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# **AIDS Care**



Psychological and Socio-medical Aspects of AIDS/HIV

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# Knowledge, empathy, and willingness to counsel patients with HIV among Indonesian pharmacists: a national survey of stigma

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#### **ABSTRACT**

This study aimed to assess the level of HIV treatment knowledge, empathy, and HIV stigma of pharmacy students and pharmacists working with patients as well as potential factors associated with stigma. This survey included 250 hospital pharmacists within 33 provinces and 1013 final-year pharmacy students from Java, the most populated island in Indonesia. The data were collected via Qualtrics® and distributed by WhatsApp. The mean age of the participants was (Mean ± SD) 24.68 ± 5.30 years, and 80.0% were female. The mean knowledge score of students and pharmacists were  $14.14 \pm 2.01$  and  $15.39 \pm 1.87$ , respectively, out of the maximum score of 21. The mean empathy score of students and pharmacists was  $72.06 \pm 5.39$  and  $77.40 \pm$ 1.35, respectively out of the maximum score of 105. The mean stigma score of students and pharmacists was  $21.02 \pm 4.65$  and  $20.66 \pm 4.41$ , respectively, out of a maximum score of 48. Regression analysis showed that knowledge, empathy, and willingness to counsel patients were negatively associated with stigma. Working with patients was positively associated with stigma. A multi-level intervention including education may reduce stigma and strengthen the role of pharmacists in caring for patients.

#### ARTICLE HISTORY

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#### **KEYWORDS**

HIV; knowledge; stigma; pharmacist; WhatsApp; Indonesia

# Introduction

Pharmacists have an important role in providing care for patients with HIV (Saberi et al., 2012). Services include medication reviews to optimize polypharmacy (Liedtke et al., 2016; McNicholl et al., 2017) and counseling patients (Chevalier et al., 2016). Studies have shown that such services improve knowledge of patients in general (Dilworth et al., 2018) and adherence to medication (Ridgeway et al., 2017). The pharmacists' role is also expanding to improve access to pre-exposure prophylaxis, thereby contributing to HIV prevention (Farmer et al., 2019). A recent systematic literature review suggested that the dispensing tasks of antiretroviral therapy (ART) could be delegated to nonpharmacist personnel to free up time of pharmacists to provide clinical care. This task shifting may be important, especially in resource-restricted settings where pharmacists are scarce (Mbeye et al., 2017).

To provide care for patients, pharmacists need to have comprehensive knowledge about HIV, including transmission mode, diagnosis, treatment options and monitoring (Schafer et al., 2016; Tseng et al., 2012). Empathy, i.e., the ability of the health provider to see the patient's perspective when providing services also plays a significant role in the care of patients (Lin et al., 2012). It has been shown that pharmacy students have positive attitudes and a higher willingness to provide services when they had sufficient HIV knowledge and empathy (Rickles et al., 2016). Other studies on empathy focused on nursing students (Levett-Jones et al., 2019) and patients (Howick et al., 2017).

Stigma remains a barrier for patients to access healthcare (Sianturi, Latifah, et al., 2020). HIV stigma among healthcare providers has been defined as the irrational feeling and negative behavior and attitude towards patients because of their HIV status (Geter et al., 2018).

The overall prevalence of HIV in Indonesia is 0.3%, but large regional variances exist, with a prevalence of 2.3% in Papua and West Papua provinces (Wijayanti et al., 2016). The government has scaled up the initiation of ART and care is increasingly shifted to primary healthcare. Even though the government provides ART free of charge, recent data suggest that only a quarter of all patients were on ART (Wijayanti et al., 2016). However, contrary to Indonesia, other areas showed the trends of declining mortality rate and HIV incidence during the past 25 years (Wang et al., 2016). Since counseling is mandatory before and after patients start with ART (Kementerian Kesehatan Republik Indonesia, 2011), pharmacists could play an important role in providing care for patients who have low health literacy (Sianturi, Perwitasari, et al., 2020) especially in counseling on ART (Pane et al., 2018). Some work has been done on competences of Indonesian nurses in HIV care (Waluyo et al., 2015), but little is known about the knowledge, empathy and stigma of pharmacists and the final-year pharmacy students in Indonesia. Therefore, the first aim of this study was to assess the level of HIV treatment knowledge, empathy, and HIV stigma of students and pharmacists working with patients in Indonesia. The second aim was to investigate the potential factors associated with stigma for the two groups.

