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RESEARCH ARTICLE (ORIGINAL)

# A psychometric evaluation of the Vietnamese version of the Affiliate Stigma Scale

Uma avaliação psicométrica da versão vietnamita da Affiliate Stigma Scale Una evaluación psicométrica de la versión vietnamita de la Affiliate Stigma Scale

#### Abstract

**Background:** The Affiliate Stigma Scale (ASS) is the most used instrument to assess affiliate stigma in caregivers with different mental health issues. However, there has not been a Vietnamese version of this scale with clear psychometric properties.

**Objective:** This study aimed to evaluate the psychometric properties of the Affiliate Stigma Scale in the Vietnamese context.

**Methodology:** This is a cross-sectional descriptive study among 300 parents of children with autism spectrum disorder (ASD) using purposive sampling and a self-administered structured questionnaire including the Affiliate Stigma Scale - Vietnamese version. Data were collected from February to September 2023.

**Results:** The psychometrics and confirmatory factor analysis confirmed the instrument's internal consistency and construct validity. The total scale showed a good Cronbach's alpha of 0.94. The three-factor model had an acceptable fit (Comparative Fit Index = 0.93, Tucker-Lewis Index = 0.92, RMSEA = 0.068).

**Conclusion:** The Vietnamese version of Affiliate Stigma Scale exhibited good validity and reliability for nurses and other pediatric professionals to assess affiliate stigma among parents of children with ASD.

Keywords: autism spectrum disorder; affiliate stigma; caregivers; factor analysis; psychometrics

#### Resumo

**Enquadramento:** A Affiliate Stigma Scale é o instrumento mais utilizado para avaliar o autoestigma em cuidadores com diferentes problemas de saúde mental. No entanto, não há uma versão vietnamita desta escala com características psicométricas claras.

**Objetivo:** Este estudo teve como objetivo avaliar as propriedades psicométricas da Affiliate Stigma Scale no contexto vietnamita.

**Metodologia:** Trata-se de um estudo transversal e descritivo com uma amostra intencional constituída por 300 pais de crianças com perturbação do espectro do autismo (PEA). Entre fevereiro e setembro de 2023, foi aplicado um questionário estruturado de autopreenchimento que incluía a versão vietnamita da Affiliate Stigma Scale.

**Resultados:** Os testes psicométricos e a análise fatorial confirmatória revelaram boa consistência interna total (alfa de Cronbach) de 0,94 e a validade de construto do instrumento. O modelo de três fatores teve um ajuste aceitável (Comparative Fit Index = 0,93, Tucker-Lewis Index = 0,92, RMSEA = 0,068). **Conclusão:** A versão vietnamita da Affiliate Stigma Scale apresentou boa validade e fiabilidade para enfermeiros e outros profissionais de pediatria avaliarem o autoestigma em pais de crianças com PEA.

Palavras-chave: perturbação do espectro do autismo; autoestigma; cuidadores; análise fatorial; psicometria

#### Resumen

**Marco contextual:** La Affiliate Stigma Scale (ASS) es el instrumento más utilizado para evaluar el estigma de los cuidadores familiares relacionado con diferentes problemas de salud mental. Sin embargo, no existe una versión vietnamita de esta escala con características psicométricas claras.

**Objetivo:** El objetivo de este estudio fue evaluar las propiedades psicométricas del afiliado.

**Metodología:** Se trata de un estudio descriptivo transversal con una muestra intencional de 300 padres de niños con trastorno del espectro autista (TEA). Se administró un cuestionario estructurado de autocumplimentado entre febrero y septiembre de 2023, que incluía la versión vietnamita de la Affiliate Stigma Scale.

**Resultados:** Las pruebas psicométricas y el análisis factorial confirmatorio revelaron una buena consistencia interna total (alfa de Cronbach) de 0,94 y la validez de constructo del instrumento. El modelo de tres factores presentó un ajuste aceptable (índice de ajuste comparativo = 0,93, índice de Tucker-Lewis = 0,92, RMSEA = 0,068).

**Conclusión:** La versión vietnamita de la Affiliate Stigma Scale mostró una buena validez y fiabilidad para enfermeros pediátricos y otros profesionales a la hora de evaluar el estigma de afiliación en padres de niños con TEA.

