

SELF-STIGMA AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN VIETNAM

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This qualitative study was conducted to explore self-stigma among 11 parents of children with autism spectrum disorder receiving treatment at the National Children's Hospital and five special education centers in Hanoi. Self-stigma was assessed through in-depth interviews using an interview guide with a semi-structured questionnaire of 5 open-ended questions. Findings from these interviews indicated that many parents experienced negative emotions when raising children with autism spectrum disorder, felt embarrassed of their children's behavior and actively avoid social interactions. The study emphasizes the importance of implementing educational intervention programs to reduce self-stigma in this group.

Keywords: Self-stigma, parents, autism spectrum disorder.

I. INTRODUCTION

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder diagnosed based on characteristic differences in two main areas: social communication and behavioral patterns.¹ In Vietnam, ASD is often viewed as a “disease” or a family issue stemming from “karma from past lives”, rather than as a neurological developmental condition. Limited awareness, along with cultural pressure to avoid “losing face”, further exacerbates the stigma and discrimination experienced by parents of children with an ASD diagnosis.²

Research shows that parents of children with ASD face stigma across various regions, ethnicities, and religions.³ Stigma among this population often includes three types: perceived stigma, self-stigma, and enacted stigma.⁴ Perceived stigma refers to parents' belief

that their community holds negative attitudes toward them or their children.⁵ Self-stigma involves the internalization of negative attitudes within the community, leading to negative cognitive responses, such as low self-esteem, as well as negative emotions associated with the caregiving role, including shame, sadness, and helplessness, along with behavioral issues such as actively avoiding social interactions.^{3,6} Enacted stigma encompasses the negative encounters that parents of children with ASD face during the process of raising their children.⁷ The concept of self-stigma, or affiliate stigma, is frequently mentioned in studies.^{3,6} The prevalence of self-stigma among parents with ASD in previous studies ranges from 33.7% to 34.5%.^{8,9}

Self-stigma imposes a significant burden on parents of children with ASD, being a key risk factor for mental health issues.⁵ It also reduces quality of life, increases caregiving burdens, and diminishes the intention to seek health care support or interventions for their children, potentially leading to delayed or absent early

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interventions, which have further consequences for both children and families.^{10,11}

However, most studies on the stigma among parents of children with ASD have been conducted in other countries.^{10, 9} Currently, research on self-stigma among parents of children with ASD in Vietnam is limited, and experiences of self-stigma may vary due to differences in language and culture.¹² To address this gap, we conducted this study with the aim to explore self-stigma among parents of children with ASD in several health care facilities in Hanoi in 2023.

II. MATERIALS AND METHODS

1. Subjects

We approached 11 participants after stage 1 quantitative research that was conducted at the Psychiatry Department of the National Children's Hospital and five special education centers in Hanoi.

Inclusion criteria: Parents whose children were diagnosed with ASD according to DSM-V-TR by a psychiatrist and were the primary caregivers of the children.

Exclusion criteria: Parents with serious physical or mental illnesses or those whose children had other disabilities.

2. Methods

Study design

Qualitative research design.

Research time and location:

Research setting: The study was conducted in Hanoi. Healthcare facilities in Hanoi are divided into two main types: hospitals and centers levels. Among the hospitals, the National Children's Hospital was chosen as the primary institution for receiving, diagnosing, and treating children with autism. As a tertiary-level facility, it offers specialized care, including advanced diagnostic and intervention services

for complex conditions, making it representative of healthcare across the northern region. At the center level, the researcher identified a list of centers in Hanoi and reached out to the directors of all five, securing their consent to participate in data collection (Dan Hoai, Ban Mai Xanh, Yen Nghia Fruit House, Long Bien, and Kazuo)

Data collection time: From February 15, 2023, to November 15, 2023.

Sampling techniques

11 parents from the initial quantitative study were directly approached and agreed to participate in in-depth interviews.

Instruments

The research team developed an interview guide that comprised a semi-structured questionnaire with five open-ended questions exploring parents' experiences of self-stigma when raising children with ASD.