#### **Methods**

## Study design

This was an online survey of pharmacists working with patients with HIV within 33 provinces and the final-year pharmacy students of 9 universities in Java, the most densely populated area in Indonesia where more than 60% of inhabitants live (Statistik, 2019). To recruit pharmacists, the Ministry of Health sent out the survey to the contact persons of all the health facilities providing ART across Indonesia (n = 675). The contact person was asked to forward the survey to the pharmacist in the health facility responsible for patients. We asked that only one pharmacist should complete the questionnaire for each health facility. To recruit pharmacy students, the university lecturers of nine universities distributed the survey to all the final-year pharmacy students who were on hospital training (n = 1046).

The data were collected via Qualtrics® (Provo, USA). The questionnaire link was distributed to the privately owned mobile phones of the participants by WhatsApp as this is a common method of communication in

Indonesia. Participants were asked to complete the survey within 3 months and they received weekly reminders to complete the survey. Data were collected between June and September 2018. Participants were informed that responses were anonymous; however, the participants needed to provide information on the university or province where they came from. Informed consent was provided at the end of the survey by ticking an "agree" button to indicate their agreements to join this study.

#### Ethical approval

The ethical approval was obtained from the Ethics Committee on Faculty of Medicine, Public Health, and Nursing Universitas Gadjah Mada (No: KE/FK/0507/EC/ 2018).

#### Measures

Demographic data on every participant, including age (18-27 years, 28-37 years,  $\geq$ 38 years), gender (male/ female), organization affiliation (without religious affiliation/religious affiliation), type of HIV information source or education (education/trained by the government/online/never), frequency providing services to patient (never/1 or 2 times/often), preference of counseling (face-to-face/online counseling), participant status (student/pharmacist), and the degree of willingness to counsel patients were asked in the online survey. The visual analog scale was used to range the degree of willingness to counsel patients which was assessed by clicking on a line between 0 and 100. HIV treatment knowledge, empathy, and HIV stigma were assessed using existing questionnaires from prior studies. To assess HIV treatment knowledge a questionnaire (Balfour et al., 2007), consisting of 21 items, was used. Correct answers received a score of one, incorrect answers scored zero. The total score ranged between 0 and 21, with higher scores indicating more knowledge.

Empathy was assessed using an adapted questionnaire consisting of 15 items (Kiersma et al., 2013). Those questions were answered on a 7-point Likert scale, ranging from strongly disagree to strongly agree. A total score (15-105) was calculated by summing up the scores of all questions, with higher scores indicating greater perceived empathy.

The AIDS-related Stigma Scale was modified to be used as the HIV stigma scale in this study (Kalichman et al., 2005). This is a brief, 12-item-self-report measure which assesses attitudes in the general population regarding HIV stigma beliefs about individuals living with HIV/AIDS. Answers were scored on a 4-point



Likert scale, ranging from strongly disagree to strongly agree. The total score ranged between 12 and 48 with higher scores indicating more stigma.

# Translations and reliability assessments

All three questionnaires, HIV treatment knowledge, empathy and HIV stigma were developed in English. To obtain a version in Bahasa Indonesia (target language) we followed the process of backward and forward translations (Groot et al., 1994). The backward translations had to be modified several times because the target language does not recognize verb tenses. The translated questionnaires were assessed in a pilot study to ensure they were all understandable and applicable to the setting. The respondents, who participated in the pilot study, were not included in the study sample. We assessed the reliability for stigma, and empathy in 79 pharmacists and pharmacy students. The Cronbach  $\alpha$  for stigma and empathy were 0.782 and 0.806, respectively. We tested the reliability of the HIV treatment knowledge questionnaire in line with the prior study (Balfour et al., 2007) in a test-retest study in 32 participants (Pearson's r = 0.893).

# Statistical modeling

Data were described descriptively with means, medians, standard deviations, and interquartile range, depending on the nature of the variables. The categorical variables were represented in frequencies and percentages. The chi-squared tests were used to analyze dichotomous variables (i.e., age, sex, items of assessments with participant status (participant status; students, pharmacists).