Palabras clave: trastorno del espectro autista; estigma afiliado; cuidadores; análisis factorial; psicometría

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# Introduction

Autism spectrum disorder (ASD) is one of the most common developmental disorders among children. The prevalence of all forms of ASD is estimated to be around 1.85%. The prevalence of boys diagnosed with ASD was four times higher than that of girls (Maenner et al., 2020). In Vietnam, ASD was widely known a few years ago; however, the number of children with autism is becoming alarming. A previous study reported that the prevalence of ASD was between 0.4-0.7% (Hoang et al., 2019). Children with ASD display difficulties in language, social interaction, and restricted interests and/ or repetitive behaviors, which emphasizes the important role of caregivers, especially parents (American Psychiatric Association, 2013).

Caring for children with autism requires long-term and continuous support. As key members of the treatment team, parents play an important role in caring for their children and working with a variety of health care providers (Hoefman et al., 2014). Parents of children with ASD face life challenges, including lack of time, lack of experience, insufficient knowledge, and economic suffers (Ali et al., 2012; Zuckerman et al., 2018). Moreover, previous studies have revealed that experiencing social stigma is common among parents of children with ASD (Alshaigi et al., 2020; Mitter et al., 2018). Stigma has various negative consequences, such as mental health problems among parents (Chan & Lam, 2017; Ting et al., 2018), lower quality of life for both children and their families (Chan & Lam, 2018; Lodder et al., 2019), higher healthcare costs (Chan & Lam, 2018), and less chance of getting medical help or intervention for children (Zuckerman et al., 2018).

# Background

There have been several classifications of stigma among parents of children with ASD. However, stigma among these parents can be divided into three main types, including perceived stigma, self-stigma/affiliate stigma, and enacted stigma (Khanh et al., 2023). Specifically, perceived stigma refers to parents' feelings during social interactions, such as "feeling blamed" or "feeling discriminated against". When parents internalize the negative public reactions into their thoughts and use those thoughts against themselves, it is called self-stigma/ affiliate stigma. This type of stigma results in feelings of shame, lack of self-esteem, a sense of inferiority, and reduced self-worth (Corrigan & Watson, 2002). Finally, enacted stigma describes the negative experiences of parents of children with ASD when they engage in social interaction (Alshaigi et al., 2020; Cantwell et al., 2015; Farrugia, 2009; Gray, 2002). A recent literature review of stigma in the Vietnamese context indicated that some existing instruments have been developed to assess stigma among parents of children with ASD (Khanh et al., 2023). Among these instruments, Affiliate Stigma Scale (ASS) (Mak & Cheung, 2008) is the most commonly used in previous studies with 12 out of 36 studies accounting for 33.3%. This scale has been validated in many countries such as India (Kumari et al., 2022), Greece (Papadopoulos et al., 2022), Malaysia (Yun et al., 2018), China (Mak & Cheung, 2008), Israel (Werner & Shulman, 2015), and Iran (Dehnavi et al., 2011), involving different populations of caregivers of people with various mental health issues. Although it has been demonstrated to have good psychometric properties, it has not been validated in Vietnamese. This hinders researchers' ability to thoroughly explore and evaluate self-stigma among parents of children with ASD in order to early identify and intervene among this population in Vietnam. Therefore, there is a need to translate and validate a Vietnamese version of the ASS (ASS-V). This study was conducted to examine the psychometric properties of the Vietnamese version of the Affiliate Stigma Scale by assessing internal consistency, item-total correlation, and construct validity.

# **Research** question

What are the psychometric properties of the Vietnamese version of the Affiliate Stigma Scale?

# Methodology

### **Study Design**

A cross-sectional, descriptive study was conducted.

## Sample and Setting

Data collection was conducted from February 2023 to September 2023 at one of the three largest pediatric hospitals in Hanoi, Vietnam, which serves as the leading institution for pediatric care in the northern region of Vietnam. Inclusion criteria were (1) parents of children with ASD who were diagnosed by a psychiatrist; (2) primary caregiver of the child; and (3) able to read and write in Vietnamese. Parents who had serious mental health problems or serious physical conditions and parents who had other children with other disabilities were excluded from this research.

A purposive sampling technique was used to collect data. According to Bentler and Chou (1987), 5–10 participants should be included for each questionnaire item to calculate confirmatory factor analysis (CFA). In this study, the total sample size was 300 parents who met the general recommendation.

