

## Stigma Experienced by the Caregivers of Patients with Chronic Plaque Psoriasis

### Abstract

**Background:** Psoriasis is a chronic inflammatory dermatosis associated with psychological morbidity. Very few studies have evaluated stigma among caregivers of patients with psoriasis. **Objective:** This study aimed to evaluate the prevalence of stigma and its correlates among the caregivers of patients with psoriasis. **Methodology:** Forty-nine caregivers of patients with psoriasis were evaluated on psoriasis adapted version of caregiver of people with mental illness (CPMI) to assess internalized stigma, Explanatory Model Interview Catalogue Stigma Scale, Family Burden Inventory (FBI), Multidimensional aspect of perceived social support scale (PSS), Cognitive behavioral avoidance scale (CBAS), and Coping checklist. **Results:** Majority of the caregivers were either spouse (42.8%) or parents (36.7%) of the patients. The caregivers were involved in the care of the patients for a mean duration of 6.5(SD; 4.8) years. On CPMI, the mean score was highest for the affective domain (3.1), this was followed by affective (2.9), and behavioral (2.9) domain. Very few (12.2%) caregivers reported significantly high caregiver burden. A higher level of stigma was associated with more often use of avoidance coping. Presence of higher social support was associated with higher level of stigma as assessed by using CPMI. A higher level of caregiver burden in all the domains of FBI was associated with higher level of stigma. **Conclusion:** Stigma is highly prevalent among the caregivers of patients with psoriasis. These findings suggest that there is an urgent need to identify the stigma and address the same.

**Keywords:** Burden, psoriasis, psychosocial, stigma

### Introduction

All illnesses, in general, not only impact the patients themselves, but also have significant negative consequences for the family members/caregivers. Skin conditions, because of the obvious skin lesions and ensuing disfigurement have significant impact on the life of patients and the caregivers.<sup>[1]</sup> Some of the authors use the term “The Greater patients” to describe the family members or caregivers of patients.<sup>[2,3]</sup>

In terms of impact on the caregivers, studies have evaluated depression and anxiety,<sup>[4]</sup> impact on the quality of life,<sup>[5]</sup> stress, and emotional burden.<sup>[6]</sup> Studies which have evaluated depression and anxiety among the caregivers suggest that 36% of caregivers of children with psoriasis suffer from anxiety and equal proportion of them also experience depression.<sup>[4]</sup> However, there is dearth of information about the impact of psoriasis on the caregivers in the form of subjective and objective burden, coping,

and stigma. Accordingly, this exploratory study aimed to evaluate the correlates of stigma experienced by the caregivers of patients with psoriasis.

### Methodology

This was a cross-sectional study, done at a tertiary care hospital in India. The study was approved by the Ethics Committee of the Institute and all the participants were recruited after obtaining written informed consent/assent. To be included in the study, the patients were required to be diagnosed with chronic psoriasis plaque lesions and aged 10–60 years. Additionally, the patients were required to be free from any diagnosed psychiatric illness. Patients with severe psoriasis, such as those with psoriatic arthritis, pustular psoriasis, erythrodermic lesions, and unstable comorbid physical illnesses were excluded.

The caregivers were required to be aged  $\geq 18$  years, living with the patient and able

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### Access this article online

**Website:** www.idoj.in

**DOI:** 10.4103/idoj.IDOJ\_358\_20

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**How to cite this article:** Grover S, Mehra A, Dogra S, Hazari N, Malhora N, Narang T, *et al.* Stigma experienced by the caregivers of patients with chronic plaque psoriasis. Indian Dermatol Online J 2021;12:110-5.

**Received:** 9-May-2020. **Revised:** 5-Jul-2020.

**Accepted:** 22-Aug-2020. **Published:** 16-Jan-2021.

to read Hindi. Additionally, the caregivers were involved in the care of the patient in the form of taking care of the them at the time of relapse, accompanying the patient to the hospital, supervising the medications and liaising with the medical professionals for management of the illness.

The patients were assessed on Psoriasis Area and Severity Index (PASI), Dermatology Life Quality Index (DLQI) and Psoriasis Disability Index (PDI).

The caregivers were assessed on Stigma scale for caregivers of people with mental illness, caregiver version of the Explanatory Model Interview Catalogue Stigma Scale, Multidimensional aspect of perceived social support scale, Cognitive behavioral avoidance scale, and Caregiver Coping checklist.

