 |
| Child's severity level | Mild | 28 | 17.10 |
| | Moderate | 59 | 36.00 |
| | Severe | 65 | 39.60 |
| | Very severe | 12 | 7.30 |

| | | | |
|---|---|---|---|
| Caregiver's marital status | Married, or living with a partner | 140 | 85.40 |
| | Divorced, separated, or widowed | 24 | 14.60 |
| Caregiver's educational level | Primary school or less | 48 | 29.00 |
| | Junior school | 32 | 19.40 |
| | Senior high school | 28 | 17.00 |
| | Junior college | 26 | 15.80 |
| | Bachelor degree or above | 31 | 18.80 |
| Caregiver's employment status | Full-time job | 59 | 36.20 |
| | Part-time job | 16 | 9.80 |
| | Job-waiting | 12 | 7.40 |
| | Unemployment | 76 | 46.60 |
| Place of residence | City | 82 | 49.70 |
| | Town | 35 | 21.20 |
| | Village | 48 | 29.10 |
| Monthly income | ≦ 2000 yuan | 45 | 27.40 |
| | 2001~4000 yuan | 63 | 38.40 |
| | 4001~6000 yuan | 18 | 11.10 |
| | 6001~8000 yuan | 14 | 8.50 |
| | 8001~10000 yuan | 13 | 7.90 |
| | ≧ 10000 yuan | 11 | 6.70 |
| Income and expenditure situation | Income far outweighs expenditure | 14 | 8.50 |
| | Income slightly exceeds expenditure | 18 | 10.90 |
| | Basic balance | 69 | 41.80 |
| | Can't make ends meet | 64 | 38.80 |

## 2.2 Procedure

Each recruited family received a letter explained the purpose of the study and stated that participation was voluntary and the family's information would be kept confidential. If the families agreed to participate in, a parent or caregiver was asked to fill out the questionnaires on behalf of the family.

## 2.3 Measures

Child's gender, age, and severity level, caregiver's marital status, educational level, and employment status, and place of residence, monthly income, and income and expenditure situation were collected in the study through caregiver's reports on a brief demographic questionnaire. Then, Chinese version of Beach Center Family Quality of Life Scale (BCFQOL) was used to evaluate quality of family life. It was developed

by Beach Center of University of Kansas and translated by Shuxian Zeng and Kai Liu from Central China University, consisting of 25 items across five subdomains: family interaction, parenting, emotional well-being, physical/material well-being and disability-related support. For each item, caregivers rated their satisfaction from 1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4 = satisfied, to 5 = very satisfied. Responses were summed to form a total score, ranging from 0 to 125, which was then averaged into a single mean score. The Chinese version of BCFQOL has been proved with high internal consistency (Li, 2016). In this study, the Cronbach alpha coefficients of each dimension of the scale ranged from 0.72 to 0.84, and the Cronbach alpha coefficients of the total scale was 0.93. The confirmatory factor analysis showed that $\chi 2/df$ (chi-square / degrees of freedom) was 1.380, CFI (Comparative Fit Index) was 0.954, TLI (Tucker Lewis Index) was 0.938, IFI (Incremental Fit Index) was 0.956, GFI (Goodness of Fit Index) was 0.878, and RMSEA (Root Mean Square Error of Approximation) was 0.049. This provided evidence that the scale was measured in a reliable and valid manner for the study population.

### 2.4 Statistical analysis

Data were analyzed using IBM SPSS version 18.0 and AMOS version 17.0. In detail, the reliability and validity of the scale were determined. Descriptive statistics were conducted to characterize the demographic characteristics of the caregivers and children, and caregiver's quality of family life. Discrepancies scores were calculated for the items on BCFQOL in demographic variables. The significance level was set at 0.05. Multiple linear regression analysis was performed to examine the effect of the demographic variables on the study variable: quality of family life.

## 3 Results

### 3.1 Quality of family life

According to the statistical analysis, the mean score of caregivers' satisfaction on quality of family life was 3.40 (SD = 0.62), which was between the general level (3 points) and the satisfaction level (4 points). As to each dimension, the mean score from high to low was family interaction, parenting, disability-related support, emotional well-being, and physical/material well-being. See Table 2. That is to say, families felt the most satisfied with family interaction and the least satisfied with physical/material well-being.

