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RESEARCH

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Psychometric evaluation and adaptation of the stigma affiliation scale into the Indonesian language in primary family caregivers of schizophrenia patients

Tuti Kurnianingsih[1*], Patricia Beta Ayu Lumbantoruan[1], Irvan Afriandi[2], Veranita Pandia[1] and Meita Dhamayanti[3,4]

Abstract

Introduction The Stigma Affiliation Scale (ASS) is an instrument to assess affiliation stigma used widely worldwide. This study aims to adapt the ASS to the Indonesian language and to evaluate the psychometric properties of the ASS among family caregivers of people with schizophrenia in Indonesia.

Methods A cross-sectional study was conducted of 94 schizophrenia patients' family caregivers in communities, i.e., an items analysis, construct validity using the known-group method, and internal consistency reliability.

Results The consistency between items and overall scores using Pearson product-moment correlation shows that all the items had Pearson's coefficient correlation ≥ 0.300, indicating good and acceptable discriminant power. The construct validity using the Mann–Whitney *U* test comparing the ASS scores between the primary caregivers and other family members of schizophrenic patients showed higher scores in the primary caregivers than the other family members in the three domains ($p < 0.0001$), indicating excellent construct validity. Cronbach's alpha was 0.80–0.89 and above 0.90, which indicate good and excellent reliability, respectively.

Conclusion The Indonesian version of ASS shows good psychometric properties among family caregivers of people with schizophrenia in Indonesia.

Keywords Stigma affiliation scale, Psychometric evaluation, Family caregivers, Schizophrenia

Introduction

Schizophrenia is a mental disorder that affects 1% of the world's population [1]. Basic Health Research by the Indonesian Health Ministry of Indonesia in 2018 found that 6.7 out of every 1000 families in Indonesia had a family member with a psychotic disorder, including schizophrenia [2]. Symptoms of schizophrenia are classified into positive, negative, and cognitive symptoms. Positive symptoms include delusions, hallucinations, and disorganized thinking and behaviour, while negative symptoms include alogia, avolition, and affective flattening. Cognitive symptoms of schizophrenia include difficulties with working memory, processing speed, and executive

*Correspondence:
Tuti Kurnianingsih
tuti.kurnianingsih14@unpad.ac.id
[1] Department of Psychiatry, Faculty of Medicine, Universitas Padjadjaran, Bandung, Indonesia
[2] Department of Public Health, Faculty of Medicine, Universitas Padjadjaran, Bandung, Indonesia
[3] Department of Child Health, Faculty of Medicine, Universitas Padjadjaran, Bandung, Indonesia
[4] Center for the study of Health Systems and Education Innovation for Health Workers, Universitas Padjadjaran, Bandung, Indonesia

function. In the acute psychotic phase, the schizophrenia patient could also exhibit aggressive and violent behaviour [3]. These symptoms could contribute to the development of stigma. Schizophrenia is associated with a strong stigma, and the stigma against schizophrenia is the strongest compared to other mental disorders. Goffman defined stigma as "a deeply discrediting attribute" that reduces the bearer "from a whole and usual person to a tainted discounted one". Stigma is not only experienced by people with mental disorders but also by their families. Gofman defines stigma against family members of people with mental illnesses as "courtesy or associative stigma, which is the process by which a person is stigmatized by virtue of association with another stigmatized individual" [4, 5]. Family stigma could be classified as associative (also known as perceived stigma) and affiliate (also known as self-stigma). Affiliate stigma is when the family members internalize societal prejudice and direct it at them [6, 7]. Affiliation stigma can cause various negative impacts on families, such as emotional distress, mental or physical disorders, self-isolation, job loss, reduced income, and poor quality of life, causing family members not to function as they should [8–12]. Thus, affiliation stigma can harm schizophrenia patients by being isolated, not taken for treatment, not being involved in social activities, and reduced family support, all of which can decrease therapy outcomes, quality of life, and happiness [9].

Considering the negative impacts of affiliation stigma on family and patients, it is crucial to examine the affiliation stigma early on in every family of schizophrenic patients so that the necessary psychiatric interventions can be implemented immediately. Currently, only a few stigma-measuring scales have been proven valid worldwide. One of these measurement scales for affiliation stigma is the Stigma Affiliation Scale [6]. This scale has been used more frequently in recent years due to evidence of its strong psychometric properties and has undergone validation and translation into multiple languages. To date, there is no published measuring tool to assess affiliate stigma in Indonesia, especially in families of schizophrenia patients. The study aims to perform an adaptation and psychometric evaluation of the Indonesian version of the Stigma Scale Affiliation in the Indonesian family of the schizophrenic patient population.