#### Instruments

The Affiliate Stigma Scale (ASS) was developed by Mak and Cheung (2008) and was originally used to assess the level of self-stigma among caregivers of people with mental illness or intellectual disability. The instrument was tested for reliability with Cronbach's alpha coefficients ranging from 0.94 to 0.95 (Mak & Cheung, 2008). When this scale was adapted to parents of children with ASD, the result also showed a high Cronbach's alpha coefficient of 0.94. The scale consists of 22 questions divided into



three parts. Part 1, "Affective", consists of seven questions describing experiences as negative emotions related to being a caregiver. Part 2, "Cognitive", consists of seven questions describing parents' perceptions of being treated or viewed negatively. Part 3, "Behavioral", includes eight questions to assess stigma, which manifests in specific behaviors such as actively avoiding social interactions. Participants were asked to rate the parents' levels of stigma with each item on a Likert scale from 1 to 4 (1 = *strongly disagree*, 4 = *strongly agree*). The mean score of 22 items was used, with a higher score indicating a higher level of affiliate stigma/self-stigma (Mak & Cheung, 2008). Previous studies used this scale to assess self-stigma and reported high reliability, with Cronbach's alpha coefficients ranging from 0.78 to 0.95 (Ting et al., 2018; Wong et al., 2016).

#### **Translation process**

The original authors gave their permission to translate the ASS into ASS-Vietnamese version (ASS-V). The English version of the instrument was translated into Vietnamese with a back-translation process following the guidelines of Sousa and Rojanasrirat (2011). The original English version of the questionnaire was first translated into Vietnamese by two bilingual translators. The first translator is a psychiatric nurse with a high knowledge of scientific and healthcare terminology. The translators were fluent in written and spoken English and had integrated the language into their professional activities. Second, the two Vietnamese versions of each translator were compared and merged into one by the principal investigator, her supervisor, and two previous translators, and the various items were discussed and revised. Third, two Vietnamese lecturers from a healthcare university, experienced in translating the questionnaire into English without prior knowledge of the instrument, translated the final Vietnamese version into English. Fourth, the principal investigator and her supervisor compared two back-translated English versions and the original instrument. Any disagreements were discussed and resolved by consensus among the team to create a pre-final ASS-V. Finally, the Vietnamese questionnaire was tested on 10 parents of children with ASD, including both mother and father, who met the selection criteria. The parents were asked about the comprehensibility and wording of the questions and provided comments for correction. The result of this process was the completed ASS-V.

During this step, some parents expressed concerns about item 8 of the scale, "Other people would discriminate against me if I am with my child". They provided comments that the meaning of "discriminate against" should be replaced with "stigma" for clarification by the readers. Participants also commented on items 10 and 13 to make them more understandable. Therefore, several concepts were adapted when translated into Vietnamese: "discriminate against" (Item 8) was translated as "kỳ thị", "turns sour" (Item 10) was translated as "khó chịu", and "lesser" (Item 13) was translated as "kém cỏi".

#### Data collection

At the hospital, the researcher approached eligible parents and invited them to a private room to participate in this study. After the parents signed a consent form to avoid bias related to missing information or not clearly understanding the question, the researcher carefully and clearly guided the participants through each question, addressing them one by one to ensure a clear and comprehensive understanding of the questions and procedures. Participants then completed the questionnaire in about 25-30 minutes in a private room with comfort and privacy. After they completed the questionnaire, the investigators promptly reviewed the set of research questions on site, and participants filled in any missing information.

#### Data analysis

Data were entered into the computer using EpiData software. They were cleaned and analyzed using SPSS version 20.0. All observations with one or more missing values were excluded, and the analysis was conducted only on observations with complete data sets. Descriptive statistics included demographic variables of both the parents and the children. Cronbach's alpha coefficient was used to determine the internal consistency of the Vietnamese version of the ASS. The acceptable value was 0.7; a value  $\geq 0.8$  was considered to indicate good reliability (Polit & Beck, 2006). Construct validity was tested by confirmatory factor analysis (CFA) using AMOS 20.0 software. The main indicators used in this study to evaluate the model fit were the root mean square error of approximation (RMSEA), the ratio of chi-square score to degrees of freedom ( $\chi^2/df$ ), the Comparative Fit Index (CFI), and the Tucker-Lewis Index (TLI). RMSEA values  $\leq 0.08$  and  $\leq 0.03$  suggest good fit and very good fit, respectively. ( $\chi^2$ /df) values  $\leq 2$ and ≤ 5 indicate *good fit* and *acceptable fit*, respectively. CFI values close to 1 indicate a very good fit, while TLI values  $\geq$  0.9 indicate *good fit* (Hair, 2010).

