

Affiliate Stigma Among Caregivers of Children with Autism: A Review of Impact Factors and Interventions

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Abstract. Autism, a group of neurological based pervasive developmental disorders, can lead to widespread difficulties in social interaction, communication, and participation in daily activities. Autism significantly impacts both the physical and mental health of children, as well as the health and social lives of their caregivers. This article reviews the concept, assessment tools, personal and social factors, and current interventions related to affiliate stigma among caregivers of children with autism, with the aim of enhancing the understanding of impact factors and interventions among healthcare professionals. Future research should delve deeper into the factors affecting affiliate stigma among caregivers of autistic children to provide a reference for developing effective interventions to mitigate the negative impacts of affiliate stigma among caregivers.

Keywords: Autism Spectrum Disorder, children, caregivers, affiliate stigma, factors, interventions, review.

Autism (Autism Spectrum Disorder, ASD) is a group of neurological based pervasive developmental disorders that typically begins to manifest in early childhood. Its common characteristics are the clinical manifestation such as widespread impairments in social interaction, verbal and non-verbal communication defects, restricted interests and repetitive behaviors, etc. (American Psychiatric Association, APA, 2000), which can cause widespread difficulties in social interaction, communication, and participation in daily activities [1-3]. Due to the complex etiology of autism, the rising prevalence has increasingly attracted global attention [2]. According to data from the Centers for Disease Control and Prevention (CDC) in 2023, the overall prevalence of autism among 8-year-old children in the United States is 27.6 per 1000 (1 / 36) [3]. A survey conducted in 2020 based on 14,2086 children aged 6-12 years in China revealed a prevalence rate of autism of 0.70% [4]. Due to the core symptoms of autism and the manifestations of complications such as attention deficit hyperactivity disorder and paresthesia [5], the long treatment cycle [6] and the high treatment costs [7] as well as the high degree of social discrimination [8], the caregiver burden of parents of autistic children is significantly higher than that of other chronic disease caregivers, which has also increased the burden of the whole society simultaneously, attracting widespread attention from all walks of life [9]. Affiliate stigma refers to the situation in which the caregivers, despite not possessing stigmatized characteristics themselves, indirectly develop stigma due to their association with the stigmatized individual or group. It usually refers to the bias, discrimination, and distress experienced by the family members, relatives and friends as well as the entire social group, as a result of their association with the patient [10]-[11]. The level of affiliate stigma for caregivers of children with autism is generally higher, especially as emotional problems due to affiliate stigma are more prominent than others [12-14]. Not only does affiliate stigma affect the health of caregivers of autistic children, but it also indirectly impacts the care and rehabilitation of the affected children themselves [15]. There is currently a lack of understanding of the impact factors of affiliate stigma among caregivers of children with autism, along with a shortage of effective interventions. This article aims to review the research progress on the influencing factors and interventions for affiliate stigma in caregivers of autistic children, with the goal of providing a reference for the development of effective and targeted interventions to reduce the level of affiliate stigma among the caregivers.

1. Overview of affiliate stigma among caregivers of autistic children

1.1. Affiliate stigma-related concepts and assessment tools

Stigma, derived from the Greek word “stigma”, was initially used in psychology by Michael Goffman in 1963 and defined as “the sense of great injury to the reputation of an individual”[16]. It refers to the patients’ inner shameful experience of being labeled, devalued and discriminated against, alienated and excluded, as well as not being understood and accepted because of the disease[17]. Affiliate stigma is a sense of shame and embarrassment resulting from prejudice and discrimination experienced by caregivers in the care process of, which may lead to cognitive and behavioral reactions including social withdrawal, self-compassion, overprotection, perceptions of lower competence and worth than their peers[18].

Common assessment tools are Affiliate Stigma Scale (ASS)[19,20], Self-stigmatizing Thinking’s Automaticity and Repetition Scale (STARS)[21,22], Family Stigma Instrument (FAMSI)[23], and Autism Stigma and Knowledge Questionnaire (ASK-Q)[24-26]. Some researchers will also use questionnaires or scales such as Perceived Courtesy Stigma Scale (PCSS)[27], Perceived Public Stigma Scale (PPSS)[28,29], Adapted Perceived Stigma Scale (APSS)[30,31] etc.. ASS encompasses a broader scope of sources and harms related to affiliate stigma, making it the most widely used; STARS focuses on the process of parents’ stigma, providing a reference for the development of further interventions; FAMSI focuses on the initiative of nursing, while PCSS, PPSS and APSS focus on the subjective perception of the degree of stigma by parents of autistic children; the ASK-Q can be used to explore the relationship between stigma and knowledge of autism, with significant implications for the assessment of sources of parents’ affiliate stigma[32]. Using appropriate assessment tools is crucial for timely identification and precise clinical decisions regarding caregivers at risk of affiliate stigma.