Materials and methods

Participants and setting

The protocol of this study was approved by the Research Ethics Committee of Universitas Padjadjaran, number 1358/UN.6KEP/EC/2022. The participants were recruited from the community through the Community Health Centre in Bandung, Indonesia. Before study inclusion, all participants received and freely signed an informed consent form. Participants were selected by purposive sampling and grouped into two groups: family members who were the primary caregivers and other family members of schizophrenic patients. We included 94 primary caregivers over 18 years old who played a significant role in patient care and could read and comprehend Indonesian in the primary caregiver group. In the other family member group, we included 94 other family members older than 18 who did not assist with patient care and could read and comprehend Indonesian. We excluded primary caregivers or family members with a mental illness.

Procedure

We received permission to translate and validate the ASS instrument into Indonesian from Prof. Winnie Wing Sze Mak, Ph.D., UCSB, the instrument developer, on March 2022. The study was conducted in six stages, following the Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measures by Beaton et al. [13]. The first stage is initial translation, which is a forward translation. The instrument was translated from English into Indonesian by two medical doctors who have Indonesian as their mother language and are fluent in English. They worked separately and independently, made a report on each translation, and recorded complicated phrases to be compared at the next step. The first translator produced translation 1 (T1), and the second produced translation 2 (T2). The second stage was a synthesis of the translations. The two translators discussed with the observer (a medical doctor and venereology specialist) and produced a combined translation (T12). The process of this discussion was documented and reported. The third stage was a back translation. Regardless of the original instrument, the two translations (T1 and T2) were re-translated into English by two translators with English as their mother language. Both translators did not have a medical background. The translation from the first translator became TK1, while the translation from the second translator became TK2. The two translators made a report on this translation process. The fourth stage was the expert committee review. This stage was the acknowledgement of the expert committee, a joint discussion of mental health professionals (three senior psychiatrists), one senior psychiatry resident, and translators. This committee consolidated all the content in the instrument and developed pre-final instruments for field testing. The material used in this consolidation was the original instrument, forward translation (T12), and back-translation (TK12). This committee produced a consolidated instrument in the Indonesian version, which will be used in the pre-field test. The consolidation process was documented in

a report. The equivalent of the original and prefinal versions covers four areas, namely the semantic, idiomatic, experiential, and contextual. The fifth stage was a test of the prefinal version. The consolidated instrument from the expert committee was tested on ten family members and caregivers of schizophrenia patients. After giving their informed consent, the participants filled out the Indonesian version of the instrument. Furthermore, interviews were conducted to assess responses regarding understanding the items in the Indonesian version of the instrument. In the sixth stage, which was the last stage, we submitted the documentation to the ASS developer to review the adaptation procedure. After the developer of ASS agreed with the Indonesian version of the instrument, we performed the characteristic psychometric test to determine the psychometric characteristics of the Indonesian version of ASS in January 2023.

Instruments

ASS was created by Mak and Cheung in 2008 to measure the stigma among caregivers of patients with mental illness. It has been used frequently due its strong psychometric properties and has been validated several times into many languages. This scale comprises 22 items to examine the internalization of stigma by caregivers, divided into 3 domains: cognitive, affective, and behavioural components of affiliation stigma. The responses use a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). A total score ≤ 55 indicates a low degree of affiliation stigma, a score of 56–62 indicates a moderate degree of affiliation stigma, and a score ≥ 63 indicates a high degree of affiliation stigma [6].

Data analysis

Item analysis

Item analysis was performed using item-total correlation. We examined the consistency between items and overall scores using Pearson product-moment correlation.

Item analysis was evaluated using Pearson's corrected item-total correlation by means of SPSS. The correlation coefficient ≥ 0.30 indicated a good item.

Discriminant validity

We assessed discriminant validity using the contrasted (know-groups) method, which compares the ASS scores between the primary caregivers and other family members of schizophrenic patients, considering that the primary caregiver had a stronger affiliation stigma than the other family members. Since the data were not normally distributed, we used the Mann–Whitney *U* test to analyse the data.