#### **Ethical considerations**

This study was approved by the Scientific Research Council of the National Pediatric Hospital (No. 93/ GCN-HĐĐĐ, dated 17 January 2023). The researcher clearly explained the purpose of the study. The subjects' participation in the study was voluntary. The participants could withdraw or refuse to answer one or several items in the questionnaire at any time without any explanation. According to the ethical considerations of the study, the rights of the participants are always ensured.

## Results

#### Characteristics of the sample

In total, 60 participants declined to take part in the study, with the primary reason being that they were generally too busy. A total of 300 parents participated in the study, 247 mothers and 53 fathers completed the study questionnaire. The mean age of participants was 35 years.



About half of them lived in an urban area (55.7%) and had a high education level (61.3%). Most respondents were married or living with a spouse (93.7%). The majority had a single child with ASD (95.7%). Regarding the children's characteristics, the mean age at the time of diagnosis was approximately 31 months. Most of them were male children (85.3%). They had a severe condition (47%), and both special and inclusive education (33.3%). The details of children's and parents' characteristics were provided in Table 1.

### Table 1

Children's and parents' characteristics

Variables	Parents	Children
Age, M (SD)	35.35 (6.66)	5.42 (3.01)
Gender (women), frequency (%)	247 (82.3)	44 (14.7)
Number of children with ASD, frequency (%)		
1	287 (95.7)	_
≥2	13 (4.3)	_
Locality, frequency (%)		
Urban	167 (55.7)	_
Rural	133 (44.3)	_
Education, frequency (%)		
High school or lower	116 (38.7)	_
Intermediate/college/undergraduate/graduate	184 (61.3)	_
Marital status, frequency (%)		
Married/living with spouse	281 (93.7)	_
Divorced/single mom/dad/widow	19 (6.3)	_
Child's school place, frequency (%)		
Special education school	_	88 (29.3)
Inclusive education school	_	92 (30.7)
Both special and inclusive education	_	100 (33.3)
Not going to school	_	20 (6.7)
Child's age at the time of diagnosis, M (SD)	_	30.96 (12.06)
Child ASD severity, frequency (%)		
Mild	_	43 (14.3)
Moderate	_	116 (38.7)
Severe	_	141 (47.0)

## Reliability of the instrument

The study was conducted with 300 participants with similar eligibility criteria. The reliability coefficient of Cronbach's alpha was calculated to measure internal consistency. The

Cronbach's alphas of the total scale, the affective domain, the cognitive domain, and the behavioral domain were 0.94, 0.87, 0.87, and 0.88, respectively, which indicates good reliability. The results are shown in Table 2.



## Table 2

Items	Corrected Item-Total correlation	Cronbach's alpha if item deleted	Cronbach's Alpha
Subscale 1:	Affective		
1	0.73	0.84	0.87
2	0.67	0.85	
3	0.70	0.84	
4	0.66	0.85	
5	0.56	0.86	
6	0.58	0.86	
7	0.60	0.86	
Subscale 2:	Cognitive		
8	0.64	0.86	
9	0.68	0.85	
10	0.60	0.86	
11	0.71	0.85	0.87
12	0.66	0.86	
13	0.64	0.86	
14	0.65	0.86	
Subscale 3:	Behavioral		
15	0.56	0.88	
16	0.64	0.87	
17	0.74	0.86	0.88
18	0.69	0.86	
19	0.57	0.88	
20	0.63	0.87	
21	0.68	0.87	
22	0.69	0.86	
Total scale			0.94

Cronbach's alpha and co	orrected item-total	correlation for A	1SS-V(n = 300)
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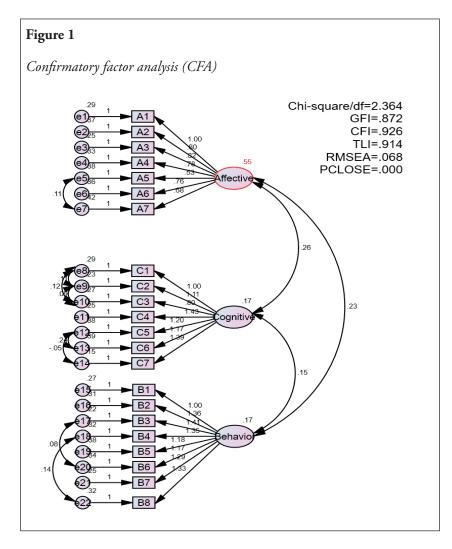
# Validity

## **Construct validity**

The first model was reported to be without a good fit. The fit of the second model was acceptable after modifying some items with high modification indices (i.e., 5 and 7, 8 and 9, 8 and 10, 9 and 10, 12 and 13, 12 and 14, 17 and 20, 18 and 22). The fit of the second model was found using CFA of the three-factor model (CFI = 0.93, TLI = 0.92, RMSEA = 0.068). The indicators for the second model that were obtained from the CFA are shown in Figure 1.



