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Psychometric evaluation of the affiliate stigma scale for caregivers of people with mental illness in Uganda

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Abstract

Background Affiliate stigma is common among caregivers of people with mental illness and impacts negatively on the caregivers' quality of life and their ability to care for the patients. Although there is evidence of affiliate stigma in sub-Saharan Africa, the psychometric properties of commonly used tools are not available in the African context. The aim of this analysis was to evaluate the factor structure of the affiliate stigma scale among caregivers of people with mental illness in southwestern Uganda. Having a validated method to assess affiliate stigma in the Ugandan setting helps to appropriately evaluate affiliate stigma among caregivers of people with mental illnesses, which could inform the development of interventions to support such caregivers.

Method A total of 385 caregivers of people with mental illness attending outpatient psychiatry clinics in selected tertiary hospitals in southwestern Uganda were enrolled in the study. The affiliate stigma and depression were assessed using the affiliate stigma scale and the patient health questionnaire (PHQ-9) respectively. We conducted exploratory and confirmatory factor analysis to determine the factor structure, reliability and validity of the affiliate stigma scale. We also evaluated the convergent validity of the affiliate stigma scale by determining the correlation between affiliate stigma scale scores and the PHQ-9.

Result More than half of participants were male (55.06%) and majority of caregivers were living in rural areas (80.26%). The sample size was adequate, as evidenced by the KMO of 0.91 and the inter-correlation was sufficient to conduct the factor analysis, according to the Bartlett test. Confirmatory factor analysis revealed four factors and all 22 items were retained as all of them had a factor loading > 0.4. The internal consistency of the total scale was excellent (alpha = 0.92). The affiliate stigma score correlated with depression which has been hypothesized to be associated with the stigma of mental illness.

Conclusion The study findings show the affiliate stigma scale as a valid measure of affiliate stigma among the caregivers of patients with mental illness in southwestern Uganda. Therefore, this scale provides an opportunity to mental health care providers to assess affiliate stigma and develop interventions aimed at prevention stigma among caregivers and improve outcomes among people with mental illness.

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Keywords Affiliate stigma scale, Factor structure, Validity, Psychometric evaluation, Caregivers, Uganda

Introduction

Mental health stigma is widespread, and also affects caregivers of people with mental illness who are usually family members or friends of those affected [1]. Affiliate stigma occurs when a person is closely associated with a stigmatized individual, causing one to be personally affected by societal stigma and developing affiliate stigma. [2–5]. Affiliate stigma is comprised of three interlocking components: cognitions (perception of self-worthlessness), affect (embarrassment and feeling of shame) and behavioral responses [2]. Affiliate stigma is quite common among caregivers of people with mental illnesses, with more than half of caregivers experiencing it, with recent studies estimating the prevalence of affiliate stigma at 75% among primary caregivers [1, 5–7]. In Uganda, as well as other sub-Saharan African countries including South Africa and Ghana, informal caregivers of people with mental illness play a vital role in providing adequate and holistic care to the patients [8–11]. They take care of the day-to-day needs of the patients by providing assistance with household tasks, self-care tasks, and health and medical care, including supervising patients to take medications and taking the patients to the hospital for regular reviews [12, 13]. However, when caregivers experience affiliate stigma, the coordination with mental health providers and provision of care for individuals with mental illness is affected, impairing the adherence to treatment and treatment outcomes of the patients [14–16].

Mak and Cheung [2] developed the affiliate stigma scale in 2008 with the goal of systematically investigating affiliate stigma among caregivers of people with mental illness. Although the affiliate stigma scale has been used in different populations including sub-Saharan African populations like in Ghana and Kenya [17–20] the factor structure, validity and reliability of the scale have not been established in these settings. Moreover, as indicated in previous research in Uganda shows that mental illness affects 24.2% of the adults and 22.9% of the children with depressive disorders being the commonest severe condition with reported prevalence ranging between 14% and 30% [21–23]. In southwestern Uganda, a study among prisoners was estimated at 86% [24]. Another study on the mediating role of affiliate stigma on the relationship between caregiving burden and caregiver involvement in southwestern Uganda showed that over 30% of the participants experienced caregiving burden and that affiliated stigma impacted their caregiving roles and increased the burden of caregiving [25]. Despite this, there are no studies in Uganda have evaluated the psychometric properties of the affiliate stigma scales. The aim of this analysis was therefore to evaluate the factor structure, validity and reliability of the affiliate stigma scale among caregivers of people with mental illness in southwestern Uganda.