Reliability

Our study used internal consistency to test reliability. The internal consistency was assessed using Cronbach's alpha, with a score of less than 0.70 considered unacceptable, 0.70 to 0.79 considered fair, 0.80–0.89 considered good, and 0.90 and above considered excellent.

Results

Demographic characteristics

Demographic characteristics of the family are shown in Table 1.

Reliability and item analysis

Item analysis is shown in Table 2. The corrected item-total correlation coefficient ranged between 0.393 and 0.867, meaning that all the items were good. Cronbach's alpha reliability coefficients for cognitive, affective, and behavioural components were as follows 0.896, 0.925, and 0.920, respectively. It can be concluded that ASS components have good and excellent reliability.

Discriminant validity

For discriminant validity, Table 3 shows that the two groups were different significantly. This means that the samples were divided into primary caregivers that play a significant role in patients' care and other family members with minimal or no role in patient's care.

Construct validity

The construct validity of the ASS is shown in Table 4. The result of the construct validity showed a significant

Table 1 Demographic characteristics

Demographic characteristics	Primary family caregivers, $n=94$	Other family members, $n=94$
Age	47.29 ± 13.19*	40.44 ± 13.18*
Years of education	7.28 ± 2.49*	9.25 ± 2.66*
Gender		
Male	9 (9.6%)	42 (44.7%)
Female	85 (90.4%)	52 (55.3%)
Employment		
Employee	11 (11.7%)	43 (45.8%)
Unemployed	83 (88.3%)	51 (54.2%)
Marital status		
Married	85 (90.4%)	71 (75.5%)
Unmarried	9 (9.6%)	23 (24.5%)
Ethnicity		
Sundanese	92 (97.8%)	90 (95.7%)
Other than Sundanese	2 (2.2%)	4 (4.3%)

*$p < 0.05$

Table 2 Item analysis

Domain	Item	Corrected item-total correlation
Affect	Q1	0.837
	Q4	0.773
	Q7	0.690
	Q10	0.847
	Q13	0.393
	Q16	0.748
	Q19	0.618
Behaviour	Q2	0.810
	Q5	0.793
	Q8	0.807
	Q11	0.604
	Q14	0.817
	Q17	0.847
	Q20	0.659
	Q22	0.650
Cognition	Q3	0.812
	Q6	0.786
	Q9	0.783
	Q12	0.814
	Q15	0.592
	Q18	0.658
	Q21	0.867

association between the whole domain scores of the ASS in the primary caregivers and other family members group, thus indicating excellent construct validity.

Discussion

The mean age of primary family caregivers was found to be 47.29 years, while other family members had a slightly lower mean age of 40.44 years. This discrepancy might be attributed to the varying roles and responsibilities these two groups undertake in caregiving. Primary caregivers tend to be older as they assume more comprehensive care tasks, including medical management and personal care. The gender distribution among the primary family caregivers was skewed towards females, while among other family members, the distribution was more balanced. This distribution echoes the gendered nature of caregiving roles, where females often assume primary caregiver roles due to societal norms and expectations [14]. The higher percentage of females among primary caregivers is consistent with the well-documented feminization of caregiving. The data indicate that a larger proportion of other family members were employed compared to primary caregivers. This suggests that primary caregivers are more likely to reduce their employment commitments to accommodate caregiving responsibilities. The financial implications of such a shift in employment status could be substantial, potentially impacting the overall economic well-being of the caregiving family. In terms of education, primary family caregivers had a lower mean level of education compared to other family members. This disparity in education could influence the caregiver's ability to access and understand complex medical information. The role of education in shaping caregiving experiences requires further exploration. The majority of primary family caregivers were married, which is consistent with the typical family structure where spouses often assume caregiving roles for their partners. In contrast, a lower percentage of other family members were married. This distinction in marital status could influence the availability of support networks for caregivers.