Procedures

As the part of ongoing study we invited all parents after they completed in a previous quantitative study. 11 parents agreed to participate in in-depth interviews held at a location of their choice, either a coffee shop or their home, lasting 30 minutes to 1 hour, delivered by an investigator who is a psychiatric nurse.

Data analysis

The researcher transcribed the interviews, and data was analyzed thematically using Nvivo14 software. After initial coding, an independent review by the instructor followed to refine and finalize the main themes.

3. Research ethics

This study was approved by the Ethics Committee of the National Children's Hospital (No. 93/BVNTW-HDDD) on January 17, 2023, with informed consent obtained from the participating parents.

III. RESULTS

1. General characteristics of parents and children

Table 1. General characteristics of parents and children (n = 11)

Variables	n (%)
Parents characteristics	
Age, M (SD)	39.27 (1.90)
Gender (women), frequency (%)	9 (81.8)
<i>Number of children with ASD, frequency (%)</i>	
1	11 (100)
<i>Locality, frequency (%)</i>	
Urban	7 (63.6)
Rural	4 (36.4)
<i>Education, frequency (%)</i>	
Intermediate/college/undergraduate/graduate	11 (100%)
<i>Marital status, frequency (%)</i>	
Married/living with spouse	9 (81.8)
Divorced/single mom/dad/widow	2 (18.2)
Children characteristics	
Age, M(SD)	9.73 (3.10)
Gender (female), frequency (%)	3.00 (27.3)
<i>Child's school place, frequency (%)</i>	
Special education school	3 (27.3)
Inclusive education school	6 (54.5)
Both special and inclusive education	2 (18.2)
Child's age at the time of diagnosis, M (SD)	3.00 (1.73)
<i>Child ASD severity, frequency (%)</i>	
Mild	4 (36.4)
Moderate	3 (27.2)
Severe	4 (36.4)

Of the 11 parents who participated in the study, 9 were mothers, and 2 were fathers. The mean age of the participants was 39.27 years old. Most of the participants were married or

living with their spouse (81.8%), and all of them had a child with ASD (100%). Regarding the children's characteristics, the mean age was 9.73 years old (± 3.10), and the mean age at

ASD diagnosis was 3.00 years old (± 1.73). Most of the children were males (72.7%), had severe ASD (36.4%), and attended inclusive education school (54.5%)

2. Self-stigma among parents of children with ASD

Our thematic analysis resulted in the generation of three themes as follows:

Negative emotions when having a child with ASD

Parents in the study reported feelings of sadness and hurt due to comments from others, particularly family members. For instance, the mother of a 4-year-old son with autism shared how her grandmother's remarks affected her: "Sometimes she says things that make me feel sad. She says that other people's grandchildren are like this and that, but my own grandson is... which makes me feel sad too" (Ms. Nham, 42 years old).

Parents also felt helpless and hurt when their children were rejected from school. One father of a 10-year-old son with ASD described his experience: "When my son was 5 years old, I applied for him to enroll in a private kindergarten, but the teacher and principal refused, saying private schools are for children from well-off families, not for children with special needs. That day I felt very sorry for myself and helpless because my child was not like other typical developmental children" (Mr. Cuong, 37 years old).

Embarrassment Due to Child's Behavior

Many parents expressed embarrassment over their child's behaviors, such as difficulty controlling bowel movements. A mother of a 9-year-old daughter with ASD recounted a time in the park: "My child had bowel movement while we were going out with my friends, and I had to clean up after her. I felt embarrassed because others might not understand and just

thought she should know how to go to the toilet" (Ms. Hoa, 39 years old). Another mother of an 8-year-old boy with ASD also shared her feelings of embarrassment as follows: "When he goes out to the yard, his personality is such that when he sees his friends, he chases after them - for example, running after them and trying to scare them, that kind of behavior. He likes to play with them; when he sees a group of friends playing, he wants to join and then touch them. He often doesn't differentiate between strangers and acquaintances; he just touches them, and when he meets strangers, they just stare at him. At times like that, I feel embarrassed by his behavior." (Ms. Lan, 40 years old).

Some parents mentioned that behaviors such as lacking social awareness or manners in public led to embarrassment. For example, the mother of an 11-year-old autistic daughter shared: "In the elevator or public places, she sometimes acts silly or talks nonsense. It's embarrassing... she'll even fart in the elevator and just laugh about it. Sometimes, she'll lift her belly or shirt. It's unavoidable, but I do feel embarrassed" (Ms. Van, 40 years old).