Materials and methods

Study setting

The study took place in four tertiary hospitals in the southwestern Uganda. These hospitals are Mbarara Regional Referral Hospital, Kabale Regional Referral Hospital, Masaka Regional Referral Hospital, and Kampala International University Teaching Hospital (KIU-TH). The hospitals' catchment area is spread across southwestern Uganda which comprises of 35 districts out of 135 districts in the country with a total population of more than 8 million [26, 27]. The hospitals are between 134 and 409 km from Kampala, the capital city of Uganda. Patients attend these clinics for treatment or follow up reviews in the outpatient psychiatry clinics of these tertiary hospitals. Almost all patients are accompanied by a caregiver, who is usually someone closer to them and helps to clarify the patient's presenting issues/complaints if the patient is unable to do it himself.

Study participants and enrollment procedure

A total of 385 caregivers were enrolled in the study and we used consecutive sampling to enroll the participants. The participants were recruited as they escorted their patients for review at the clinics. We enrolled adults aged 18 years and above, who were providing care for a patient with mental illness for at least 6 months, and provided consent to participate in the study. We excluded potential participants who had communication challenges including being deaf or dumb making it impossible for them to communicate with the research assistants to provide consent or respond to the contents of the questionnaire. After the regular clinic review, a trained research assistant explained the study's purpose, including the benefits of participating and potential risks of taking part in the study to the potential participants. Participants were informed that participation in the study was voluntary and that they could withdraw from the study at any moment without incurring any penalties. Those who agreed to participate, provided written informed consent before enrollment in the study. Data collection tools were translated by two independent mental health care providers from English to the local language (Runyankore) and back translated to English to ensure fidelity. The final draft's readability and clarity were pre-tested on 12 caregivers of patients with mental illnesses. There was

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no need to adjust the questionnaire based on the pre-test findings.

Study measures

We use a comprehensive questionnaire that included socio-demographic information such as age, sex, address, level of education, the relationship with the patient, years of caregiving, caregiving days in a week, the affiliate stigma scale and patient health questionnaire tool (PHQ).

The affiliate stigma scale was used to collect information on affiliate stigma.

The affiliate stigma scale was developed in 2008 from University of Hong Kong [2]. The scale has 22 items rated on a 4-point Likert scale and a higher score indicates a higher level of affiliate stigma. The scale has three domains: cognitive=7 items, affect=7 items, and behavior=8 items, and has shown good psychometrics property in non-African settings [17, 20]. The affiliate stigma scale measures the extent to which individuals experience stigma related to their association with a person with mental illness. It asks questions about social exclusion, discomfort, or feelings of embarrassment, related to their association with the stigmatized person.

Depression was measured using the Patient Health Questionnaire and it is a 9-item depression screening tool [28]. PHQ-9 score ranges from 0 to 27 and each of the 9 items is scored from 0 ("not at all") to 3 ("nearly every day"). A PHQ-9 score of 10 and above indicate depression. The depression severity score is as follows: 0–4 none, 5–9 mild, 10–14 moderate, 15–19 moderately severe, 20–27 severe [28]. PHQ-9 has been validated in African settings including Uganda with good validity and reliability [29, 30].