The primary outcome was stigma. A two-way ANOVA/t-test was conducted with the following independent variables: HIV treatment knowledge, empathy, age, gender, organization affiliation, type of media to receive HIV information, frequency meeting with patient, participant status, and the degree of willingness to counsel patients. Normality, linearity, homoscedasticity and multicollinearity were assessed for continuous variables. We used visual methods by using p-p and q–q plots to investigate the normality of the distribution of the data (Michael, 1983). Because there was multicollinearity, we selected participant status rather than age since participant status resulted in a better model than the model including age as a variable. Multiple linear regression analyses were performed to assess the influence of independent variables on stigma. We coded and entered data into SPSS software (version 23.0). A

p-value <.05 was considered statistically significant for all analyses.

#### **Results**

The mean age of the participants was (Mean  $\pm$  SD)  $24.68 \pm 5.30$  years, and 80.0% were female.

Overall, 250 pharmacists and 1013 students were included. The response rates of pharmacists and students were 37% and 96%, respectively. The mean age of the participants was (Mean  $\pm$  SD) 24.68  $\pm$  5.30) years, and 80.0% were female. The most commonly reported source of information about HIV treatment knowledge was education (75%), and more than half of the students reported that they had no experience with patients.

The mean knowledge score of students and pharmacists was  $14.14 \pm 2.01$  and  $15.39 \pm 1.87$ , respectively. The mean empathy score of students and pharmacists was  $72.06 \pm 5.39$  and  $77.40 \pm 1.35$ , respectively. The mean stigma score of students and pharmacists was 21.02 ± 4.65 and 20.66  $\pm$  4.41, respectively (Table 1).

Pharmacists scored better on HIV treatment knowledge, empathy, and the degree of willingness to counsel patients than the student group. Questions, which were frequently incorrectly answered, were whether medication should be stopped in patients with an "undetectable" viral load, whether it was better to take half the dose of HIV medications than stopping the HIV medications, the consequences of using herbal medications during ART and whether ART could reduce the risk of babies being infected with HIV (Table 2).

Table 3 shows that perceived empathy among students was more diverse than pharmacists since there was proportion of students having neutral perceptions. In particular, the ability of participants to build a strong relationship with patients and difficulties in identifying someone else's feelings had a relatively low percentage of positive scores.

The results of the assessment of stigma towards patients are shown in Table 4. In particular, relatively high percentages of negative responses were shown on the items whether patients should be far from children, should feel guilty and expect to be restricted in their freedom.

The linear regression result is shown in Table 5. HIV treatment knowledge, empathy, and the degree of willingness to counsel patients were associated with stigma. Linear regression analysis indicated empathy ( $\beta$  = -0.139, p = .000), HIV treatment knowledge ( $\beta =$ -0.087, p = .003) as well as the degree of willingness to counsel patients ( $\beta = -0.265$ , p = .000) were negatively associated with stigma. Working with patients was

Table 1. Sociodemographic characteristics of the final-year pharmacy students and pharmacists participating in the survey.

Independent vari	ables	Total ( <i>N</i> = 1263)	Final-year pharmacy students ( <i>N</i> = 1013)	Pharmacists ( <i>N</i> = 250)	
Age, mean (SD)		24.68 (5.3)	22.94 (1.83)	34.75 (7.69)	
Age, N (%)	18–27 years	1022 (80%)	991	31	
	28–37 years	112 (8%)	18	94	
	≥38 years	129 (12%)	4	125	
Sex, N (%)	Male	255 (20%)	207	48	
	Female	1008 (80%)	806	202	
Religious affiliation, N (%)	Without religious affiliation	522 (41%)	297	225	
	Religious affiliation	741 (59%)	716	25	
Type of HIV information source, N (%)	Education	951 (75%)	860	91	
	Trained by the government	144 (11%)	0	144	
	Online	118 (10%)	116	2	
	Never	50 (4%)	37	13	
Frequency meeting with HIV patient, N	Never	788 (62%)	781	7	
(%)	1 or 2 times	353 (28%)	225	128	
	Often	122 (10%)	7	115	
Preference of counseling, N (%)	Face-to-face	608 (48%)	438	170	
	Online counseling	655 (52%)	575	80	
Degree of willingness to give counseling, mean (SD)		58.30 (24.19)	55.09 (23.78)	70.46 (21.78)	
Total empathy, mean (SD)		73.12 (5.31)	72.06 (5.39)	77.40 (1.35)	
Total HIV treatment knowledge, mean (SE	D)	14.39 (2.05)	14.14 (2.01)	15.39 (1.87)	
Total stigma, mean (SD)		20.95 (4.61)	21.02 (4.65)	20.66 (4.41)	