### ***Stigma scale for caregivers of people with mental illness***

This 22-item scale (CPMI) was developed to measure internalized/Affiliate stigma among the caregivers of patients with mental illnesses.<sup>[7]</sup> The items are grouped into 3 domains, that is, cognitive, affective, and behavioral components of affiliate stigma. Total score of CPMI is calculated by all the total score of all the 3 domains. The overall scale's internal consistency is excellent with Cronbach's  $\alpha = 0.95$ . This scale has been translated and adapted in Hindi and has been used in previous studies from India to evaluate stigma among the caregivers of patients with severe mental disorders.<sup>[8]</sup> For this study, this scale was suitably modified to suit the assessment of internalized stigma among the caregivers of patients with psoriasis.

### ***Explanatory model interview catalogue (EMIC) stigma scale***

EMIC is used to assess anticipated stigma/perceived stigma<sup>[9]</sup> from the perspective of stigmatized individual. Outcome is assessed as total score, which is calculated by adding the score obtained on all the items, with higher scores indicating higher perceived stigma. The scale has generic application and can be used for different health conditions. This scale was suitably modified for use among the caregivers of patients with psoriasis.

### ***Family burden interview schedule (FBI)***

The interview schedule was developed by Pai and Kapur in 1981 to assess caregiver burden.<sup>[10]</sup> This scale has been mostly used for the caregivers of patients with severe mental disorders. The scale consists of 24 items grouped under six areas. Score of all the 6 domains is added to obtain the total score. Each item is rated on 0–2 scale. The reliability and validity are more than 0.87 and 0.72, respectively.

### ***Multidimensional aspect of perceived social support scale***

This scale comprises of 12 items to assess perceived social support. The scale is divided into 3 subscales, based on the source of support, each subscale comprising of 4 items. Each item is rated on a 7-point scale varying from “definitely no” to “definitely yes”. The reliability and the internal consistencies of the scale and the sub-scales are high, ranging from 0.79 to 0.98 in various samples; furthermore, the test-retest reliability over a 2 to 3-month period produces correlations ranging from 0.72 to 0.85.<sup>[11]</sup> This scale has been translated in to Hindi, in one of the previous studies and the available Hindi version was used.<sup>[12]</sup>

### ***Cognitive behavioral avoidance scale (CBAS)***

The scale has 31 items and evaluates the avoidance coping in 4 domains, i.e., cognitive social, cognitive non-social, behavioral social, and behavioral non-social dimensions of avoidance. The various subscales of CBAS have significant correlation with the depression and anxiety measures.<sup>[13]</sup> The Coping Checklist-Hindi version<sup>[14]</sup> This checklist has 14 items, grouped into 5 domains/subscales, i.e., problem focused (3 items), seeking social support (4 items), avoidance (5 items), collusion (1 item), coercion (1 item). Each item is rated on a three point scale (0 – never; 1 – sometimes and 2 is always used). The Cronbach's alpha of the scale is 0.62.

Statistical Package for Social Sciences, 14<sup>th</sup> version (SPSS-14) was used to analyze the data. Continuous variables are described as mean and standard deviation. Categorical variables are described in terms of frequency/percentage. Correlation of stigma with other variables was evaluated by using Pearson's or Spearman's correlation coefficients.

## **Results**

The study included 49 patients and their family members, who were involved in the care of the patient. The demographic and clinical profile of the patients and the demographic caregivers is shown in Tables 1 and 2.

Table 3 shows the scores on various scales assessing stigma, caregiver burden, social support, and coping of the caregivers.