Data analysis

Data was analyzed using STATA Version 17. The normality of the data was tested using the Shapiro-Wilks test and histograms. Participants' demographics were summarized using descriptive statistics. The categorical characteristics were presented as frequencies and percentages, and the continuous variables were presented as means and standard deviations (SD). These measures of central and variational tendency were provided after checking for the Gaussian assumption that was tested using the Shapiro-Wilks test and histograms. At the beginning of the factor analysis, we assessed the sampling adequacy and sphericity using the Kaiser-Meyer-Olkin (KMO) and the Barlett measures, respectively [31, 32]. We considered a KMO≥0.60 as adequate for factor analysis [33]. We tested the psychometric properties of the affiliate stigma scale focusing on factor structure, convergent validity, and internal consistency using the Cronbach's alpha.

Factor analysis

First, we divided the total sample (385) in half, where half of the sample (192 participants) was used for exploratory factor analysis and the other half (193 participants) for confirmatory factor analysis. We performed exploratory factor analysis using principal components analysis to determine the factor structure of the affiliate stigma. We conducted exploratory factor analysis using promax rotation to understand the internal structure of the scale [34]. Assuming a correlation between the scale's underlying factors and items, we employed oblique promax rotation. Three criteria enabled us choose which elements to retain. Initially, factors with eigenvalues>1.0 were examined closely. Second, the scree - the area of the graph where the slope of decreasing eigenvalues approaches zero - was found by plotting the eigenvalues in descending order. Finally, we looked at factor loadings and if an item's factor loading was greater than 0.40, it was allocated to that factor [35]. Confirmatory factor analysis was conducted using the maximum likelihood estimation to test the factors identified during exploratory factor analysis. We specified a 4-factor model according to the results from the exploratory factor analysis with the affiliate stigma scale. Model fit was assessed using multiple goodness of fit measures including comparative Fit Index (CFI), Root Mean Square Error of Approximation (RMSEA), and standardized root mean-square residual (SRMR). SRMR represented absolute fit indices and CFI provided incremental indices, and RMSEA presented a parsimony-adjusted measure. We considered CFI≥0.95, RMSEA≤0.08, and SRMR≤0.08 as cutoffs [36].

Convergent validity

The convergent validity of the affiliate stigma scale was assessed using the overall sample (385 participants) and was evaluated by determining the correlation between affiliate stigma scale scores and depression using the PHQ-9.

Reliability

The internal consistency of the scale was measured using Cronbach's alpha, considering a Cronbach's alpha of 0.70 or greater to be acceptable [37]. We also calculated the average inter-item correlation, Pearson correlations across items, and correlations of the scores of each item with the total score of the scale.

Ethical considerations

The study was approved by the Research Ethics Committee of Mbarara University of Science and Technology (MUST-REC 602), and the administrators of respective hospitals provided clearance. Prior to enrollment in the study, all participants provided written informed consent after being fully informed of the study's objectives and

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procedures. Individuals found to have psychological distress received counseling and additional support services from the mental health professionals in the respective hospitals.

Results

Sociodemographic characteristics of participants

A total of 385 caregivers were included in the study. The mean age of caregivers was 45.63 (SD 12.13). More than half of participants were male (55.06%) and majority of caregivers were living in rural areas (80.26%). Among caregivers, 41.56% were single and 44.68% had attained primary level of education (see Table 1).

Factor structure

The sampling adequacy statistics results showed that the sample size was adequate, as evidenced by the KMO of 0.91 [38]. The inter-correlation was sufficient to conduct the factor analysis, according to the Bartlett test ($\chi2=4986.171$; $p<0.001$). Exploratory factor analysis identified four factors with an eigenvalue greater than 1.

Table 1 Sociodemographic characteristics of the study participants

Variable	Proportion or mean (SD)	% or SD
Age of the participant	45.63 (14.13)	
Gender		
Female	173	44.94
Male	212	55.06
Marital status		
Divorced / Widowed	88	22.86
Married/cohabiting	137	35.58
Single	160	41.56
Address		
Urban	76	19.74
Rural	309	80.26
Level of education		
No formal education	11	2.86
Primary	172	44.68
Secondary	131	34.03
Tertiary	71	18.44
Relationship with the patient		
Child (Daughter or son)	18	4.68
Spouse	48	12.47
Sibling	113	29.35
Parent (Father or mother)	178	46.23
Others (Fiends, Grandparents, Uncles, aunties and in law)	28	7.27
Years of caregiving {Median (IQR)]	1 (0.5–5)	
Caregiving days in a week {*Median (IQR)]*	7 (5–7)	
Affiliate stigma score	38.45 (12.12)	
Depression		
No	288	74.81
Yes	97	25.19