Note: N = number; SD: standard deviation.

positively associated with stigma ( $\beta = 0.133$ , p = .003). However, the effects were small, since R square was 0.098 which means that the model explained about 10% of the variability.

#### **Discussion**

Our study showed that two-thirds of respondents had good knowledge on HIV treatment. Reasonable levels of empathy and the moderate level of stigma were shown among pharmacists and students. Pharmacists had more HIV treatment knowledge and showed more empathy than students. Those differences in knowledge and empathy may be due to many pharmacy students not having any experience in caring for patients. Besides stigma was significantly associated with poor knowledge and less empathy, pharmacists, who experienced meeting with patients rather than students, had significantly associated with stigma. More than two-thirds of participants completed all items in

Table 2. Results of the HIV treatment knowledge questionnaire presented as percentage of incorrect answers for final-year pharmacy students and pharmacists.

No	Questions	Final-year pharmacy students (%)	Pharmacists (%)	<i>p</i> Value
1	Once the HIV viral load results are "undetectable", HIV medications should be stopped	37.7	13.6	.000*
2	If HIV medications are not taken at the right time of day, HIV drug resistance can occur	17.7	13.2	.033*
3	HIV is cured when the HIV viral load blood test result is "undetectable"	35.3	10.4	.000*
4	Condoms during sex are not needed when the HIV+ blood test results are at "undetectable" levels	16.1	18.4	.200
5	It is better to take a half dose of HIV medications than stopping the HIV combination medications completely	45.4	28.4	.000*
6	One can get infected with a drug-resistant type of HIV	32.9	40.0	.000*
7	HIV medications can cause unpleasant side effects (e.g., nausea, diarrhea, vomiting)	3.3	0.8	.017*
8	If sexual partners are both HIV-positive condoms are no longer needed	19.0	21.2	.421
9	Treatments are available to reduce HIV medication side effects	6.7	11.2	.034*
10	Recreational drugs (e.g., ecstasy) can affect the effectiveness of HIV medications	10.9	12.0	.607
11	Providing HIV medications to a pregnant woman reduces the baby's risk of being infected with HIV	24.4	8.4	.000*
12	There currently exists an HIV vaccine that prevents HIV infection	44.2	11.2	.000*
13	HIV medications can be taken at a different time of day on weekends or holiday	16.8	17.6	.757
14	Over-the-counter herbal pills could make HIV medications less effective	53.3	54.0	.844
15	It is best to stop HIV medications as soon as you feel better	2.8	0.4	.025*
16	Missing a few doses of HIV pills can increase the amount of HIV virus in the body	16.6	10.4	.015*
17	After a few months, it becomes less important to take HIV medications at the right time of day	4.8	0.4	.001*
18	HIV medications help the body's immune system get stronger (CD4 increase)	11.1	4.8	.003*
19	When HIV medications work well, the HIV viral load increases	38.6	36.0	.449
20	Taking antibiotic medication protects a person from getting infected with HIV	18.5	11.2	.006*
21	Physical exercise (e.g., yoga, tai chi) can help reduce stress levels in HIV patients	2.2	4.0	.099



Table 3. Results of the empathy questionnaire, reported as number of respondents reporting perceived positive and neutral responses for final-year pharmacy students and pharmacists.

