

Status of Chinese Children with Autism Spectrum Disorder

Subjects: Nursing

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Autism spectrum disorder (ASD) is characterized by an individual's deficits in social communication and interaction, accompanied by repetitive and stereotyped behaviors and a restricted scope of interests. The prevalence of ASD among Chinese children over the past two decades has attracted substantial attention from practitioners, researchers, and policymakers.

Keywords: parental involvement ; family SES ; children with ASD

1. Introduction

Autism spectrum disorder (ASD) is characterized by an individual's deficits in social communication and interaction, accompanied by repetitive and stereotyped behaviors and a restricted scope of interests ^{[1][2]}. The prevalence of ASD among Chinese children over the past two decades has attracted substantial attention from practitioners, researchers, and policymakers. Although there is no official report on the exact number of children with ASD, it is estimated that the ratio of children being diagnosed with various autistic symptoms in China has reached approximately 1 per 100 ^[3]; given the immense population of China, this ratio translates into some 13 million children across the country. Education and care for children with ASD have become a pressing social issue in contemporary Chinese society.

Chinese parents attach great importance to children's education and academic success; therefore, they are usually actively involved in children's learning; parents of children with ASD are no exception ^{[4][5]}. Parental involvement refers to a series of parental practices to promote children's learning and development at home and school, including parents' educational beliefs, academic expectations, and various forms of parenting behaviors ^[6]. Parental involvement in education plays an important role in the development of children with ASD. Extensive research has suggested that children with ASD benefit from parental involvement in various developmental areas, including improved social skill acquisition, maintenance, and generalization across school, home, and community settings ^{[1][7]} and increased opportunities for social, cognitive, and language development ^[8]. Furthermore, since children with ASD have difficulties communicating with their parents about their learning in schools, educational involvement is necessary and beneficial for parents to acquire information and join hands with educators to coordinate the best possible services for their children. In addition, parental involvement provides teachers with critical information about family values, routines, and children's strengths and weaknesses, based on which educators and specialists can design more targeted interventions for children with ASD ^[9]. Nevertheless, several studies have demonstrated that low family socioeconomic status (SES) is a salient risk factor that undermines the effect of parental involvement ^{[10][11]}. This gives rise to numerous challenges for the large number of Chinese parents who not only face the difficulty of raising children with ASD, but also live in low socioeconomic conditions. In comparison to parents with higher SES, parents of lower SES show disadvantages in the frequency and quality of their involvement in their children's education ^[12]. For parents raising children with ASD, prior studies have found that family SES, such as parents' low education level and household income, can constrain their ability to make decisions to meet the children's educational needs ^{[13][14]}.

According to Belsky's (1984) process model of parenting ^[15], parenting behaviors are shaped by family contextual sources, parental psychological traits, and children's characteristics. In addition to family SES, two other influencing factors of parental involvement, namely, parenting stress and ASD symptom severity, have received extensive attention from researchers ^{[5][8]}. According to Eccles and Harold's (1996) parental involvement model ^[16], the association between family SES and parental involvement reflects the processes in which the distal contextual factors affect parental involvement via the proximal factors internal to them. Therefore, family SES, as a family contextual source, may influence parental involvement through parenting stress and children's ASD symptom severity. However, to date, little is known

about the relationship between family SES and parental involvement and the potential role of parenting stress and ASD symptom severity in the Chinese context.

2. Family Socioeconomic Status and Parental Involvement

It has been shown by prior research that family SES is a strong predictor of parental involvement ^{[17][18]}. It reflects the degree to which a family possesses, receives, and manages the available resources, including wealth, power, social status, etc.; it is usually measured by parents' educational and income level ^[19]. Previous research has found that parents with higher levels of income and education are more likely to participate in children's education, indicating that the family's socioeconomic resource plays an important role in increasing parental involvement ^[20]. In general, upper-middle-SES parents feel more comfortable communicating with teachers when participating in school activities than lower-SES parents do ^[21]. Lee and Bowen (2006) found that compared to parents with higher educational degrees, parents with lower educational levels showed considerably less attendance in the activities or meetings organized by the school; they also tended to talk less about educational issues with their children and had lower expectations for their children's academic achievement ^[22].

For parents of children with ASD, research evidence has suggested that family SES is an important contextual factor affecting parental involvement ^[23]. Norbury and Sparks (2013) found that parents with low SES faced the priority of maintaining a residence and providing for the family; consequently, they tended to spend less time on educating their children with ASD compared to those who had no such family economic pressure to attend to ^[24]. Similarly, Benson et al. (2008) found that family SES exerted a significant positive effect on maternal home-based educational involvement ^[13]. However, despite the established link between family SES and parental involvement, it is unlikely and infeasible for all family-based interventions to include direct financial support to raise family SES. Thus, empirical research needs to target potentially amenable factors that may improve parental involvement among those who raise children with ASD.