No items were dropped. Factor 1 had six items loaded on it with factor loadings ranging from 0.72 to 0.92. These items correspond with affective symptoms of stigma such as embarrassment, shame, or distress associated with being linked to the person with mental illness. Factor 2 also had six items loaded with factor loadings ranging from 0.49 to 0.84 which correspond with cognitive symptoms of stigma. It includes thoughts and beliefs related to stigma, such as negative attitudes or misconceptions about oneself or others because of the affiliation with the person with mental illness. On the other hand, five items loaded on factor 3 with factor loadings ranging from 0.45 to 0.97and these correspond with self-esteem as related to affiliate stigma. It captures changes in self-worth or self-image as a result of being associated with a person with mental illness. Lastly, factor 4 had five items loaded on it with factor loadings ranging from 0.46 to 0.84 and these were characteristic of behavior associated with affiliate stigma. It includes actions or reactions that are influenced by the affiliate stigma, such as avoidance, withdrawal, or changes in social interactions. (see Table 2).

Validity

A confirmatory factor analysis showed factor loadings and measurement errors for each item (Fig. 1). The factorial weights were satisfactory between 0.43 and 0.87. The goodness of fit indices was as follows: SRMR=0.096; RMSEA=0.1; CFI=0.825. Regarding convergent validity, we found significant correlations between affiliate stigma scores and depression ($r=0.7235$, $p<0.001$).

Reliability

The level of internal consistency among the affiliate stigma scale was 0.92. Internal consistency was also excellent with Cronbach alpha values of 0.92, 0.84, 0.84 and 0.77 for factors 1, 2,4 and 4 respectively (see Table 3).

Discussion

This study aimed to evaluate the factor structure, validity and reliability of affiliate stigma scale in southwestern Uganda. The psychometric measures indicate that the affiliate stigma scale is a valid and reliable measure of affiliate stigma among caregivers of people with mental illness in southwestern Uganda which is in line with previous validation studies [18, 20, 39–42]. The factor analysis provided satisfying factor loadings indicating a good construct validity and reliability was excellent. Considering the convergent validity, we found a significant and direct correlation between the affiliate stigma scale and depression based on the patient health questionnaire −9 [28–30].

The EFA and CFA demonstrated item loading that fell into four factors (affective, cognitive, self-esteem, and

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Table 2 Factor structure of the affiliate stigma scale among caregivers of patients with mental illness in southwestern Uganda

		Factor loading			
Variable		Factor1	Factor2	Factor3	Factor4
q14	I am under great stress because of my family member with mental illness	0.9229			
q9	I feel emotionally disturbed because of my family member with mental illness	0.8853			
q12	I feel sad because I have a family member with mental illness	0.8480			
q10	The behavior of my family member with mental illness embarrasses me	0.8381			
q4	Having a family member with mental illness negatively affects me	0.8149			
q11	I feel hopeless because I have a family member with mental illness	0.7245			
q2	My reputation is damaged because I have a family member with mental illness		0.8381		
q22	Because of my family member with mental illness, I have reduced my contacts with my neighbors		0.7700		
q1	Others will discriminate against me if I am with my family member with mental illness		0.7621		
q3	Peoples attitude towards me turns sour when am my family member with mental illness		0.6824		
q18	Because of my family member with mental illness, I have reduced my contacts with friends and relatives		0.5796		0.4103
q16	I dare not tell others that my family member has mental illness		0.4902		
q5	Having a family member with mental illness makes me think that I am incompetent compared to others			0.9719	
q6	Having a family member with mental illness make me think that I am lesser than others			0.8748	
q7	Having a family member with mental illness make me lose face			0.6596	
q8	I feel inferior because one of my family members has mental illness			0.4833	
q13	I warry whether others know my family member has mental illness			0.4545	
q20	I have reduced my contact with my family member with mental illness				0.8393
q15	I avoid communicating with my family member with mental illness				0.8124
q17	I have cut down on going out with my family member with mental illness				0.7028
q19	When am with my family member with mental illness, I keep an especially low profile				0.5148
q21	I don't participate in activities related to mental illness lest others suspect that my family member has mental illness				0.4647