Our study assessed the psychometric properties of the Indonesian version of ASS among caregiver patients with schizophrenia. We examined the consistency between items and overall scores using Pearson product-moment correlation to determine the discriminant power. The results show that all the items of the Indonesian versions of ASS had Pearson's coefficient correlation ≥ 0.300, which is 0.528–0.897 for the items in the affect domain, 0.681–0.895 for the items in the behaviour domain, and 0.677–0.901 for the items in the cognitive domain. These results indicate that all items in the three domains of the Indonesian versions of ASS had good and acceptable discriminant power. Previous studies in other countries assessed the item analysis of the ASS using methods

Table 3 *U* Mann–Whitney test

Component	Caregiver	Mean	Standard deviation	*Z* Mann–Whitney	*p*-value	Conclusion
Affect	Primary	20.12	4.736	−6.372	0.000	Significant
	Others	15.15	4.450			
Behaviour	Primary	22.50	5.736	−6.409	0.000	Significant
	Others	16.80	5.349			
Cognition	Primary	19.09	4.801	−6.376	0.000	Significant
	Others	13.97	4.793			

Table 4 Construct validity

	Comparison group		*P* value
	Primary family caregivers, $n=94$	Other family members, $n=94$	
Affect domain			
Mean ± Std	20.12 ± 4.736	15.15 ± 4.450	0.0001**
Median	21.00	12.00	
Range (min–max)	11.00–28.00	9.00–26.00	
Behaviour domain			
Mean ± Std	22.50 ± 5.736	16.80 ± 5.349	0.0001**
Median	24.00	14.00	
Range (min–max)	12.00–32.00	11.00–32.00	
Cognitive domain			
Mean ± Std	19.09 ± 4.801	13.97 ± 4.793	0.0001**
Median	21.00	11.00	
Range (min–max)	9.00–26.00	9.00–26.00	

**$p < 0.01$

different from ours. Studies in India and Malaysia using Kaiser-Meyer measure high and excellent results, respectively, with Bartlets's test showing a significant correlation of the variables [15, 16]. Item analysis examination using the Rasch partial-credit model in a study in Iran showed that all items had high item-to-total correlation [17].

The construct validity analysis in our study uses the known-group method that compares the ASS scores between the primary caregivers and other family members of schizophrenic patients. The primary caregiver spends more time and effort caring for schizophrenic patients than other family members. Affiliation stigma is related to the longer duration of time and more caregiving efforts carried out by caregivers for schizophrenic patients, and primary caregivers have higher stigma affiliation compared to other family members. The results of the Mann–Whitney *U* test comparing the scores of the two groups showed that the scores of the Indonesian version of ASS in the primary caregivers were higher significantly compared to the other family members in the three domains ($p < 0.0001$), indicating that it has excellent construct validity. Previous studies in other countries assessed the validity of the ASS using a different method than ours. The study in India assessed the concurrent validity using Pearson's correlation showing ASS significantly positively correlated with the General Health Questionnaire-12 and Hospital Anxiety and Depression Scale [18], while a study in China showed that ASS has a significant correlation with caregiver burden, depression, anxiety, and quality of life [16]. A study in Taiwan showed a significant correlation between ASS and Rosenberg Self-Esteem Scale and Beck Anxiety Inventory [19].

Regarding reliability, in our study, the internal consistency using Cronbach's alpha showed a result between 0.80–0.89 and above 0.90 which are considered to have good and excellent reliability, respectively. Previous studies in other countries showed similar results, such as in Turkey [20], India [18], Malaysia [15], Taiwan [19], Iran [17], and Greek [21].

Study limitations

The limitation of this study is that the participants came from less varied ethnic backgrounds in Indonesia. The other limitation is that this study only examined some psychometric aspects of the ASS.

Conclusion

In conclusion, the Indonesian version of the Affiliate Stigma Scale demonstrated good reliability and validity in primary family caregivers of schizophrenia patients. This instrument may serve as a useful measure to assess the affiliate stigma of families of schizophrenia patients.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s43045-024-00394-w.

Additional file 1:

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Authors' contributions

TK, IA, VP, and MD made substantial contributions to the conception of this research. PB contributed to the acquisition, analysis, and interpretation of the data. TK has drafted the work or substantively revised it. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

The protocol of this study was approved by the Research Ethics Committee of Universitas Padjadjaran, number 1358/UN.6KEP/EC/2022. The participants were recruited from the community through the Community Health Centre in Bandung, Indonesia. Before study inclusion, all participants received and freely signed an informed consent form.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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References