		Studen	ts (N)	Pharmacists (N)			
No	Item of Empathy Scale	Perceived positive	Neutral	Perceived positive	Neutral	<i>p</i> Value	
1	It is necessary for a healthcare practitioner to be able to comprehend someone else's experiences	992	20	250	0	.000*	
2	I am able to express my understanding of someone's feelings	820	181	250	0	.000*	
3	I am able to comprehend someone else's experiences	971	39	250	0	.000*	
4	I will not allow myself to be influenced by someone's feelings when determining the best treatment	971	39	250	0	.000*	
5	It is necessary for a healthcare practitioner to be able to express an understanding of someone's feelings	996	17	250	0	.000*	
6	It is necessary for a healthcare practitioner to be able to value someone else's point of view	976	33	250	0	.000*	
7	I believe that caring is essential to building a strong relationship with patients	218	212	250	0	.000*	
8	I am able to view the world from another person's perspective	838	163	250	0	.000*	
9	Considering someone's feelings is not necessary to provide patient-centered care	674	253	250	0	.000*	
10	I am able to value someone else's point of view	895	112	250	0	.000*	
11	I have difficulty identifying with someone else's feelings	150	340	250	0	.000*	
12	To build a strong relationship with patients, it is essential for a healthcare practitioner to be caring	994	18	250	0	.000*	
13	It is necessary for a healthcare practitioner to be able to identify with someone else's feelings	965	45	250	0	.000*	
14	It is necessary for a healthcare practitioner to be able to view the world from another person's perspective	898	104	250	0	.000*	
15	A healthcare practitioner should not be influenced by someone's feelings when determining the best treatment	791	244	250	0	.000*	

Note: Perceived positive reports the number of respondents who ticked very strongly or agree.

HIV treatment knowledge, with pharmacists performing slightly better than students. But this was lower than prior studies investigating HIV treatment knowledge, conducted in Guyana, Malaysia and Botswana (Balfour et al., 2010; Chew & Cheong, 2013; Letshwenyo-Maruatona et al., 2019). In particular the questions when to stop, reduce doses or combine ART with herbal medication were often incorrectly answered. The latter is important, since herbal medicines are commonly used in Indonesia (Suswardany et al., 2017). Although some research has been done on effects of combining ART with herbal medicines, a lot of uncertainties remain (Abyot et al., 2017). Furthermore, almost onefourth of students did not know that ART reduced the risk of HIV transmission to babies. Empathy scores in our study were lower than previous studies in developed

countries (Rickles et al., 2016). Pharmacists showed a higher level of empathy than students. Generally, higher levels of empathy have been shown to be associated with better quality of pharmacy services (Lin et al., 2012). In a systematic review of studies done in general practice, a higher level of empathy of general practitioners was associated with improved clinical outcomes in patients (Frank et al., 2013). Overall, the level of stigma was moderate. The level of stigma in pharmacists seemed to be lower compared to a study in Indonesian nurses. But results are difficult to compare directly because of differences in instruments used (Waluyo et al., 2015). In line with a previous study from South America (Balfour et al., 2010), the stigma level among pharmacists was lower compared to students. In particular, pharmacy students felt that patients should not work with

Table 4. Results of the HIV stigma guestionnaire reported as percentage of respondents giving a negative response for the final-year pharmacy students and pharmacists.

No	Questions	Final-year pharmacy students %	Pharmacists %	p Value
1	People who have HIV/AIDS are cursed	1.8	2.0	.038*
2	It is safe for people who have HIV/AIDS to work with children (R)	30.7	14.0	.000*
3	People who have HIV/AIDS should be ashamed	7.4	7.2	.070
4	People who have HIV/AIDS have nothing to feel guilty about	26.1	24.8	.803
5	People who have HIV/AIDS should be isolated	1.2	0.4	.016*
6	I do not want to be friends with someone who has HIV/AIDS	4.8	1.2	.040*
7	People who have HIV/AIDS should not be allowed to work	10.1	0	.000*
8	A person with HIV/AIDS must have done something wrong and deserves to be punished	3.3	3.2	.442
9	People who have HIV/AIDS cannot be trusted	1.4	1.6	.404
10	People with HIV/AIDS must expect some restrictions on their freedom	22.4	11.2	.001*
11	Most people become HIV-positive by being weak or foolish	12.0	13.6	.517
12	People who have HIV/AIDS are dirty	3.4	0.8	.045*

Note: Negative response is the total percentage of strongly disagree to disagree.

Table 5. Results of the univariate and multivariate linear regression analysis on factors associated with HIV-stigma score.

