

# High Perceived Stigma Among People Living with HIV/AIDS in a Resource Limited Setting in Western Ethiopia: The Effect of Depression and Low Social Support

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**Background:** Antiretroviral therapy (ART) is only one part of a successful range of care among people living with HIV/AIDS (PLWHA). Stigma and low social support are emerging issues worsening the success of ART for PLWHA. This study thus aimed to investigate the level of perceived stigma among PLWHA.

**Methods:** An institution-based cross-sectional study was conducted in Nekemte, western Ethiopia. A multivariable logistic regression model was used to identify associations between perceived stigma and low social support, depression, and other potential predictor variables using SPSS version 24.0 and adjusted odds ratios (AORs), considering statistical significance at  $p < 0.05$ .

**Results:** A total of 418 study participants were included in the study, with a response rate of 100%. About 48.6% of PLWHA had experienced perceived stigma, and more than two-fifths had poor social support. The following factors were associated with perceived stigma among PLWHA: age (18–29 years) (AOR=4.88, 95% CI:1.76–13.5), female sex (AOR=2.10, 95% CI 1.15–3.82), <12 months on ART (AOR=2.63, 95% CI 1.09–6.34), depression (AOR=1.86, 95% CI 1.08–3.19), social support (poor: AOR=3.45, 95% CI 1.65–7.23; medium: AOR=2.22, 95% CI 1.09–4.54), and non-disclosure of HIV status (AOR=2.00, 95% CI 1.11–3.59).

**Conclusion and Recommendation:** The magnitude of perceived stigma among PLWHA was high, highlighting the importance of integrating social and mental health support within standard ART for PLWHA.

**Keywords:** stigma, social support, HIV/AIDS, Nekemte, Ethiopia

## Introduction

Globally, more than 74.9 million people have been infected with HIV and 32 million have died of AIDS-related illnesses.<sup>1</sup> HIV is among the leading public health challenges in sub-Saharan Africa.<sup>2</sup> However, the expansion of antiretroviral therapy (ART) has changed HIV infection into a manageable chronic disease, thereby reducing HIV transmission and reducing the number of people dying from AIDS-related illnesses.<sup>3,4</sup> Since 2010, new HIV infections have dropped by 38% and AIDS-related deaths have declined by 49% in the eastern and southern African regions.<sup>5</sup>

According to UNAIDS, 690,000 people were living with HIV, and 11,000 people had died of AIDS-related illnesses in Ethiopia by 2018. Consequently, the country adopted the UNAIDS 90–90–90 targets, which envision that 90% of people living with HIV would know their HIV status, 90% of people who know their HIV-

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positive status would be able to access therapy, and 90% of people on treatment would have suppressed viral loads by 2020.<sup>6</sup> As such, the UNAIDS Fast Track Strategy has reported 81%, 79%, and 73% success rates for the first, second, and third of the 90–90–90 targets for the country,<sup>7</sup> implying that the country needs to have a strong linkage system across HIV/AIDS care continuum to achieve this goal.

According to the UNAIDS 2015 report, in 35% of countries with available data, over 50% of people report experiencing discriminatory attitudes because of their HIV status.<sup>8</sup> Stigma affects multiple domains of people's lives, and interference with the continuum of care for HIV/AIDS is also rampant. For example, one in eight people living with HIV is denied access to lifelong ART because of enacted stigma and discrimination.<sup>9</sup> Research from the USA showed that 89% of people living with HIV/AIDS (PLWHA) reported perceived stigma.<sup>10</sup> In Ethiopia, about 15–31.2% of PLWHA reported internalized stigma.<sup>11,12</sup>

Non-communicable diseases such as mental health problems, stigma, and substance use are emerging issues challenging successful treatment for PLWHA.<sup>13</sup> Common mental disorders such as hopelessness, depression, anxiety, suicidal ideation, and substance abuse are more common among PLWHA than the general population.<sup>13,14</sup> This suggests the need for an integrated intervention for PLWHA alongside ART. A complex interplay of factors, including low socioeconomic status, non-adherence to ART, and advanced WHO clinical stage III and IV, is associated with stigma (either perceived or enacted) among PLWHA.<sup>10,15–18</sup> Moreover, impaired mental health states, such as depression, and perceived stigma are linked with a compromised adherence to ART and poor treatment outcomes,<sup>18–20</sup> as well as substance use<sup>21</sup> and risky sexual behaviors.<sup>22</sup>

Understanding the level of perceived stigma and its associated factors will play an important role in successful care for HIV/AIDS patients. However, there is a dearth of research in this regard and limited information on factors that are associated with perceived stigma. This study therefore aims to assess the level of perceived stigma and associated factors among PLWHA attending public health hospitals in Nekemte town in western Ethiopia.