**Table 2:** *Satisfaction ratings of the overall quality of family life and its dimensions*

| Description | M±SD |
|---|---|
| Family interaction | 3.57±0.77 |
| Parenting | 3.48±0.72 |
| Emotional well-being | 3.25±0.77 |
| Physical/material well-being | 3.24±0.77 |
| Disability-related support | 3.34±0.76 |
| Overall quality of family life | 3.40±0.62 |

*Note: M = mean; SD = standard deviation*

## 3.2 Differences of family quality of life in demographic variables

The Table 3 showed that there were no significant differences on the scores of quality of family life in child's gender and age ($p > 0.05$), but there were significant differences on the scores of quality of family life in child's severity level, caregiver's marital status, educational level, and employment status, and place of residence, monthly income, and income and expenditure situation ($p < 0.01$).

**Table 3:** *Score comparison on overall quality of family life in different demographic variables*

| Demographic variables | Quality of family life (M±SD) | F or t | p | LSD |
|---|---|---|---|---|
| Child's gender | | | | |
| Male | 3.43±0.64 | 0.846 | 0.399 | |
| Female | 3.33±0.57 | | | |
| Child's age | | | | |
| Aged 6 and under | 3.42±0.77 | 0.021 | 0.979 | |
| Aged 7~14 | 3.40±0.58 | | | |
| Aged 15~17 | 3.37±0.87 | | | |
| Child's severity level | | | | |
| ① Mild | 3.57±0.83 | 4.404 | 0.005 | ① > ③, ④ |
| ② Moderate | 3.55±0.50 | | | ② > ③, ④ |
| ③ Severe | 3.23±0.59 | | | |
| ④ Very severe | 3.12±0.45 | | | |
| Caregiver's marital status | | | | |
| Married, or living with a partner | 3.44±0.63 | 2.771 | 0.009 | |
| Divorced, separated, or widowed | 3.14±0.45 | | | |

| | | | | |
|---|---|---|---|---|
| Caregiver's educational level | | | | |
| ① Primary school or below | 3.11±0.45 | 4.480 | 0.002 | ①<②, ③, ④, ⑤ |
| ② Junior school | 3.39±0.56 | | | |
| ③ Senior high school | 3.50±0.61 | | | |
| ④ Junior college | 3.56±0.69 | | | |
| ⑤ Bachelor degree or above | 3.62±0.71 | | | |
| Caregiver's employment status | | | | |
| ① Full-time job | 3.62±0.67 | 7.204 | <0.001 | ①, ②>④ |
| ② Part-time job | 3.56±0.63 | | | |
| ③ Job-waiting | 3.44±0.51 | | | |
| ④ Unemployment | 3.16±0.50 | | | |
| Place of residence | | | | |
| ① City | 3.58±0.66 | 7.016 | 0.001 | ①>②, ③ |
| ② Town | 3.24±0.51 | | | |
| ③ Village | 3.22±0.54 | | | |
| Monthly income | | | | |
| ① ≦ 2000 RMB | 3.16±0.49 | 3.623 | 0.004 | ①<②, ③, ⑤ |
| ② 2001~4000 RMB | 3.40±0.61 | | | ②, ⑥<⑤ |
| ③ 4001~6000 RMB | 3.56±0.63 | | | |
| ④ 6001~8000 RMB | 3.48±0.76 | | | |
| ⑤ 8001~10000 RMB | 3.93±0.43 | | | |
| ⑥ ≧ 10000 RMB | 3.39±0.75 | | | |
| Income and expenditure situation | | | | |
| ① Income far outweighs expenditure | 3.61±0.68 | 11.417 | <0.001 | ①, ②, ③>④ |
| ② Income slightly exceeds expenditure | 3.80±0.68 | | | |
| ③ Basic balance | 3.55±0.60 | | | |
| ④ Can't make ends meet | 3.09±0.46 | | | |

*Note: M = mean; SD = standard deviation; F = Fisher's ratio; t = t statistic; p = p-value; LSD = least significant difference*

Independent t-test was conducted for the score comparison of overall quality of family life between child's genders.

One-way ANOVA was conducted for the score comparison of overall quality of family life among child's ages, severity levels, caregiver's marital status, educational levels, employment status, places of residence, monthly income, and income and expenditure situations.

LSD method was used for post-hoc comparisons in cases when significant difference were found in one-way ANOVA.

### 3.3 Regression analysis for variables predicting quality of family life

This study conducted multiple linear regression analysis with demographic variables as independent variables and the quality of family life as the dependent variable, in which classification demographic variables had been set as dummy variables. As demonstrated in Table 4, caregiver's employment status, place of residence, monthly income, and income and expenditure situation were found as a significant impact on the quality of family life.