1.2. Harmful effects of affiliate stigma among caregivers of autistic children

1.2.1. Harmful effects on the caregivers themselves

Affiliate stigma not only impaired the caregivers’ mental health, but also affected their normal social life[33]. The abnormal behavior of autistic children is discriminated against by the public, which damages the self-esteem of caregivers and leads to remorse, shame, anxiety, depression and other emotions, thus results to a decline in the life satisfaction of caregivers. Simultaneously, in order to reduce or hide the sense of shame, caregivers tend to avoid social interaction, actively avoid interpersonal communication, and reduce the contact with their relatives and friends, causing strained interpersonal relationships[34,35]. Mak and Kwok[36] conducted a study on 188 Hong Kong parents of autistic children to evaluate the relationship between mental health and affiliate stigma, finding a significant negative correlation between them. Su[37] conducted interviews with 54 parents of autistic children in 2022 and found that 10 participants reported feelings of anxiety, worry, rejection and unhappiness etc., and 6 participants reported that affiliate stigma reduced quality of life and made it difficult for them to lead a normal life. Therefore, affiliate stigma can have serious negative impacts on mental health and social support among caregivers of autistic children.

1.2.2. Harmful effects on the children with autism

Negative emotions brought by the affiliate stigma of autistic children’s caregivers may reduce their behaviors to seek social support, leading to caregivers not bring children to the targeted treatment and hindering children involved in rehabilitation training, which seriously affecting the treatment effect of children and negatively impacts the children’s normal behavioral development and social skills[34-35]. Meanwhile, negative emotions such as depression and anxiety may reduce caregivers’ ability to provide supportive parenting for autistic children. Studies demonstrated that autistic children may have more severe behavioral problems if mothers with high anxiety adopt hostile or coercive parenting styles[38]. The better the mental health status of autistic children’s parents, the better the quality of life and rehabilitation effect of autistic children[39], which otherwise may negatively affect

the parent-child relationship and increase the risk of behavioral problems in children. In addition, because the family's mental environment and parents' personality characteristics have a significant impact on the formation and development of children's personality[40-41], the mental state of parents or caregivers and the mental environment of the family directly affect the psychological behavior outcomes of autistic children. Consequently, the negative emotions derived from affiliate stigma of autistic children's caregivers such as remorse, anxiety and depression will also bring a certain degree of psychological burden like anxiety to autistic children themselves.

2. Impact Factors factors of affiliate stigma among caregivers of autistic children

The impact factors of affiliate stigma among caregivers of autistic children mainly include personal factors and social factors. Personal factors include personal traits (e. g., age, gender, economic level, level of resilience, religious belief, subjective well-being, sleep quality), the caregiver's perception of the illness, the impact of the children's disease; social factors include cultural background, family and social support, and the perceptions of public and healthcare professionals.

2.1. Personal factors

2.1.1. Personal traits

The study by Yu Ma indicated that the age of parents and the monthly household income were significant predictors of the ASS score of autistic children's parents[42]. Sarkar's research involving 97 parents demonstrated that those under the age of 65 were more socially susceptible to stigma[43]. The possible reason is that young parents may be more inclined to seek the recognition from others and value a good reputation. Meanwhile, the young caregivers may face heavier family and social responsibilities and have not yet established a stable life pattern[44,45]. Multiple studies[46-48] have shown generally higher affiliate stigma in women than in men among caregivers of autistic children. This may be because females typically spend more time and energy taking care of children than males, and autistic children are often seen accompanied by their mothers in daily life, while fathers primarily provide financial support. Therefore, mothers can experience external prejudice and discrimination more directly, leading to affiliate stigma[49].