## Methods

### Study Design, Period, and Area

This study was embedded in a large-scale project on substance use among PLWHA on ART who were followed up at

Nekemte public hospitals, western Ethiopia. An institutional-based study design was used, and the study was conducted from February to April 2020. The institutions comprised two health centers and two public hospitals, one specialized hospital and Wilega University Teaching and Referral Hospital. The hospitals provide adult ART and care services; 24-hour emergency, pharmacy, and delivery services; antenatal care; and physiotherapy, inpatient, and psychiatry services to the community.

### Source and Study Population

The source population was made up of all ART patients on treatment follow-up at Nekemte public hospitals. The study population comprised sampled ART patients who had treatment follow-up during the study period.

### Eligibility Criteria

Patients who were aged above 18 years and those who had enrolled in HIV care within the previous 3 months were eligible.

### Exclusion Criteria

Records with incomplete data (baseline clinical and laboratory data, date of HIV diagnosis, date of ART initiation, and outcome not recorded) and transfer in from other institutions with incomplete baseline data were excluded from the study.

### Sample Size and Sampling Procedure

The sample size for this study was calculated by applying a single population proportion formula considering the 95% CI level, 5% margin of error, and 10% contingency rate by taking the proportion ( $p$ ) of stigma of 43.9% from a previous study, conducted in southern Ethiopia.<sup>23</sup>

$$n = \frac{((Z\alpha/2)^2 * p(1 - p))}{d^2}$$

where  $n$  is the sample size, the  $Z$  value corresponds to the 95% significance level, and  $P$  is substance use prevalence, taken from the previous study.<sup>23</sup>

$$n = \frac{((1.96)^2 * 0.439(1 - 0.439))}{(0.05)^2}$$

Therefore,  $n=380$ ; by adding a 10% non-response rate, the final sample size was estimated to be  $n=418$ .

Then, a consecutive sampling technique was used to select study participants based on the inclusion criteria until the required sample size was achieved.

## Study Variables

### Dependent Variable

The dependent variable was perceived stigma.

### Independent Variables

Independent variables included 1) socio-demographic variables, such as residence, age, sex, marital status, educational status, and level of income; 2) HIV/AIDS-related characteristics of the participants, such as time since diagnosis, duration on treatment, and CD4 level; 3) behavior-related characteristics of the patients, such as alcohol use disorder (AUD), smoking, and current khat chewing; 4) level of social support; and 5) disclosure status.

## Measurements

Data on alcohol disorder were collected by adapting a previously validated WHO questionnaire.<sup>24</sup> Psychoactive substance use (khat in our case) was also collected by a tool which was adapted from the WHO, ASSIST v3.0. A questionnaire adapted from a tool previously validated in developing countries was used for assessment of the level of depression.<sup>25</sup> Data on social support were collected by the Oslo 3-item Social Support Scale (OSS-3).<sup>26</sup> The OSS-3 has three categories: “poor support”, 3–8; “moderate support”, 9–11; and “strong support”, 12–14.<sup>26</sup> In this study, perceived HIV stigma was measured based up on a tool consisting of nine items which was previously used by Fido et al for measurement purposes; then, individuals who had an attitude score equal to or greater than the mean score of the study population were categorized as having high perceived stigma.<sup>27</sup>

## Data Collection

Data were collected using an interviewer-administered structured questionnaire. A version of the questionnaire in the local language, Afan Oromo, was used to collect the data. The questionnaire covered socio-demographic information and baseline clinical and laboratory data (baseline CD4 count, WHO clinical stage, hemoglobin level, opportunistic infections, WHO functional status, time of HIV diagnosis, time since ART initiation, and comorbidity). In addition, family-related data (disclosure status, partner’s HIV status) and regimen-related data (side effects of drug, time of ART initiation) were included in the checklist.