Caregivers of patients who were single reported higher stigma in the affective ( $P = 0.011^*$ ) and cognitive ( $P = 0.03^*$ ) domains. Additionally, higher stigma as reflected by total CPMI score ( $P = 0.04^*$ ) was seen in among the caregivers of patients who were single. In terms of other variables, correlation of stigma with demographic and clinical variables of patient did not reveal any significant associations, except that the caregivers of patients with poor quality of life, as assessed by DQLI,

**Table 1: Sociodemographic profile of the patients and the caregivers**

| Variables  | Frequency (%)/<br>Mean (SD)-Caregiver n=49 | Frequency (%)/<br>Mean (SD)-Patient n=49 |
|--|--|--|
| Age (years)  | 41.6 (12.5)                                | 32.6 (12.8%)                             |
| Sex  |  |  |
| Male   | 28 (57.1%)                                 | 19 (38.8%)                               |
| Female   | 21 (42.9%)                                 | 30 (61.2%)                               |
| Marital status   |  |  |
| Single   | 2 (4.1%)                                   | 19 (38.8%)                               |
| Married  | 47 (95.9%)                                 | 30 (61.2%)                               |
| Locality   |  |  |
| Urban  | 33 (67.3%)                                 | 33 (67.3%)                               |
| Rural  | 16 (32.7%)                                 | 16 (32.7%)                               |
| Education  | 11.3 (3.1)                                 | 10.7 (3.1)                               |
| Relationship with the patient                          |  |  |
| Parents <sup>1</sup>                                   | 18 (36.7%)                                 |  |
| Spouse   | 21 (42.8%)                                 |  |
| Brothers   | 6 (12.2%)                                  |  |
| Children   | 4 (8.1%)                                   |  |
| Duration of caregiving (years)                         | 6.5 (4.8)                                  |  |
| Number of visit by the same caregiver in last 6 months | 95.7 (11.5)                                |  |
| Medication supervision                                 |  |  |
| Yes  | 46 (93.9%)                                 |  |
| No   | 3 (6.1%)                                   |  |
| Physical illness in caregivers- Yes                    | 4 (8.2%)                                   |  |

1- Father (n=8), Mother (n=10)

**Table 2: Clinical profile of the study participants**

| Variables                         | Frequency (%)/<br>Mean (SD)-Caregiver |
|-----------------------------------|---------------------------------------|
| Age of onset of illness (years)   | 26.12 (13.1)                          |
| Duration of illness (months)      | 83.8 (57.2)                           |
| Body surface area                 | 7.5 (4.2)                             |
| Psoriasis and severity index      | 3.8 (3.2)                             |
| Mild                              | 40 (81.6)                             |
| Moderate                          | 7 (14.3)                              |
| Severe                            | 2 (4.1)                               |
| Dermatology quality of life index | 6.0 (3.9)                             |
| Small effect on patient's life    | 25 (51.0)                             |
| Moderate effect on patient's life | 16 (32.7)                             |
| Large effect on patient's life    | 8 (16.3)                              |
| Psoriasis and disability index    | 4.1 (5.4)                             |

reported higher stigma in the cognitive (Pearson correlation coefficient: 0.30;  $P = 0.036^*$ ), and behavior (Pearson correlation coefficient: 0.33;  $P = 0.021^*$ ) domains of CPMI and had significantly higher total CPMI (Pearson correlation coefficient: 0.31;  $P = 0.029^*$ ) scores. In terms of association with CPMI, higher stigma was associated with higher age of onset (Pearson correlation coefficient: 0.32;  $P = 0.025^*$ ) and higher involvement of body surface area (Pearson correlation coefficient: 0.29;  $P = 0.04^*$ ).

In terms of the caregiver demographic and caregiving profile, caregivers who were more educated reported higher level of stigma in the cognitive (Pearson correlation coefficient: 0.33;  $P = 0.02^*$ ) domain of CPMI and reported overall higher level of stigma as indicated by total CPMI score.

Association of psychosocial variables with stigma is shown Table 4.

## Discussion

This exploratory study attempted to evaluate the psychosocial impact of illness on the caregivers of patients with psoriasis. As there is lack of data on stigma and caregiver burden experienced by the caregivers of patients with psoriasis or other skin diseases, it is not possible to compare the findings with the existing literature in dermatology. However, when the findings of the present study are compared with the caregiver burden data, as reported for various mental disorders, by using the same scale, that is, FBI, it is apparent that the caregiver burden experienced by the caregivers of patients with psoriasis is much lower with that of severe mental disorders like schizophrenia,<sup>[15]</sup> bipolar disorder,<sup>[16]</sup> depression,<sup>[17]</sup> and obsessive compulsive disorder.<sup>[18]</sup> Further, the caregiver burden experienced by patients with psoriasis is also lower than that reported by the caregivers of patients with acute lymphoblastic leukemia<sup>[19]</sup> and acute myeloblastic