behavior). These were not similar to the three original subscales theorized by the scale creators (affective, cognitive, and behavioral) [2]. However, the findings were similar to other two validation studies of the affiliate stigma scale conducted in Malaysia and Turkey [18, 42]. In this study, the goodness of fit was acceptable considering the RMSEA and SRMR and this finding was comparable to the results from validation study conducted in Malaysia [18]. The validity findings of the affiliate stigma scale demonstrate that the scale is able to accurately measure levels of affiliate stigma. A good convergent validity was proven between the affiliate stigma scale and depression as assessed using the patient heath questionnaire. This was in aggrement with the previous studies that have demonstrated an association between the stigma experienced by caregivers and depression [43–46]. This association may be due to the fact that stigma often leads to social isolation and lack of support, which are known risk factors for depression [47]. The affiliate stigma scale demonstrated excellent internal consistency with a Cronbach's alpha of 0.92. In addition, the scale showed excellent inter item correlation indicating the balance between internal consistency and amplitude of measurement [48]. These finding were consistent with those reported in the other validation studies of the instrument among caregivers [18, 20].

However, the results should be interpreted considering some limitations, first, as for many other studies on psychometric properties, the data was based on self-report questionnaires, and the responses might have been swayed by social desirability. Interviews would therefore strengthen the findings. Secondly, the sample size was small since it was below 500. However, during the analysis, the confirmatory factor analysis was conducted using the maximum likelihood estimation with the main goal of reducing the risk of having false positives (type I errors) and false negatives (type II errors) The maximum likelihood estimation was used to check the relationship between the observed responses and the latent constructs by estimating mainly the factor loadings, variances, and covariances [49].

Conclusions

The findings show that the affiliate stigma scale is a valid and reliable measure of affiliate stigma among caregivers of people with mental illness in southwestern Uganda. Considering that caregivers of people with mental illness continue to experience high levels of affiliate stigma in Uganda, the affiliate stigma scale could potentially be