## Data Processing and Statistical Analysis

Each completed questionnaire was coded on a prepared coding sheet by the principal investigator to minimize errors. Data were entered into a computer using the statistical program Epi Info for Windows version 7.0. Data were cleaned and exported to SPSS Windows version 20.0 for further analysis. Descriptive analyses, such as proportions, percentages, frequency distribution, and measures of central tendency, were carried out. Bivariable and multivariable logistic regression models were used. Initially, bivariable analysis was performed between the dependent variable and each of the independent variables, one at a time. Their odds ratios (ORs), 95% confidence intervals (CIs), and *p*-values were obtained. Then, all variables found to be significant at the bivariable level ( $p < 0.2$ ) were considered as candidates for the multivariable logistic regression model. Violations of regression model assumption were checked by inspection multicollinearity tests and variance inflation factors. Model goodness of fit was tested by the Hosmer–Lemeshow model goodness-of-fit test. A *p*-value of  $< 0.05$  and 95% confidence level was used as a statistically significant difference for the final models.

## Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki. Ethical clearance and permission were obtained from Tsinghua University review board, and permission was secured from Nekemte Specialized Hospital and Wollega University Teaching and Referral Hospital and submitted to ART focal persons in each public health facility. Informed consent was obtained from each respondent before the interview. Study participants were provided with information about the objectives of the study and their right to respond fully or partially to the questionnaire. Confidentiality of individual client information was ensured by using unique identifiers for study participants and limiting access by third parties by storing the completed questionnaires and all documents with participant information in a lockable cabinet. In addition, the phone number and email address of the principal investigator were provided, so that participants could ask questions related to ambiguous or unclear aspects of the study, prior to agreeing to participate. The hard copy of the data, recorded data, and all the interviewers’ notes were kept in a private place, accessible only by the proxy of the principal investigator.

## Results

### Socio-Demographic Characteristics

A total of 418 PLWHA who were on ART participated in the interview, with a 100% response rate. The predominant ethnicity and religion among the participants were Oromo, 358 (85.6%) and Protestant, 204 (48.8%), respectively. The mean age of the participants was 37.84 (SD=9.54) years, ranging from 20 to 67 years. About one-third of the respondents, 135 (32.3%), fell in the 30–38-year age group. About 274 (65.6%) of them were married and about one-third, 159 (38%), had an educational level of college and above (Table 1).

**Table 1** Socio-Demographic Characteristics of the Study Participants

	Categories	Frequency	Percentage (%)
Age (years)	18–29	107	25.6
	30–38	135	32.3
	39–42	77	18.4
	≥43	99	23.7
Sex	Male	218	52.2
	Female	200	47.8
Residence	Urban	266	63.6
	Rural	152	36.4
Ethnicity	Oromo	358	85.6
	Amhara	46	11
	Gurage	14	3.3
Religion	Protestant	204	48.8
	Orthodox	138	33
	Muslim	42	10
	Catholic	34	8.1
Marital status	Single	103	24.6
	Married	274	65.6
	Divorced	41	9.8
Educational status	No formal education	96	23
	Primary education	101	24.2
	High school (9–12)	62	14.8
	College and above	159	38
Occupation	Unemployed	105	25.1
	Government employee	119	28.5
	Farmer	61	14.6
	Merchant	60	14.4
	Other	73	17.5
Income	<500	238	56.9
	501–999	58	13.9
	≥1000	122	29.2

### HIV/AIDS-Related Characteristics of the Participants

From a total of 418 participants, more than half had experienced adverse drug reactions after initiating the treatment. The majority of the study participants, 350 (83.7%), had a history of opportunistic infections. About two-thirds, 277 (66.3%), had disclosed their HIV status, while about two-fifths of the participants had missed their ART and practiced risky sexual behavior due to substance use (Table 2).

### Social Support and Perceived Stigma for HIV/AIDS Patients on ART Follow-Up in Nekemte Town

About one-third of the participants, 138 (33.01%), had poor social support, whereas 8% had strong social support.