**Table 3: Stigma, social support and coping of caregivers**

| Variables   | Mean (SD)   | Frequency (%) Mean weighted scores (SD) |
|---|-------------|---|
| <b>Family Caregiver Burden Interview Schedule</b>                     |             |   |
| Financial burden  | 1.1 (2.2)   |   |
| Disruption of routine family activities                               | 0.5 (1.1)   |   |
| Disruption of family leisure activities                               | 0.5 (1.2)   |   |
| Disruption of family interaction                                      | 0.3 (0.8)   |   |
| Effect on physical health   | 0.1 (0.5)   |   |
| Effect on mental health   | 0.1 (0.4)   |   |
| Other burden  | 0.4 (0.6)   |   |
| Total Objective burden  | 2.6 (4.9)   |   |
| Subjective burden   | 0.5 (0.7)   |   |
| <b>Objective Burden</b>   |             |   |
| <12   |             | 43 (87.8%)                              |
| ≥12   |             | 6 (12.2%)                               |
| <b>Stigma scale for caregivers of people with mental illness</b>      |             |   |
| Affective   | 21.4 (5.9)  | 3.1 (0.9)                               |
| Cognitive   | 20.3 (5.6)  | 2.9 (0.9)                               |
| Behavioral  | 23.2 (6.5)  | 2.9 (0.8)                               |
| Total score   | 65.3 (18.4) | 2.9 (0.8)                               |
| <b>Explanatory Model Interview Catalogue Stigma scale total score</b> |             |   |
|   | 11.5 (11.2) | 11.5 (11.2)                             |
| <b>Multidimensional aspect of perceived social support scale</b>      |             |   |
| Total score   | 63.8 (17.7) | 5.3 (1.4)                               |
| Family  | 21.1 (6.1)  | 1.6 (0.8)                               |
| Friend  | 21.3 (5.9)  | 1.5 (0.8)                               |
| Others  | 21.3 (5.9)  | 5.3 (1.5)                               |
| <b>Level of social support</b>  |             |   |
| Low (1-2.9)   |             | 5 (10.2%)                               |
| Medium (3-5)  |             | 4 (8.2%)                                |
| High (5.1-7)  |             | 40 (81.6%)                              |
| <b>Cognitive behavioral avoidance coping scale</b>                    |             |   |
| Behavioral social   | 14.8 (3.6)  | 1.8 (0.4)                               |
| Behavioral non-social   | 10.6 (3.4)  | 1.8 (0.6)                               |
| Cognitive social  | 12.4 (3.5)  | 1.8 (0.5)                               |
| Cognitive non-social  | 17.2 (4.6)  | 1.7 (0.5)                               |
| Cognitive behavioral avoidance scale (overall)                        | 54.9 (14.1) | 1.8 (0.5)                               |
| <b>Caregiving coping checklist</b>                                    |             |   |
| Problem focused   | 4.2 (2.4)   | 1.4 (0.8)                               |
| Seeking social support  | 3.9 (2.5)   | 0.9 (0.6)                               |
| Avoidance   | 0.4 (1.1)   | 0.1 (0.2)                               |
| Collusion   | 0.1 (0.3)   | 0.1 (0.3)                               |
| Coercion  | 0.1 (0.5)   | 0.1 (0.5)                               |
| Overall score of caregiving   | 8.7 (5.2)   | 0.6 (0.4)                               |

leukemia.<sup>[18]</sup> The lower level of caregiver burden could be due to lack of dependency needs or much lower dependency needs among patients with psoriasis compared to other mental and physical illnesses. Other reason could be that this study was limited to those patients with mild psoriasis, and hence, the prevalence of caregiver burden was lower.

In terms of stigma, when the findings on the CPMI as obtained for the caregivers of patients with psoriasis is compared with that for caregivers of patients with severe

mental disorders,<sup>[7,20]</sup> it is evident that the caregivers of patients with psoriasis experience higher level of stigma. Similarly, comparison of findings of EMIC also suggests that the caregivers of patients with psoriasis experience higher level of stigma.<sup>[20]</sup> A higher level of internalized and anticipated stigma/perceived stigma among the caregivers of psoriasis can be understood from the perspective of evident skin lesions, which lead to more discrimination.