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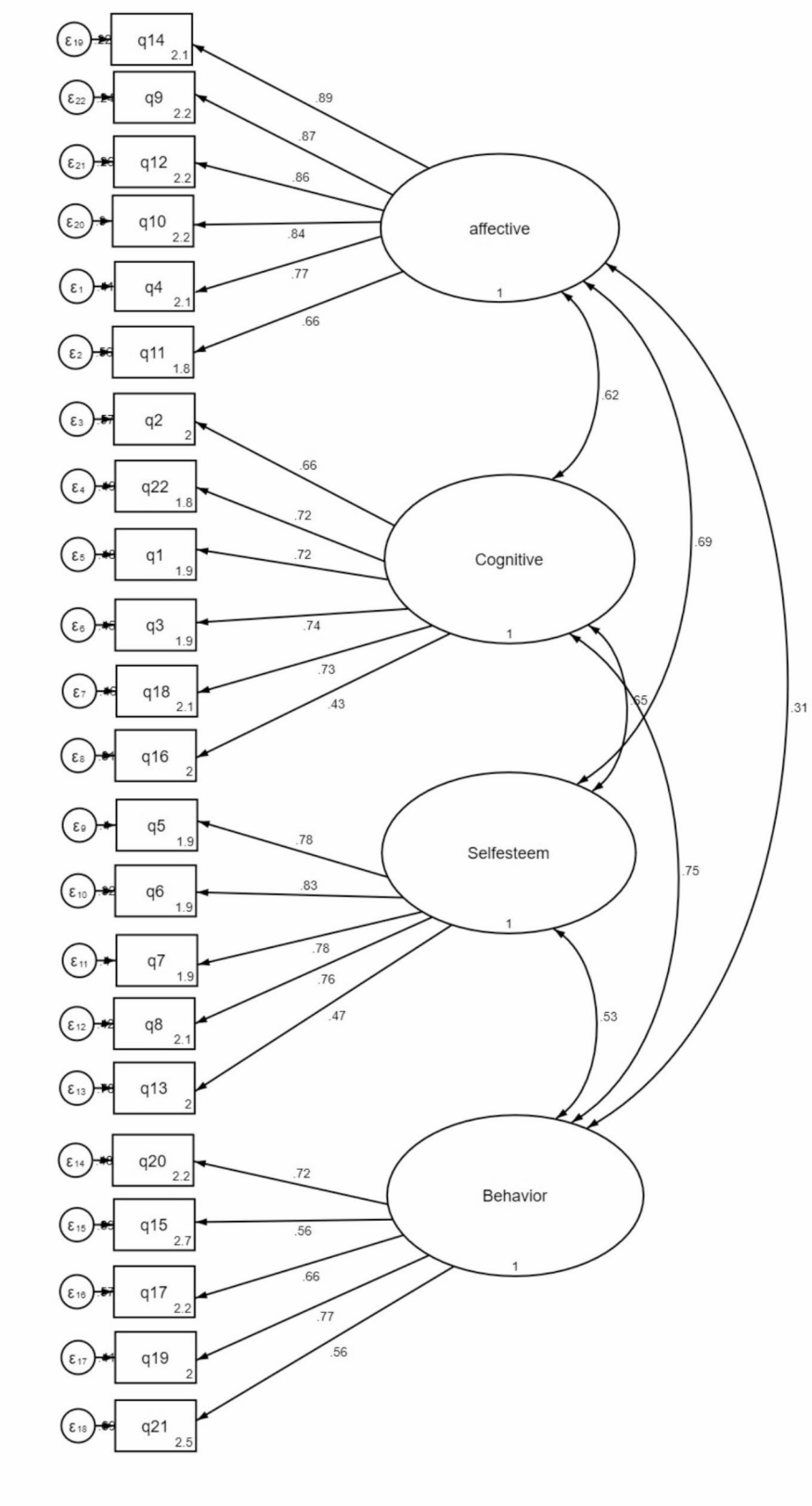


Fig. 1 Loading factors of the affiliate stigma scale

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Table 3 Cronbach alpha of affiliate stigma scale

	Cronbach alpha values	Average inter-item correlation
Total affiliate stigma scale	0.92	0.35
Factor 1	0.92	0.67
Factor 2	0.84	0.46
Factor 3	0.84	0.52
Factor 4	0.77	0.40

used in a wide range of future studies on affiliate stigma among caregivers of people with mental illness. The scale may also be useful in assessing affiliate stigma among caregivers and tracking the evolution of affiliate stigma leading to development of interventions aimed at reducing affiliate stigma among caregivers. However, the usage of affiliate stigma across Uganda may be limited by varied cultural beliefs across Uganda, as caregivers of people with mental illnesses might perceive and internalize stigma differently with regard to their culture.

Ethical considerations

The present study was conducted in accordance with the Declaration of Helsinki 2013. The study was approved by the Research Ethics Committee of the Mbarara University of Science and Technology (MUST-REC 602) and the hospital administrators provided clearance. All participants provided written informed consent before enrollment the study. During data collection, all participants identified as depressed or having any psychological distress were promptly connected with a clinician by the research assistant to ensure they received appropriate care.

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Author contributions
AF: conceptualization, data collection, data analysis, the initial draft, validation. GM, MM, AR, and DL: subsequent revisions. SM: subsequent revisions, visualization, and validation. SA: conceptualization, data curation, visualization, validation, subsequent revisions, supervision. All authors approved the final manuscript for publication.

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Data availability
The data that support the findings of this study are available from the corresponding author, AF, upon reasonable request.

Declarations

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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