**Table 2** HIV/AIDS-Related Characteristics of the Participants

Variables	Categories	Frequency (n)	Percentage (%)
Adverse drug reaction	No	177	42.3
	Yes	241	57.7
History of chronic illness	No	244	58.4
	Yes	174	41.6
History of opportunistic infections	No	68	16.3
	Yes	350	83.7
Ever diagnosed with TB	No	372	89
	Yes	46	11
Current TB status	No	315	75.4
	Yes	103	24.6
History of hospitalization	No	273	65.3
	Yes	145	34.7
History of psychiatric disorder	No	335	80.1
	Yes	83	19.9
Taking psychiatric medication	No	340	81.3
	Yes	78	18.7
Disclosure status	No	141	33.7
	Yes	277	66.3
Time since diagnoses	≤24	108	25.8
	>24	310	74.2
Duration treatment	<12	69	16.5
	13–24	49	11.7
	≥25	300	71.8
Social support	Poor social support	179	42.8
	Medium social support	180	43.1
	Strong social support	59	14.1

Analysis of the study data revealed that most of the study participants who experienced high perceived stigma were those who had poor social support (Figure 1).

## Factors Associated with Perceived Stigma Among PLWHA

Based on bivariable logistic regression analyses, socio-demographic variables such as age (18–19 years; COR=3.85, 95% CI 1.98–7.5), sex (female; COR=0.96, 95% CI 0.64–1.46), residence (rural; COR=0.66, 95% CI 0.43–1.01), marital status (single; COR=1.8, 95% CI 0.815–3.99), educational status (no formal education; COR=0.74, 95% CI 0.42–1.307), and income level (<500 Ethiopian birr; COR=1.67, 95% CI 1.04–2.68), as well as clinically related factors such as time of diagnosis (<24 months; COR=1.95, 95% CI 1.12–2.38) and duration of treatment (<12 months; COR=4.61, 95% CI 2.13–9.98), and behavior-related factors such as current smoking (COR=2.57, 95% CI 1.64–4.03), khat chewing (COR=1.50, 95% CI 0.97–2.35), AUD (COR=2.54, 95% CI 1.56–4.12), social support (poor social support; COR=3.04, 95% CI 1.64–5.64), and disclosure status (COR=2.48, 95% CI 1.49–3.94) were associated with high perceived stigma. On multivariable logistic regression, participants being aged 18–29 years (AOR=4.88, 95% CI 1.76–13.5), being female (AOR=2.10, 95% CI 1.15–3.82), less than 12 months' treatment duration (AOR=2.63, 95% CI 1.09–6.34), current smoking (AOR=2.42, 95% CI

1.19–4.9), reported depression (AOR=1.86; 95% CI 1.08–3.19), poor social support (AOR=3.45, 95% CI 1.65–7.23), medium social support (AOR=2.22, 95% CI 1.09–4.54), and not disclosing HIV status (AOR=2.00, 95% CI 1.11–3.59) were significantly associated with high perceived stigma (Table 3).

## Discussion

In PLWHA, the provision of ART is found to improve the lifespan of the patients. However, this prolonged lifespan is compromised by discrimination and a high burden of HIV/AIDS-related stigma, which is triggered by socio-demographic, psychosocial, behavioral, and clinical factors. In this study, high perceived HIV-related stigma was significantly associated with poor social support. This is due to the fact that higher levels of social support give a patient a sense of belonging and a feeling of love and affection, so the patient can cope psychologically better with the disease compared to people with lower levels of social support and self-esteem.<sup>28,29</sup> Moreover, social support and care are the most important factors impacting the quality of life of PLWHA.<sup>30</sup>

In this study, younger age groups were more stigmatized than older PLWHA. This finding is in line with other findings from a cross-sectional study.<sup>31</sup> This could be explained by both cognitive (e.g., fear of aging or getting sick) and social issues (e.g., fear of separation/divorce, family stress, and career transition) that could affect how stigma is anticipated. Most of these experiences are likely to wield less influence as they tend to