**Table 4:** *Multipleregression for variables predicting quality of family life*

| Dependent variable | Independent Variables | B | SE | β | t | p |
|---|---|---|---|---|---|---|
| Quality of family life | Caregiver's employment status | –0.290 | 0.117 | –0.235 | –2.481 | 0.014 |
| | Place of residence | –0.252 | 0.120 | –0.168 | –2.096 | 0.038 |
| | Monthly income | –0.451 | 0.227 | –0.185 | –1.988 | 0.049 |
| | Income and expenditure situation | –0.545 | 0.190 | –0.433 | –2.874 | 0.005 |
| | Adj $R^2$ | | | 0.226 | | |
| | F | | | 4.308 | | |
| | p | | | < 0.001 | | |

*Note: Method = Enter. B = unstandardized coefficient; SE = standard error; β = standardized regression coefficient; t = t statistic; p = p-value; Adj $R^2$ = explained variance in the dependent variable; F = Fisher's ratio*

## 4 Discussion

One objective of the study was to describe the perceived quality of life of families raising a child with ASD in China. This study found that caregivers' satisfaction on quality of family life was at the medium level, meaning that there was still much room for improvement in the quality of family life. This result is consistent with previous researches (Luo, 2014; Li, 2016; Ma, 2014; Xue, 2014). Families of children with ASD tended to have depression, anxiety, obsession-compulsion, interpersonal sensitivity, hostility, schizoid trait, paranoia, and schizophrenia (Gau, Chou, Chiang, et al., 2012). In other words, families of children with ASD usually experienced higher level of psychological stress than families of children with other developmental disabilities (Sanders, Morgan, 1997; Bromley, Hare, Davison, et al., 2004). Besides, families of children with ASD had heavier professional and financial burdens than families with typically developing children (Yang, & Wang, 2014). So caregivers of children with ASD might face pressure from a smaller range of interpersonal relationships, lower financial resources, changes in family structure, lack of specific rehabilitation methods, and children's medical conditions and so on (Sun, 2011). All of these seriously affect the quality of life of families with children with ASD.

The mean score of satisfaction on five dimensions of quality of family life from high to low was family interaction, parenting, disability-related support, emotional well-being, and physical/material well-being, illustrating that caregivers of children with ASD felt the most satisfied with the communication and interaction between family members. The result is consistent with the result found by Luo (2014), Li (2016), and Hu and Wang (2012). It explains that the appearance of children with disabilities can improve some families' marital status. As one survey showed, 50 percent of families believed the arrival of children with autism had a positive impact on their marriage bonds (Luo, 2014). This is probably because some families communicated more with each other due to the educational needs of children with ASD, and thus their satisfaction on the internal family interaction was improved. And Rodrigue et al. (1990) found the family cohesion of caregivers of children with autism was at a high level, which further lends evidence that there are close emotional connections between family members of children with ASD. Besides, consistent with the research of Hu and Wang (2012), but inconsistent with those of Luo (2014), and Li (2016), caregivers of children with ASD reported the least satisfied with their physical or material well-being, such as medical care, and transportation and so on. Children with ASD usually have difficulties in understanding social cues and facial expressions, issues expressing emotions in conventionally recognizable ways, inflexibility and discomfort with change, and difficulty adapting to new tasks and routine (Wehman, Lau, Molinelli, et al., 2012). Therefore, compared with families of children with other disability types, families of children with ASD experienced the highest level of stress in performing parental roles and parent-child interaction (Guan, Yan, & Deng, 2015). This means that families of children with ASD have more material needs than families with other types of disabilities. However, a study found that China's current social security system was not perfect, and there were relatively few preferential and universal policies for caregivers of children with ASD (Liu, & Liu, 2018). Therefore, policy support for families of children with ASD needs to be strengthened to promote family stability and harmony, so as to ensure the benign development of children with ASD.

Another objective of the current study was to explore the influencing factors of quality of family life. Studies have shown that there was a high correlation between children's characteristics and the quality of family life (Li, 2016). This study examined the effect of child's gender, age, and severity level on the quality of family life, and found that there were significant differences in the quality of family life among different severity levels. Caregivers of children with mild and moderate autism scored significantly higher on family quality of life than caregivers of children with severe and very severe autism. It is similar to the result of Wang et al. (2004). There is no doubt that the more severely disabled a child is, the more complex the problem

behaviors will be and the more difficult it will be to deal with them. Therefore, education and rehabilitation will be more difficult for them, which will bring some negative effects on the quality of family life. However, the severity level of autism was not included in the regression analysis, showing that the severity level had no significant impact on the quality of family life under the comprehensive effect of caregivers and family factors. This may be because the diagnosis of autism can be devastating to the family regardless of the child's condition, and the ensuing confusion and constant worry about the future combined affect the quality of family life.