1. World Health Organization (2022) Schizophrenia. https://www.who.int/news-room/fact-sheets/detail/schizophrenia. Accessed 17 Jul 2023.
2. Kemenkes RI (2018) Laporan Nasional Riskesdas 2018. Balitbang Kemenkes RI
3. McCutcheon RA, Reis Marques T, Howes OD (2019) Schizophrenia - an overview. JAMA. Psychiatry 77:201–210. https://doi.org/10.1001/jamapsychiatry.2019.3360
4. Goffman E (1963) Erving Goffman Stigma
5. Aakansha S, Mattoo S, Grover S (2016) Stigma associated with mental illness: conceptual issues and focus on stigma perceived by the patients with schizophrenia and their caregivers. Indian J Soc Psychiatry 32:134. https://doi.org/10.4103/0971-9962.181095
6. Mak WWS, Cheung RYM (2008) Affiliate stigma among caregivers of people with intellectual disability or mental illness. J Appl Res Intellect Disabil 21:532–545. https://doi.org/10.1111/j.1468-3148.2008.00426.x
7. Shi Y, Shao Y, Li H et al (2019) Correlates of affiliate stigma among family caregivers of people with mental illness: a systematic review and meta-analysis. J Psychiatr Ment Health Nurs 26:49–61. https://doi.org/10.1111/jpm.12505
8. Karambelas GJ, Filia K, Byrne LK, et al (2022) A systematic review comparing caregiver burden and psychological functioning in caregivers of individuals with schizophrenia spectrum disorders and bipolar disorders. BMC Psychiatry 22. https://doi.org/10.1186/s12888-022-04069-w
9. Minichil W, Getinet W, Kassew T (2021) Prevalence of perceived stigma and associated factors among primary caregivers of children and adolescents with mental illness, Addis Ababa, Ethiopia: cross-sectional study. PLoS One 16:. https://doi.org/10.1371/journal.pone.0261297
10. Ong HC, Ibrahim N, Wahab S (2016) Psychological distress, perceived stigma, and coping among caregivers of patients with schizophrenia. Psychol Res Behav Manag 9:211–218. https://doi.org/10.2147/PRBM.S112129
11. Ran MS, Wang YZ, Lu PY, et al (2022) Effectiveness of enhancing contact model on reducing stigma of mental illness among family caregivers of persons with schizophrenia in rural China: a cluster randomized controlled trial. https://doi.org/10.1016/j
12. Wu HC, Chen FP (2016) Sociocultural factors associated with caregiver-psychiatrist relationship in Taiwan. Psychiatry Investig 13:288–296. https://doi.org/10.4306/pi.2016.13.3.288
13 Beaton Dorcas E, Bombardier Claire, Francis Guillemin MBF (2000) Guidelines for the process of cross-cultural adaptation of self-report measures. Spine (Phila Pa 1976) 25:3186–3191
14. Pinquart M, Sörensen S (2006) Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis
15. Yun YS, Syed Jaapar SZ, Fadzil NA, Cheng KY (2018) Validation of the Malay version of the affiliate stigma scale among caregivers of patients with mental illness. Malays J Med Sci 25:127–136. https://doi.org/10.21315/mjms2018.25.6.13
16. Chang CC, Su JA, Lin CY (2016) Using the Affiliate Stigma Scale with caregivers of people with dementia: psychometric evaluation. Alzheimers Res Ther 8:1–8. https://doi.org/10.1186/s13195-016-0213-y
17. Saffari M, Lin CY, Koenig HG et al (2019) A Persian version of the affiliate stigma scale in caregivers of people with dementia. Health Promot Perspect 9:31–39. https://doi.org/10.15171/hpp.2019.04
18. Kumari R, Ranjan JK, Verma S, Asthana HS (2022) Hindi adaptation and psychometric validation of the Affiliate Stigma Scale. Indian J Psychol Med 44:167–172. https://doi.org/10.1177/0253717620939253
19. Chang CC, Yen CF, Jang FL et al (2017) Comparing affiliate stigma between family caregivers of people with different severe mental illness in Taiwan. J Nerv Ment Dis 205:542–549. https://doi.org/10.1097/NMD.0000000000000671
20. Kasimoglu N, Arikan D (2020) Validity and reliability of the Turkish version of the Affiliate Stigma Scale in parents of children with intellectual disability. Int J Caring Sci 13:665–674
21. Papadopoulos A, Tafiadis D, Tsapara A et al (2022) Validation of the Greek version of the Affiliate Stigma Scale among mothers of children with autism spectrum disorder. BJPsych Open 8:1–8. https://doi.org/10.1192/bjo.2021.1083