	Univariate			Multivariate			
Independent variables	β	Lower	Upper	β	Lower	Upper	p Value
Age (28–37 years, ≥38 years)	-l.021	-l0.547	0.247	_	_	_	_
Participant status	-l.030	-10.992	0.286	0.133	0.510	2.497***	.003
Sex	0.019	-10.421	0.848	-10.003	-10.651	0.591	.924
Religious affiliation	0.035	-l0.186	0.848	-10.006	-10.663	0.558	.866
Type of media to receive HIV information	-l.039	-l0.531	0.092	-l0.026	-10.470	0.175	.369
Frequency meeting with HIV patient	-l.047	-10.709	0.056	-l0.026	-10.709	0.353	.511
Degree of willingness to give counseling	-l.277	-10.063)	-10.042	-l0.265	-10.061	-10.039***	.000
Total empathy	-l.159	-l0.186	-10.091	-l0.139	-l0.171	-10.068***	.000
Total HIV treatment knowledge	-l.099	-10.345	-10.098	-l0.087	-10.322	-10.068***	.003
Overall model				$R^2 = 0.098$			
				F = 17.157			

<sup>\*\*\*</sup>Significant.

children and should expect restrictions in their freedom. A fourth of respondents felt that patients should feel guilty. In contrast, very few respondents felt that patients cannot be trusted or should be isolated. In line with previous studies in developed and developing countries, poorer HIV knowledge and lower levels of empathy were significantly associated with stigma (Mak et al., 2017).

Increasing HIV treatment knowledge as well as increasing empathy may be a way to reduce the level of stigma and improve services for patients. This may require a multi-level approach (Rao et al., 2019). Students should be familiar with diversity of gender, sexual orientation and religion make them ready in providing better services for patients in future. Improving undergraduate education of pharmacists and the HIV training program by involving patients as trainers or speakers may be a priority to be done immediately (Gove et al., 2008; Lin et al., 2012). Furthermore, integrating caring for patients in internships, e.g., hospital placements, would increase the experience of students. We recommend universities to recognize the urgency of pharmacy curriculum modification to adapt with public health issues. Continuing education should be available for pharmacists working with patients by offering training regularly with varied topics related to HIV care. The training may focus on the effectiveness of ART, combining ART with herbal medication and transmission of HIV. Training could also include interprofessional collaboration with physicians and nurses (Coovadia & Hadingham, 2005). Such programs at the undergraduate and postgraduate level should reduce stigma and increase willingness of pharmacists to provide services for patients (Jin et al., 2018; Liljestrand, 2004).

# Strengths and limitations

This study included pharmacists working with patients with HIV in 33 provinces in Indonesia and the final-year pharmacy students who had training in hospitals

within 9 universities, achieving a reasonable response rate. The response rate by pharmacists may have been lower due to the poor signal internet reception by a tsunami during the study period. Although our sample size was large, we were only able to include students from universities based in Java. Students in other regions may have different levels of knowledge, empathy or stigma, especially if pharmacy programs and practice experience differ from those schools we surveyed. We performed a cross-sectional study; we suggest that a longitudinal research is needed to investigate whether increasing HIV treatment knowledge and empathy will reduce the stigma among pharmacists and students. Furthermore, while we assessed knowledge, empathy and stigma using established validated instruments, with a robust translation process and readability assessments and pre-testing, no such instrument was available to assess willingness to counsel patients. We, therefore, tested this aspect using a self-developed visual analog scale. This should be taken into account when interpreting our findings. Further work should be done to test the validity of this instrument. Furthermore, our model could explain only 10% of the variance, so other factors need to be investigated which impact on stigma.

# **Conclusions**

Pharmacists and pharmacy students had reasonable knowledge on HIV, showed empathy toward patients and a moderate level of stigma. Lower levels of HIV treatment knowledge, empathy and being a pharmacist were associated with stigma. A multi-level intervention improving undergraduate and postgraduate training in care for patients may reduce stigma and strengthen the role of pharmacists in caring for patients with HIV in Indonesia.

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2015). Conceived and designed the study: EIS, KT, EL, MP, DAP, Si, SAK, EBH, JP. Analyzed the data: EIS, KT, EL. Wrote the paper: EIS, KT, EL, MP, DAP, Si, SAK. All authors read and approved the final manuscript.

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No potential conflict of interest was reported by the author(s).

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#### **Data availability statement**

The data that support the finding of this study are available from the corresponding author, upon reasonable request.

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