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# Discussion

The ASS was translated into several different languages using both forward and backward translation techniques (Dehnavi et al., 2011; Kumari et al., 2022; Mak & Cheung, 2008; Papadopoulos et al., 2022; Werner & Shulman, 2015; Yun et al., 2018). This study aimed to provide insights into the psychometric properties of the questionnaire in the Vietnamese context and to contribute to the understanding of stigma among parents of children with ASD in Vietnam.

The translation process followed the recommendations of Sousa and Rojanasrirat (2011) to ensure that the translated scale maintained similar characteristics to those of the original. The guidelines facilitated the translation process, ensuring a high degree of cross-cultural and cross-linguistic applicability. The ASS-V was found to be a reliable and valid scale. Data analysis revealed a range of good Cronbach's alpha coefficients for both the total scale and its subscales. It demonstrated the homogeneity and strong correlation among the items of the scale in the Vietnamese version. These results are in line with previous studies (Dehnavi et al., 2011; Kumari et al., 2022; Mak & Cheung, 2008; Papadopoulos et al., 2022; Werner & Shulman, 2015; Yun et al., 2018), in which the internal consistency of the ASS ranged from 0.78 to 0.95. The scale proved to be easily understood and accepted by

parents of children with ASD, facilitating its widespread use to assess the level of stigma among parents of children with ASD in Vietnam.

Three factors (affective, cognitive, and behavioral) were used to assess the construct validity of the ASS-V. Items 5 and 7, 8 and 9, 8 and 10, 9 and 10, 12 and 13, 12 and 14, 17 and 20, and 18 and 22 exhibited high modification indices in the first model. The error covariance may be caused by the overlaps in the meaning of these items, or these items may be related to each other. Items 5 and 7 were undoubtedly related to the sadness and pressure of having a child with ASD, items 8, 9, and 10 to discrimination, items 12, 13, and 14 to self-esteem, items 17 and 20 to contact with a child with ASD, and items 18 and 22 to contact with friends, relatives, and neighbors. The second model was improved and then had a good CFI score of 0.93, a TLI score of 0.92, and good RMSEA of 0.068 (Hair, 2010). This study is consistent with other study that showed good model fit with the three-factor model of the Chinese version of the ASS (Chang et al., 2016). However, this result showed stronger model fit indices than those obtained in the study of Yun (2018) with the four-factor model (CFI = 0.904, TLI = 0.888, RMSEA = 0.065). These differences can be explained by variations in the populations of the studies, which included caregivers of patients with mental illness and larger sample sizes (n = 372) (Yun et al., 2018).



Overall, the ASS-V is a valid and reliable tool that may be used to assess affiliate stigma among parents with ASD. By using this scale, healthcare providers can identify parents who have high levels of affiliate stigma and take steps to design intervention programs to help them cope with the stigma they experience.

The present study has some limitations. First, the reliability assessment for this study was conducted over a short period of time using a cross-sectional design, without the use of a "test-retest" structure. Using the same participants, the same measurement tool, and testing twice at various intervals is referred to as test-retest reliability, which is used to assess the stability of the measurement tool. Second, selecting individuals expected to have high levels of the measured attribute and statistically comparing their scores to those expected to have low levels of the same attribute was not examined to assess contrasted or known groups validity (Vilagut, 2014). The validity and reliability of the ASS-V scale were initially established by this study. However, the ASS-V was only validated for parents of children with ASD. Therefore, future studies are necessary to confirm the results with other participants who are caregivers of children with ASD.

# Conclusion

The ASS-V was found to be a reliable and valid scale. The total scale and all three subscales of the ASS-V, including a total of 22 items, exhibited good internal consistency and construct validity. The ASS-V may be useful for nurses to early assess the level of affiliate stigma among parents of children with ASD and to provide appropriate support to them.

#### Author's contributions

Conceptualization: Khanh, T. L. Data Curation: Nguyen, H.T. Formal analysis: Nguyen, H.T. Methodology: Khanh, T. L. Supervision: Mai, T. L. A. Validation: Hoang, P. A. Writing - Review & Editing: Hoang, P. A.

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