A research by Zuckerman[50]indicated that parents with lower incomes are more likely to experience higher levels of stigma, as those with higher income have more access to social resource to cope with it. This finding is inconsistent with the study by YuMa[42], which suggested that higher-income caregivers are more likely to develop stigma. On the one hand, families with lower average monthly household income may exacerbate the caregiver burden due to the imbalance between high rehabilitation costs and their own income, leading to a higher level of affiliate stigma[51]. On the other hand, high-income caregivers may be more sensitive to negative evaluations,as individuals with high socioeconomic status are more involved in social and economic activities and may be more committed to maintaining existing status and regulating their behavior by following social norms in their behavior[42]. The survey[13] conducted by Wu on 258 caregivers of children with autism revealed that unemployed caregivers had higher levels of affiliate stigma compared to part-time caregivers. This finding may be attributed to the occupational loss and economic pressure of children's recure experienced by unemployed caregivers. Although part-time caregivers faced the same care stress, the part-time jobs provide them with a respite. Marriage relationship is a significant factor in affiliate stigma. The research conducted by Brian Lovell indicated that marital status is a more predictive factor of stigma than age, gender, race and income[44]. Non-partnered caregivers may be more likely to report higher levels of affiliate stigma, possibly because having a partner allows them to share and alleviate negative emotions and psychological stress, reducing the level of stigma. The analysis by Wu demonstrated that the worse the relationship between the partner caregiver, the stronger the affiliate stigma is. If the relationship between husband and wife is not harmonious, the family support is insufficient, resulting in a higher subjective caregiver burden and affiliate

stigma[13]. Furthermore, the caregivers' self-esteem level[52], resilience level[53,54], religious belief[8], and sleep duration[43] can all affect the caregivers' affiliate stigma level.

2.1.2. Perception of the illness

The perception of disease-related knowledge is a significant factor for affiliate stigma among caregivers of autistic children. A study revealed that caregivers of autistic children have misconceptions or even errors in their perception of autism, which is more likely to lead to the development of affiliate stigma[47]. The more knowledge caregivers have about the cause and treatment of autism, the more comprehensive their understanding of autism is. The study found that parents of autistic children have reduced level of affiliate stigma with increased education level[46-47, 52]. A survey of 489 US white parents of children with diagnosed autism by Zuckerman demonstrated that families with less-educated parents are more likely to have higher stigma scores[50]. The possible reason is that higher educational level leads to more rational and flexible thinking, enabling parents to respond objectively and actively to public views and the symptom. They can also use their own resources to extensively obtain help and utilize them efficiently, resulting in lower levels of stigma experience. The survey by Wen Lili of 118 primary caregivers of autistic children found a negative correlation between affiliate stigma of main caregivers and positive coping strategies, and a positive correlation with negative coping strategies [46]. This suggests that coping strategies are important factors affecting affiliate stigma. The more the caregivers tend to adopt negative coping strategies, the higher their level of stigma[55]. The reason may be that the long-term use of negative coping methods by caregivers is not conducive to the active access to social support, nor is it advantageous to solving the problem of social discrimination, thus increasing their psychological pressure and leading to an increase in stigma level.

2.1.3. The impact of the children's disease

The more severe the degree of the disease and pronounced the disease characteristics of autistic children, the more likely caregivers are to have emotional behavior problems, resulting in a greater risk of affiliate stigma[12]. The study conducted by Qi-Yuan Lyu on the parents of 180 children diagnosed with autism in Guangdong Province, China found a positive correlation between the severity of the child's autism symptoms and affiliate stigma. The more behavioral issues the child has, the heavier the psychological pressure and the stigma of the caregiver is[56]. Parents of autistic children with aggressive or violent tendencies, those caring for moderately to severely autistic children, or those with more autistic children in their home may experience higher levels of affiliate stigma[50, 57, 58], which may be related to increased caregiver burden. This is also consistent with the relevant factors of affiliate stigma among Alzheimer's caregivers, where the more severe the symptoms are, the more frequent the onset is, the longer the duration is, and the higher the affiliate stigma level is[59]. In addition, the longer the care duration is, the heavier the caregiver's caregiver burden is, the deeper the caregivers' experience of various behavioral symptoms is, the higher the affiliate stigma level is[60].

2.2. Social factors

2.2.1. Cultural background

The stigma experienced by caregivers varies across different cultural backgrounds. Compared with Western culture which emphasizes personal achievement and independence, East Asian culture attaches great importance to cultural value and social status. Under the influence of Confucian and Buddhist culture, Oriental parents pay more attention to the upbringing and cultivation of their children, so they are more likely to develop affiliate stigma[34, 60].

2.2.2. Family and social support

Stigma among caregivers of autistic children is related to the unmet social needs of autistic children, such as educational issues, inadequate social welfare, and healthcare service issues[8]. Studies have shown that the less family support, the worse the affiliate stigma among autistic caregivers is[61,62].