This study also examines the impact of caregiver's marital status, education level, and employment status on the quality of family life. First of all, there was a significant difference in the quality of family life between caregiver's marital status. Married or having a life partner families scored significantly higher on quality of family life than divorced, separated or widowed families. It indicates that family marital status would affect the quality of family life, which is consistent with the findings of Ren et al. (2018). Because of the complex of autism, caregivers of children with ASD have the greatest difficulty in raising child and bearing the greatest pressure compared with those of other disabled children (Guan, Yan, & Deng, 2015). So well-married family members can encourage and support with each other and jointly cope with the pressure and challenges of raising children with ASD, which is of great significance to improve their quality of family life. Secondly, there were significant differences in the quality of family life on the educational level of caregivers. Caregivers with primary school or less degree had significantly lower score on quality of family life than those with junior school degree or above. It reveals that the education level was related to the quality of family life, which is consistent with the research of Ma (2014). The higher the degree of education parents received, the higher their expectations for their children were, the more they could actively acquire as many special education books as possible, and they would choose a more active way to deal with the problems while educating children (Huang, & Liu, 2006). Therefore, the higher the education level of caregivers of children with ASD, the more able they were to cope with the challenges in raising their children. At the same time, they could regulate their emotions more reasonably and seek ways to release pressure, thus improving the quality of family life. At last, there were significant differences in the quality of family life among different employment status. Regression analysis found that caregivers' employment status had a significant impact on the quality of family life. It is consistent with the research of Ma (2014). Regular work could help caregivers reduce their pain and increase their happiness (Möller-Leimkühler, Wiesheu, 2012). Therefore, full-time working families could not only get a relatively stable source of income, but also obtain a sense of career achievement to relieve the physical and mental burden of long-term care for children with ASD. However, unemployed caregivers need to take care of children with ASD around the clock for a long time, and they may also

be constantly on the move to seek suitable jobs. So physical fatigue and psychological burden lead to the decline of quality of family life.

The study explored the impact of place of residence, monthly income, and income and expenditure situation on the quality of family life as well. First of all, there were significant differences in the quality of life among different places of residence. Further regression analysis showed that the place of residence had a significant impact on the quality of family life. It is inconsistent with the research of Ma (2014), may be related to the difference of the sample region. Effective social support could improve the quality of life of parents with disabled children (Guan, Yan, & Deng, 2015) because appropriate social support could improve the ability of families to cope with challenges and adapt to the environment to some extent (Gray, 2002). However, a survey found that the social support for families of children with ASD was affected by where the family lives. Education resources were relatively abundant in big cities, while insufficient in small towns and rural areas (Xiong, & Sun, 2014). This suggests that we should strengthen social support for families and improve their quality of life, so as to create a good family environment for the development of children with ASD. In addition, there were significant differences in the quality of family life in terms of monthly income, and income and expenditure situation. The result is similar to researches conducted by Ma (2014), Wang et al (2004), and Schlebusch, Dada, & Samuels (2017). The monthly income, income and expenditure situation of the family were included in the regression analysis, indicating that family's socioeconomic status was an important factor affecting the quality of family life. Families with high socioeconomic status had more resources at their disposal than low-income families to overcome the challenging problems posed by children's disabilities (Turnbull, & Turnbull, 2001) and children received intervention training or not affected the quality of family life (Ren, et al., 2018). Therefore, families with higher income were more able to cope with education costs of children, and the progress made by children in intervention training increases the positive psychology of families, thus improving the quality of family life. However, the annual income of families of children with ASD was lower than that of families with typically developing children, and the annual average cost of education training for children with ASD was higher (Yang, & Wang, 2014). It suggests that it is necessary to strengthen financial support for families to help them increase their ability to cope with challenges and improve the quality of family life, and finally contribute to create a good family environment for children with ASD.

## 5 Conclusion

The present study found that the satisfaction on quality of family life of children with ASD was at the medium level. Families felt the most satisfied with family interaction

and the least satisfied with physical/material well-being. Quality of family life was affected by caregiver's employment status, place of residence, monthly income, and income and expenditure situation.

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