**Table 4: Correlation of caregiver stigma with coping and social support**

| Variables                                   | Affective         | Cognitive         | Behavior          | CPMI Total score  | EMIC total score  |
|---|-------------------|-------------------|-------------------|-------------------|-------------------|
| <b>Cognitive behavioral avoidance scale</b> |                   |                   |                   |                   |                   |
| Behavioral social                           | 0.302 (0.035*)    | 0.322 (0.024*)    | 0.350 (0.014*)    | 0.338 (0.017*)    | 0.536 (<0.001***) |
| Behavioral non-social                       | 0.461 (0.001**)   | 0.426 (0.002**)   | 0.520 (<0.001***) | 0.488 (<0.001***) | 0.567 (<0.001***) |
| Cognitive social                            | 0.398 (0.005**)   | 0.391 (0.005**)   | 0.413 (0.003**)   | 0.417 (0.003**)   | 0.672 (<0.001***) |
| Cognitive non-social                        | 0.429 (0.002**)   | 0.478 (0.001**)   | 0.478 (0.001***)  | 0.482 (<0.001***) | 0.585 (<0.001***) |
| Total score                                 | 0.425 (0.002**)   | 0.436 (0.002**)   | 0.470 (0.001***)  | 0.462 (0.001***)  | 0.628 (<0.001***) |
| <b>Caregiving coping scale</b>              |                   |                   |                   |                   |                   |
| Problem focused                             | 0.654 (0.001**)   | 0.621 (<0.001**)  | 0.648 (0.001***)  | 0.666 (0.001***)  | 0.585 (<0.001***) |
| Seeking social support                      | 0.654 (0.001**)   | 0.545 (<0.001**)  | 0.662 (0.001***)  | 0.644 (0.001***)  | 0.537 (<0.001***) |
| Avoidance                                   | 0.285 (0.047*)    | 0.209 (0.149)     | 0.240 (0.097)     | 0.253 (0.079)     | 0.319 (0.026*)    |
| Collusion                                   | 0.243 (0.093)     | 0.138 (0.344)     | 0.211 (0.145)     | 0.204 (0.160)     | 0.152 (0.299)     |
| Coercion                                    | 0.114 (0.434)     | 0.131 (0.37)      | 0.139 (0.342)     | 0.134 (0.36)      | 0.260 (0.071)     |
| <b>Perceived social support scale</b>       |                   |                   |                   |                   |                   |
| Family support                              | 0.876 (<0.001***) | 0.802 (<0.001***) | 0.895 (<0.001***) | 0.892 (<0.001***) | 0.667 (<0.001***) |
| Friend support                              | 0.834 (<0.001***) | 0.731 (<0.001***) | 0.849 (<0.001***) | 0.837 (<0.001***) | 0.571 (<0.001***) |
| Other support                               | 0.792 (<0.001***) | 0.638 (<0.001***) | 0.741 (<0.001***) | 0.751 (<0.001***) | 0.237 (0.101)     |
| Total PSS score                             | 0.798 (<0.001***) | 0.658 (<0.001***) | 0.750 (<0.001***) | 0.763 (<0.001***) | 0.124 (0.122)     |
| <b>Family Burden Interview Schedule</b>     |                   |                   |                   |                   |                   |
| Financial burden                            | 0.436 (0.002**)   | 0.608 (<0.001***) | 0.409 (0.003**)   | 0.602 (<0.001***) | 0.498 (<0.001***) |
| Disruption of routine family activities     | 0.504 (<0.001***) | 0.589 (<0.001***) | 0.561 (<0.001***) | 0.554 (<0.001***) | 0.574 (<0.001***) |
| Disruption of family leisure activities     | 0.492 (<0.001***) | 0.603 (<0.001***) | 0.582 (<0.001***) | 0.677 (<0.001***) | 0.585 (<0.001***) |
| Disruption of family interaction            | 0.250 (0.083)     | 0.463 (0.001***)  | 0.361 (0.011*)    | 0.357 (0.012*)    | 0.389 (0.006**)   |
| Effect on physical health                   | 0.452 (0.001***)  | 0.507 (<0.001***) | 0.470 (0.001***)  | 0.438 (0.002**)   | 0.520 (<0.001***) |
| Effect on mental health                     | 0.458 (0.001***)  | 0.506 (<0.001***) | 0.474 (0.001***)  | 0.440 (0.002**)   | 0.519 (<0.001***) |
| Other Burden                                | 0.164 (0.262)     | 0.292 (0.042*)    | 0.257 (0.074)     | 0.356 (0.012*)    | 0.233 (0.107)     |
| Objective burden                            | 0.500 (<0.001***) | 0.690 (<0.001***) | 0.519 (<0.001***) | 0.752 (<0.001***) | 0.592 (<0.001***) |
| Subjective burden                           | 0.458 (0.001***)  | 0.645 (<0.001***) | 0.483 (0.001***)  | 0.713 (0.002**)   | 0.553 (<0.001***) |