Family support and care can provide emotional support and information communication for caregivers, helping individuals actively cope with stress and reduce the affiliate stigma level. Also, social support is an important influencing factor for affiliate stigma among caregivers of autistic children. A significant negative correlation is found between affiliate stigma score and social support score[46], indicating that the more social support the caregivers receive, the lower the affiliate stigma level is, much like findings in previous studies[45, 52]. Higher social support level of caregivers leads to greater willingness to seek help from relatives, friends and society, which improves their care motivation and reduces negative emotions, ultimately leading to a lower affiliate stigma level.

2.2.3. Perceptions of public and healthcare professionals

The general public and some autism professionals have certain degrees of deviations and stereotypes, or even wrong cognition, which leads to affiliate stigma among caregivers of autistic children[63-66]. A survey of parents of autistic children revealed that some community residents still hold stereotypes of autistic children as “stupid” “foolish” or “mental illness”[37]. The public does not accept autistic patients and staring at them and their families with strange eyes. Alsehem surveyed 259 people in Saudi Arabia and found that some still associate autism with electronic products or parenting style, while others view it as akin to mental retardation or cerebral palsy[67]. Some healthcare professionals and students may also lack sufficient knowledge about autism, which may have negative impacts on autistic patients and their caregivers[68].

3. Interventions of affiliate stigma among caregivers of autistic children

There are few researches on interventions of affiliate stigma among caregivers of autistic children, which are summarized below.

3.1. Intervention to the caregivers

3.1.1. Mental intervention

The physical and mental health of the parents is crucial to the prognosis of autistic children. Research has indicated that negative psychological damage caused by the parenting of autistic children can affect children and reduce the positive effect of treatment[69]. Lodder [70] conducted a psychological stigma protection intervention (SOLACE) for 9 autistic children’s parents, using a multi-component intervention using psycho-education, cognitive restructuring strategies and compassion focused techniques, with specific methods like lectures, group discussions on stigma experiences, sharing experiences, and cultivating self-compassion. The results indicated that the intervention reduced parents’ affiliate stigma level and improved their self-esteem and mental health, with improvements maintained for 6 weeks post-intervention. Chan’s research[71] suggested that mindfulness therapy can guide autistic children’s caregivers to fully experience their current emotions and feelings, leading to relaxation and attention transfer, thus weakening the relationship between stigma and depression or anxiety, as well as increasing the resilience, ultimately decreasing caregivers’ affiliate stigma levels and enabling better coping with stigma-related negative effects. Fumiyo Oshima [72] developed the Awareness and Care for My Autistic Traits (ACAT), including joint psychoeducation and cognitive-behavioral therapy, psychological education about autism traits, the use of the CBT model, and discussing and planning problem-solving strategies. The study involved 49 autistic patients and their caregivers receiving 100-minute ACAT interventions weekly. The intervention group showed significant improvements in self-awareness of autism traits and difficulties, indicating that ACAT intervention can effectively help caregivers understand autism traits, improving parent-child communication and understanding of child autism characteristics, so as to reduce the level of affiliate stigma. Ameena [73] developed a 4-week online self-compassion intervention for caregivers of children with developmental disabilities, including psychoeducation and therapeutic activities related to self-compassion such as online resources, introspection and experiential exercises. The results revealed significant increases in caregivers’ self-compassion and subjective well-being and reductions in depression and stress after the intervention, which are

beneficial for reducing caregivers' affiliate stigma level[14, 56]. Previous studies[74] have shown that caregivers of autistic children have significantly lower scores on objective, subjective, and total support compared with parents of typically developing children. Therefore, actively developing communication meetings for autistic children's caregivers, paying attention to their psychological and emotional states and the quality of life, and providing timely help can alleviate caregivers' mental stress and provide emotional and information support to some extent. Timely and effective social support can also help them adapt to the new care role as soon as possible and reduce the negative emotional stress[40].