3. Mediation Effect of Parenting Stress between Family SES and Parental Involvement

Parenting stress is conceptualized as a stressful experience in which parents fulfill their child-rearing roles while undergoing various negative psychological episodes such as anxiety, frustration, and self-blame ^{[25][26]}. In particular, parents raising children with ASD are more likely to experience substantial psychological, financial, and physical burdens, given the severity of their children's disabilities ^[27]. Previous studies have reported that compared to parents of children with other developmental disorders, such as Down's syndrome or developmental delay, parents of children with ASD typically report higher levels of parenting stress and depression ^{[26][28]}. Among non-ASD groups, the links between parenting stress and parental involvement have also been revealed, with recent evidence showing the negative effects of cumulative stress on parental involvement ^[29]. Consistent with this notion, Yao and Liu (2018) reported that stressful events throughout the lifespan could produce a spillover effect in which the negative emotions of family members transferred from one situation to another under long-term high pressure, which reduced the motivation, frequency, duration, and quality of parental participation in children's education ^[30]. According to Hoover-Dempsey et al.'s (2005) family involvement model ^[31], parenting stress is identified as an adverse psychological factor hindering parents' involvement in children's education. Other research has also indicated that the high level of stress associated with raising a child with severe behavioral challenges could lead to parents' low level of self-efficacy, which in turn, discourages them from actively engaging in children's educational activities ^{[13][32]}. Similarly, the parenting stress of raising a child with ASD has been identified as a factor associated with the negative long-term outcome of parental involvement, such as less parent-child interaction and low frequency of home-school communication ^{[8][33]}.

Prior research has demonstrated the association between family SES and parenting stress ^{[34][35][36]}. Some researchers have found that mothers from low-SES households are more likely to undergo uncontrollable negative life events and stressful experiences, which significantly increase the risk of developing mental health problems, including parenting stress ^{[37][38]}. Moreover, the combined effect of low SES and parenting stress may result in family dysfunctions that can further worsen the quality of parent-child interaction and parental involvement ^[39]. According to the family stress model ^[40], stressors such as socioeconomic strains (i.e., low family socioeconomic status) can result in psychological distresses, including depression and anxiety, thereby leading to less involved parenting. Consistent with this model, Emmen et al.'s (2013) research demonstrated that the relation between family SES and positive parenting was partially mediated by general maternal psychological stress and maternal acculturation stress ^[35]. Likewise, it is plausible that high family SES can provide social support and proximal resources that help parents cope with parenting stress, thereby improving parental involvement. In contrast, low family SES may give rise to parenting stress, which further undermines parental involvement.

4. Moderation Effect of ASD Symptom Severity

Research demonstrates that children found on the two ends of the autism spectrum show different developmental trajectories and outcomes in the domains of cognition, emotion, and behavior ^[41]. Therefore, the severity of children's autism symptoms should be accounted for when studying the family environment and the child–caretaker relationship. Levinson et al.'s (2021) recent study showed that parents who raised children with severe ASD symptoms were likely to develop negative beliefs regarding the education of their children, which translated into their decreased involvement in a variety of educational activities ^[42]. This finding corroborates that of Benson et al.'s (2008) research ^[13], which shows that the children's display of severe behavioral difficulties (e.g., lack of functional language and inability to maintain ongoing social interaction with caregivers) resulted in less parental involvement. In contrast, more parental involvement was observed when children with ASD demonstrated abilities to follow directions and maintain focus on the given tasks.

The current literature has also shown that the severity of children's ASD symptoms interacts with family SES and parenting stress in the production of influence on parental involvement. For example, McNeal (2001) found that the parental involvement of low-SES parents was significantly lower than that of high-SES parents when children showed only mild behavioral problems ^[43]. However, such a significant difference was not observed when children displayed severe behavioral problems. Semke et al. (2010) found that reducing parenting stress for parents of children with severe disruptive behaviors alone failed to significantly increase their parental involvement ^[32]; this is due to the parents' low self-efficacy in their ability to help children achieve educational pursuits. In addition, mothers who experienced high stress levels from taking care of children with ASD rated their children's behavioral problems as more severe than those who experienced less parenting stress ^[44].

5. Parental Involvement in Children with ASD in China

Conducting culturally responsive research to understand parenting characteristics in different cultures serves as an important prerequisite for creating and improving learning opportunities for children with ASD. However, most studies focusing on parental involvement and its impact on children with ASD relied on samples drawn from Western societies ^[45], leaving parental involvement in non-Western cultures much less understood. Therefore, it is necessary to examine how family SES, parenting stress, and children's developmental characteristics influence parental involvement in Chinese society, where parents typically hold high expectations for their children and are highly responsive to their children's educational needs ^[46].

In China, the national education policy and the traditional Confucius beliefs emphasize the significance of parental involvement in children's education. In 2016, the Chinese government issued the Five-year Plan on Guiding and Promoting Family Education (2016–2020) ^[47]. This government document rigorously promotes parental involvement as a critical parenting aspect that gives rise to children's academic success and all-round development. Such governmental attitude reflects the deeply rooted Confucius teaching that parents are responsible for participating in their children's education to help them pursue academic excellence, which would ultimately lead to a happy and successful life for children and bring honor to the whole family ^[48].

Despite such a socio-cultural background, prior studies have found that Chinese parents of children with ASD tend to be less involved in their children's educational activities. For example, Xiong and Sun's (2014) study found that parents of children with ASD demonstrated little or no involvement in their children's individualized education programs (IEP) or individual family service plans (IFSP) ^[49]. The lack of social support and relevant social resources may have restricted these parents' capability to participate in their children's educational activities ^[50]. It might be even more so for parents from low-SES households, who are forced to devote all their energy and efforts to supporting the family. To further complicate the situation, parents raising a child with a developmental disorder are more prone to be discriminated against in a society where the public knows little about and holds biased opinions towards the disabled ^[51]. This could lead to parents' elevated sense of guilt and demotivate them from engaging in their children's education. Although Chinese parents with typically developing (TD) children are usually actively involved in their children's education regardless of the family SES, it may not be the case for parents raising children with ASD. However, the impact mechanism underlying the relationship between family SES and parental involvement has received little research attention in the Chinese context. Filling this research gap would address this knowledge gap from a cross-cultural perspective and provide insights for policymakers to design more targeted intervention programs to increase parental involvement of children with ASD.

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