\* $P \leq 0.05$ ; \*\* $P \leq 0.01$ ; \*\*\* $P \leq 0.001$

In terms of association of stigma and caregiver burden, this study suggests that higher level of stigma is associated with higher caregiver burden. Studies involving patients with mental disorders have also come up with similar findings.<sup>[8,18]</sup>

Accordingly, it can be said that the caregivers of patients with psoriasis experience considerable caregiver burden and stigma, which requires attention. Accordingly, clinicians involved in the management of psoriasis should also focus on the 3<sup>rd</sup> dimension, that is, “The Greater patients”. It can be said that clinicians should routinely evaluate the caregiver’s aspects in patients with psoriasis and try to address the same by themselves or seek help of mental health professionals to address the same.

In terms of coping mechanism, present study suggests that higher level of use of avoidance coping is associated with higher level of stigma. The concept of “avoidance” is understood as refraining from, or escaping from, an action, person or thing.<sup>[13]</sup> In this context, “cognitive avoidance coping” is understood as various kinds of responses of a person, which are directed at denying or minimizing a crisis and/or its consequences. It also refers to accepting the situation, because of the understanding that the situation cannot be changed. Whereas the “Behavioral

avoidance coping” are understood as responses, helps to seek a solution for the problem or crisis, by seeking alternative rewards or escape mechanism, or avoiding behaving in direct response to a stressor. Further these avoidance strategies are understood as “social”, and non-social involvement in dealing with the problem. The social avoidance means involving other people, whereas “non-social” avoidance suggests not involving others.<sup>[13]</sup> If we try to understand the association of avoidance coping and stigma in this study, it is apparent that avoidance possibly acts as a negative or maladaptive coping to deal with stigma.

In this study, higher use of problem focused coping and seeking social support were also associated with higher level of stigma. Similarly seeking social support was associated with higher level of stigma. These findings are in contradiction to the existing literature, for various psychiatric disorders,<sup>[14]</sup> which suggest that higher use of problem solving and seeking social support are either not associated with stigma or are associated with lower level of stigma.<sup>[14]</sup> Association of seeking social support and stigma can be understood from the perspective of rejection of the caregivers of the patients with psoriasis by others, because of their association with the patients.



This study has certain limitations. The study was limited to a small sample of clinic attending patients and their caregivers. Accordingly, the findings may not be generalizable to those in the community and not seeking help from dermatologists. The study relied on cross-sectional assessment and do not provide any information about the longitudinal course of psychosocial impact of psoriasis on the caregivers. Further, the study was limited to the caregivers of patients, who had lower severity of psoriasis. Hence, the findings cannot be generalized to the caregivers of patients with more severe psoriasis.

To conclude, this study suggests that the caregivers of patients with psoriasis experience high level of caregiver stigma which is comparable to the caregivers of patients with severe mental disorders. The caregivers of patients with psoriasis also experience lower level of caregiver burden, compared to the caregivers of patients with mental disorders. Higher level of caregiver stigma is associated with higher level of caregiver burden. Accordingly, there is a need to evaluate the caregiver issues among the caregivers of patients with psoriasis and proper psychosocial intervention should be designed to address their needs. The psychosocial issues among the caregivers also call for a good liaison between the dermatologist and the mental health professionals to improve the overall outcome of psoriasis.

### **Declaration of patient consent**

The authors certify that they have obtained all appropriate participant consent/assent forms. In the form the participants(s) has/have given his/her/their consent/assent for clinical information to be reported in the journal. The participants understood that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

### **Financial support and sponsorship**

Nil.

### **Conflicts of interest**

There are no conflicts of interest.

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