3.1.2. Cognitive intervention

Study[75] suggested that caregivers can seek identify for themselves and children and have reasons to maintain the uniqueness of children to reduce the affiliate stigma through understanding the pathogenesis, etiology, clinical manifestations and other relevant medical knowledge of autism. Masaki Tsujita[76] conducted the simulate autism visual perception and video-based social contact intervention for 217 autistic children's caregivers, including watching short lectures about autistic perception and autism self-reported video, experiencing autistic visual perception, followed by a 90-minute group discussion to share their feelings of simulation experience and the video. The findings demonstrated that the intervention can reduce the stigma associated with autism and that a significant increase in positive behavioral attitudes was observed within 6 weeks after the intervention, with a decrease in stigma persisting. Medical institutions can provide education through lectures, promotional posters, short education information, videos, seminars and distributing leaflets to inform caregivers about autism knowledge such as clinical characteristics, course of disease and available treatment, family rehabilitation concept and skills, parents emotional management skills, improving caregivers' autism knowledge level, and releasing their emotions like anxiety or depression to reduce their stigma level[77,78].

Additionally, the parent-mediated intervention can be used to improve the level of affiliate stigma among caregivers of autistic children. Simpson[79] conducted a study of parent-mediated intervention for 3 autistic children, emphasizing teaching intervention treatment strategies to parents of autistic children to improve the symptoms of children. After 4 months, parents in intervention group were able to correctly deal with children's behavior, and the knowledge of autism and anxiety increased parents' understanding of children's behavior, thereby reducing affiliate stigma level. Estes[80] conducted a 12-week randomized controlled trial (RCT) of 98 autistic children's caregivers, demonstrating a decrease in parenting stress levels in the intervention group compared to the control group. The reduction in parenting stress can assist in alleviating the relevant psychological stress among caregivers and decrease the level of affiliate stigma. Lin huanxi[81] conducted a meta-analysis of 12 RCT trials, indicating a reduction in stress levels among parents of autistic children who received parent-mediated intervention, a finding inconsistent with the Meta-analysis by Conrad [81]that the parent-mediated intervention showed some improvement in disruptive behavior of children but had no significant effect on stress and subjective well-being of autistic children's parents.

3.2. Intervention to the public and society

Multiple studies[35][82-84] have shown that participation in autism disease knowledge training is helpful in improving public understanding of autism. Knowledge education and online knowledge training of the public can increase their tolerance and acceptance of autistic children and their caregivers, raising public awareness of autism and helping reduce public discrimination. Social support helps to enhance the parenting ability of parents of autistic children as they urgently need to get more social support to solve difficulties and relieve pressure. In addition, social support can reduce negative emotions such as anxiety and depression and the negative psychology of parents, and then reduce the level of affiliate stigma[79].

Participating in autism knowledge training can help improve public understanding of autism and effectively reduce public misunderstanding and discrimination, thereby reducing the affiliate stigma

among caregivers[37][85]. While another study suggests that intervention strategies should fully take the socio-cultural differences of different intervention subjects into consideration to ensure their effectiveness[68]. It is recommended to improve the treatment and rehabilitation systems by considering cultural differences, provide relevant policy support and diagnosis and post-treatment guidance, as well as respite services and health education for the public. Communities can hold parent-child activities regularly, encourage family members to actively participate in, set up a psychological consultation room for caregivers to provide psychological counseling to improve their mental health[35][59].

4. Conclusion

Caregivers of autistic children commonly experience high levels of affiliate stigma, which has severe consequences on both themselves and their children. Therefore, the article can be used to have a general understanding of affiliate stigma among caregivers of autistic children and to recommend the aspects of future research on factors and interventions. Future research on interventions for affiliate stigma among caregivers of autistic children should be accelerated, with a focus on randomized controlled studies with large sample sizes to enhance the credibility and persuasiveness of the evidence. In addition, the effects of various interventions should be further combined quantitatively, and the best intervention content, time, frequency and other detailed guidance should be clarified to make the best recommendations. Meanwhile, identify effective prevention strategies whenever possible. The article reveals a need for corresponding preventive measures for caregivers who have the risk of affiliate stigma. Taking it a step further, there is also a need for authoritative guidelines for assessments and interventions of affiliate stigma among caregivers of autistic children. Establishing a screening mechanism for affiliate stigma of autistic children's caregivers so as to achieve early detection, early intervention and early treatment is strongly recommended and urgently demanded. It is also suggested that future research should involve caregivers of children with autism from more diverse cultural backgrounds and whose relationship with the children include grandparents and siblings of more gender-diverse to determine whether their experiences are similar. This is important as all these factors may affect mental conditions and parenting experiences. Lastly, with regard to the public awareness, healthcare professionals should adopt various methods to enhance their understanding of autism, pay attention to the mental health of caregivers during the treatment for autistic children in order to provide communication and emotional support immediately.

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