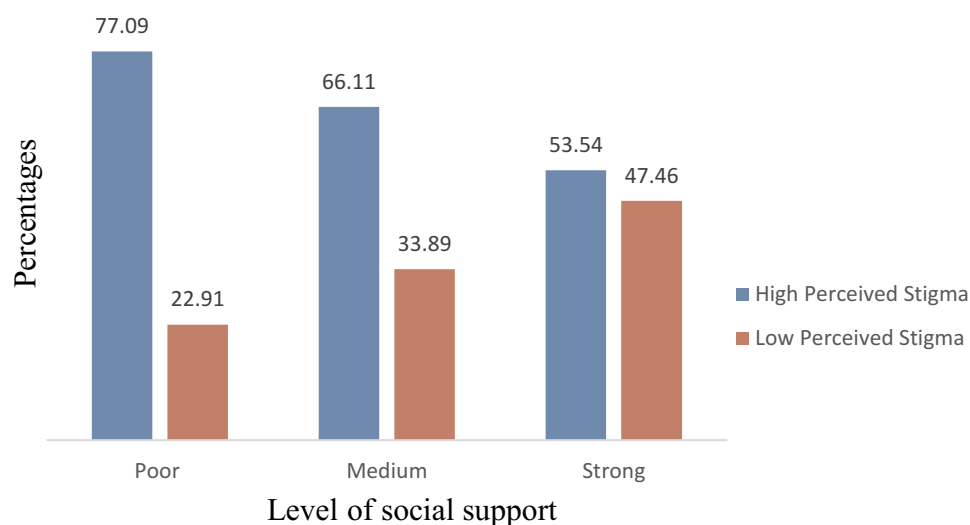


Figure 1 Social support and perceived stigma among PLWHA.

**Table 3** Factors Associated with Perceived Stigma Among HIV/AIDS Patients on Antiretroviral Therapy in Nekemte Town

Independent Variables	Categories	Perceived Stigma		COR (95%)	AOR (95%)	p-Value
		Yes	No			
Age (years)	18–29	91	16	3.85 (1.98–7.5)	4.88 (1.76–13.5)*	0.002
	30–38	87	48	1.23 (0.72–2.09)	1.34 (0.69–2.59)	0.391
	39–42	51	26	1.33 (0.72–2.47)	1.55 (0.74–3.27)	0.246
	≥43	59	40	Ref	Ref	
Sex	Male	151	67	Ref	Ref	0.002
	Female	137	63	0.96 (0.64–1.46)	2.10 (1.15–3.82)*	
Residence	Urban	192	74	Ref	Ref	0.794
	Rural	96	56	0.66 (0.43–1.01)	0.91 (0.44–1.87)	
Marital status	Single	80	23	1.8 (0.815–3.99)	0.34 (0.09–1.25)	0.104
	Married	181	93	1.01 (0.5–2.01)	1.47 (0.06–3.59)	0.391
	Other	27	14	Ref	Ref	
Educational status	No formal education	68	28	0.74 (0.42–1.307)	0.86 (0.32–2.31)	0.764
	Primary education	62	39	0.48 (0.28–0.83)	0.38 (0.15–0.99)	0.05
	High school (9–12)	36	26	0.42 (0.225–0.78)	0.50 (0.23–1.08)	0.079
	College and above	122	37	Ref	Ref	
Income level	<500	178	60	1.67 (1.04–2.68)	2.07 (0.93–4.62)	0.075
	501–999	32	26	0.69 (0.37–1.3)	0.65 (0.26–1.63)	0.354
	≥1000	78	44	Ref	Ref	
Time of diagnosis	≤24 months	85	23	1.95 (1.12–2.38)	1.09 (0.57–2.06)	0.802
	>24 months	203	107	Ref	Ref	
Duration of treatment	<12 months	61	8	4.61 (2.13–9.98)	2.63 (1.09–6.34)*	0.031
	13–24 months	40	9	2.68 (1.25–5.74)	2.38 (0.96–5.90)	0.061
	≥25 months	187	113	Ref	Ref	
Alcohol use disorder	No	173	103	Ref	Ref	0.599
	Yes	115	27	2.54 (1.56–4.12)	1.2 (0.59–2.43)	
Current smoker	No	148	95	Ref	Ref	0.014
	Yes	140	35	2.57 (1.64–4.03)	2.42 (1.19–4.9)*	
Khat chewer	No	175	91	Ref	Ref	0.800
	Yes	113	39	1.50 (0.97–2.35)	1.078 (0.604–1.92)	
Depression	No	139	89	Ref	Ref	0.024
	Yes	149	41	2.32 (1.50–3.59)	1.86 (1.08–3.19)*	
Social support	Poor	138	41	3.04 (1.64–5.64)	3.45 (1.65–7.23)*	0.001
	Medium	119	61	1.76 (0.97–3.20)	2.22 (1.09–4.54)*	0.028
	Strong	31	28	Ref	Ref	
Disclosure status	No	112	27	2.48 (1.49–3.94)	2.00 (1.11–3.59)*	0.024
	Yes	176	103	Ref	Ref	

Note: \* $p < 0.05$ .