Avoiding Social Interactions

Parents in the study also shared that they sometimes avoided social interactions, even with family members, due to a lack of understanding about autism. A 39-year-old single mother raising a 9-year-old autistic son explained: "When he was younger and not well-integrated, I rarely let him interact with others. He was stressed, and so were the grandparents because they didn't understand each other. There were times and actions that left me feeling disappointed and hurt" (Ms. Thao, 39 years old).

Parents also limited their children's social interactions, such as by restricting outings, due

to concerns over their child's unpredictable behaviors or the possibility of damaging other people's property. A 39-year-old mother with a 10-year-old autistic son shared: "I also limit my child from going out because of these behavioral issues. I avoid taking him to neighbors' houses because he might damage something..." A 42-year-old mother with an 11-year-old autistic daughter added: "I avoid taking her to places where cleanliness is valued, solemn ceremonies, or sacred spaces, as these environments are not suitable for her" (Ms. Nham).

IV. DISCUSSION

The study results indicated that parents of children with ASD experienced emotional challenges, such as feelings of sadness, hurt, and disappointment, especially when receiving negative comments, even from their own family members. This result is in line with a previous study of Oduyenmi (2020) reported that 15.3% the participants felt disappointed because they have the child with ASD.⁷ Moreover, this result supported the study of Mitter (2018) with 11% parents had negative emotions when raising the child with ASD.¹³ These negative feelings are understandable because ASD is a lifelong disability.¹ Furthermore, in Vietnamese society and culture, autism is frequently perceived as a "disease" or a repercussion of "karma from a past life," potentially intensifying self-stigma among parents.²

In-depth interviews also indicated that children's behaviors contributing to parental shame included incontinence, shamelessness, and lack of manners. Behavior patterns are a core deficit in children with ASD. These children may exhibit socially inappropriate behaviors that can appear in various ways, such as meltdowns, self-stimulatory actions, aggression, or refusal to follow instructions. It's important to

understand that these behaviors often serve as a means for the child to communicate their needs, discomfort, or anxiety rather than simply reflecting naughtiness or misbehavior.¹ However, managing inappropriate behaviors in autistic children can be challenging, particularly in public settings where social expectations are high. As a result, these behaviors often lead to feelings of shame for parents. These findings are consistent with previous studies showing that shame is a common manifestation of self-stigma.¹⁴ Parents in this study described loud crying and tantrums in social settings as embarrassing and cited these behaviors as the most common reasons for avoiding social gatherings.¹⁴ Although children with ASD may have typical physical appearances, their socially inappropriate behaviors often lead parents to experience shame.¹⁵ Manifestations of shame may include concealing the child's condition from others, restricting the child to the home or limiting social interactions out of concern for potential misbehavior, withholding information about the child's difficulties, concealing unusual behavior, and experiencing discomfort or embarrassment when others judge the child's actions.¹⁵

Parents in this study also actively avoided social interactions, resulting in limited engagement with their children and less time spent outdoors. These findings are consistent with previous studies that report parents of children with ASD often do not take their children outdoors or participate in social activities.⁹ These results supported Ijalba's study reporting that parents frequently avoided social situations due to their children's disruptive behaviors, limited social awareness, and inadequate social support.¹⁴ Therefore parents of children with ASD are often isolated and marginalized in society. This creates a vicious cycle where inappropriate behavior fuels internal self-stigma

and embarrassment and resulting in actively avoiding social interactions among parents of children with ASD.

Future studies should explore the influence of Vietnamese cultural values on self-stigma among parents of children with ASD. Additionally, intervention programs that address emotional issues and provide skills training for parents to cope with self-stigma are needed to reduce withdrawal, isolation, and avoidance of social interactions.

V. CONCLUSION

Parents of children with ASD reported various forms of self-stigma. Many experienced negative emotions during parenting, including feelings of shame about their child's behavior and a tendency to avoid social interactions. This study highlights the importance of implementing educational interventions to reduce self-stigma among these parents.

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