Abbreviation: Ref, reference category.

stabilize with older age. As people grow older they may become more comfortable with their HIV status as they are likely to have more counselling as long as they stay in HIV/AIDS continuum of care.<sup>31</sup>

The odds of perceived HIV-related stigma among females with HIV were about two times higher than in their male counterparts. This is consistent with other literature finding that women living with HIV are vulnerable to

enacted, anticipated, and internalized stigma.<sup>10,17,32</sup> Stigma is highly related to depression, which affects more women than men as women are more vulnerable to HIV-related stigma. Moreover, women in developing countries are less powerful in decision-making regarding their sexual and other life matters. These underlying gender-based inequalities are compounded and exacerbated by HIV status. As a result, women living with HIV often experience an interwoven and overlapping jigsaw of stigma due to their HIV status and being female. Biological factors are another problem that increases the susceptibility of females to HIV infection, favored by socio-behavioral practices and socioeconomic differences, which in turn lead to HIV-related stigma.<sup>17</sup> However, this result contradicts a study from India in which males were more stigmatized than females. This is because in India, but not in our set-up, males were the breadwinners.<sup>15,29,33,34</sup>

Not disclosing their HIV status was positively associated with HIV-related stigma among PLWHA. The same result was reported in other studies.<sup>32,35–37</sup> This can be explained as stigma appearing to interfere in the relationship between misconception and willingness to disclose HIV status in the event of infections. For both sexes of PLWHA, misconception is associated with stigma, which in turn is negatively associated with willingness to disclose.<sup>38</sup>

HIV patients with depression were about two times more likely to experience perceived stigma than those who were not depressed. This result is in line with the study findings from another part of Ethiopia<sup>23</sup> and a systematic review.<sup>39</sup> The possible explanation for this could be people that with HIV are seen as immoral or unsafe, which is associated with stigmatizing beliefs. Being an HIV patient, by itself, is associated with the likelihood of depression,<sup>39</sup> in which poor psychosocial functioning, the presence of opportunistic infections, poor immune status, and fear of dying from a chronic illness could explain the existence of depression and HIV-related stigma, as well as their association with each other.<sup>40</sup>

The findings of this study should, be interpreted with caution, owing to the following limitations. First, the cross-sectional design of this study only allows the development of hypotheses and cannot establish cause–effect relationships. No randomization or power calculations were performed. Even though our interviewers were well trained, some participants could be vulnerable to giving socially desirable answers rather than expressing their genuine feelings, and this could lead to a bias in understanding the real burden of HIV-

related stigma in PLWHA. In addition, the findings from limited public health institutions in Nekemte cannot fully show the true picture either in Ethiopia or in sub-Saharan Africa. Moreover, our findings only indicate the associated factors of HIV-related stigma among registered PLWHA. Hence, it is strongly recommended for future researchers to assess the effects of perceived stigma on ART outcomes. Nevertheless, the findings of this study highlight the importance of integrating social and mental health support within standard ART for PLWHA.

## Conclusion and Recommendation

The magnitude of perceived stigma among PLWHA was high, highlighting the importance of integrating social and mental health support within standard antiretroviral therapy for PLWHA.

## Abbreviations

AOR, adjusted odds ratio; ART, antiretroviral therapy; AUD, alcohol use disorder; COR, crude odds ratio; PLWHA, people living with HIV/AIDS.

## Data Sharing Statement

Data will be available upon request from the corresponding authors.

## Ethical Approval and Consent to Participate

This study was conducted in accordance with the Declaration of Helsinki. Ethical clearance and permission was obtained from Tsinghua University review board, and permission was secured from Nekemte Specialized Hospital and Wollega University Teaching and Referral Hospital, and submitted to each public health facility HIV/AIDS focal person. Written informed consent was obtained from each respondent before the interview.

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## Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design,

execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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## Disclosure

The authors declare that they have no conflicts of interest for this work.

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