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Cultural adaptation of the *Tuberculosis-related stigma* scale to Brazil

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Abstract *The process of stigmatization associated with TB has been undervalued in national research as this social aspect is important in the control of the disease, especially in marginalized populations. This paper introduces the stages of the process of cultural adaptation in Brazil of the Tuberculosis-related stigma scale for TB patients. It is a methodological study in which the items of the scale were translated and back-translated with semantic validation with 15 individuals of the target population. After translation, the reconciled back-translated version was compared with the original version by the project coordinator in Southern Thailand, who approved the final version in Brazilian Portuguese. The results of the semantic validation conducted with TB patients enable the identification that, in general, the scale was well accepted and easily understood by the participants.*

Key words *Validation studies, Social stigma, Translations, Tuberculosis*

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Introduction

The stigma associated with tuberculosis (TB) is a social phenomenon present in several cultures and communities[1]. Historically, the moral change after the identification of its pathogen by Robert Koch, as well as the confirmation of its transmissivity, contributed to evidence certain social categories as the only ones to be affected by the disease[2].

This is due to the fact that the spread of TB was more prevalent among the poor due to their precarious life conditions in large industrial cities in the late nineteenth and early twentieth centuries, conditions which contributed to infection and development of the disease. According to the author[3] this fact led to changes in the speeches of spokespersons regarding the social image of TB, and as a result, the stigma of contagion was developed.

In the current epidemiological reality of TB in Brazil and worldwide, reports on the impact of stigma both in the search for a diagnosis and adherence to treatment was seen in Asian and African countries[4,5], the Americas[6,7] and Europe[8]. Extended, substantial investigations on this phenomenon are very important.

According to Goffman[9] the process of stigmatization occurs because of the contradictory relation between the attributes and stereotypes that the normal population creates for a given set of people. Such a relation generates inferior identities and may vary according to the evidence and exposure of the characteristics of the individual. In turn, the psychosocial aspect emphasizes the contextual and dynamic nature of stigma and its immediate effects in the perspective of stigmatizer, stigmatized, and the interaction between them[10].

Therefore, beyond the biologicist perspective, the experience with the stigma of TB presents different results according to historical, cultural, and social aspects. In general, the reasons for such stigmatizing attitudes are divided into three categories: lack of knowledge and/or myths about the disease; association of TB with other health conditions, such as AIDS; poverty and marginalizing behaviors[11].

In different geographical regions, authors have been trying to understand the prevalence and extent of the stigma in the community through the use of standardized assessment tools[12-14]. However, cultural adaptation and validation between the different versions of these instruments are required so that the TB stigma assessment actions and the analysis of determining factors provided by scales developed in other countries with their sociocultural differences are relevant in the Brazilian environment.

No specific scale that has been adapted for use in the country was identified in the national literature to assess stigma in TB patients. Thus, the present work aims at culturally adapting the *Tuberculosis-related stigma* scale for use in Brazil.

Method

This study is a methodological investigation consisting of the process of translation and semantic validation of the items of the *Tuberculosis-related stigma* scale developed and validated in Southern Thailand. The scale consists of 23 items and the total score ranges from 0 to 27.9. Higher score indicates higher level of stigma. Two subscales enable the assessment of stigma associated with TB in specific domains: (1) the perspectives of the community in relation to TB; (2) the perspectives of patients in relation to TB[14].

Contact with the project coordinator in Southern Thailand was initially established, and an authorization to translate and culturally adapt the process to the Brazilian context was requested. The items were subsequently translated and semantically validated through the procedures indicated by Beaton et al.[15] and the Group DISABKIDS®[16] (Figure 1), respectively.

The scale was translated independently by two translators one fluent in the source language and the other a native speaker of the target language. The first one was familiar with the assessed construct, while the other was not aware of the objectives of the translation. With these two translated versions, synthesis was initiated by discussion with both the research group and the researchers responsible for the original scale. The back-translation to the original language was then performed by two native speakers of the target language who were not aware of the theme. The consensus version in English was subsequently compared with the original version of the scale and approved by the project coordinator in Southern Thailand.

Semantic validation of the scale was performed with patients undergoing TB treatment in the city of Ribeirão Preto. Located in the Northeastern region of the state of São Paulo, 313 kilometers from the state capital and 706 kilometers from Brasília, Ribeirão Preto has an estimated population of 658,059 inhabitants in a terri-

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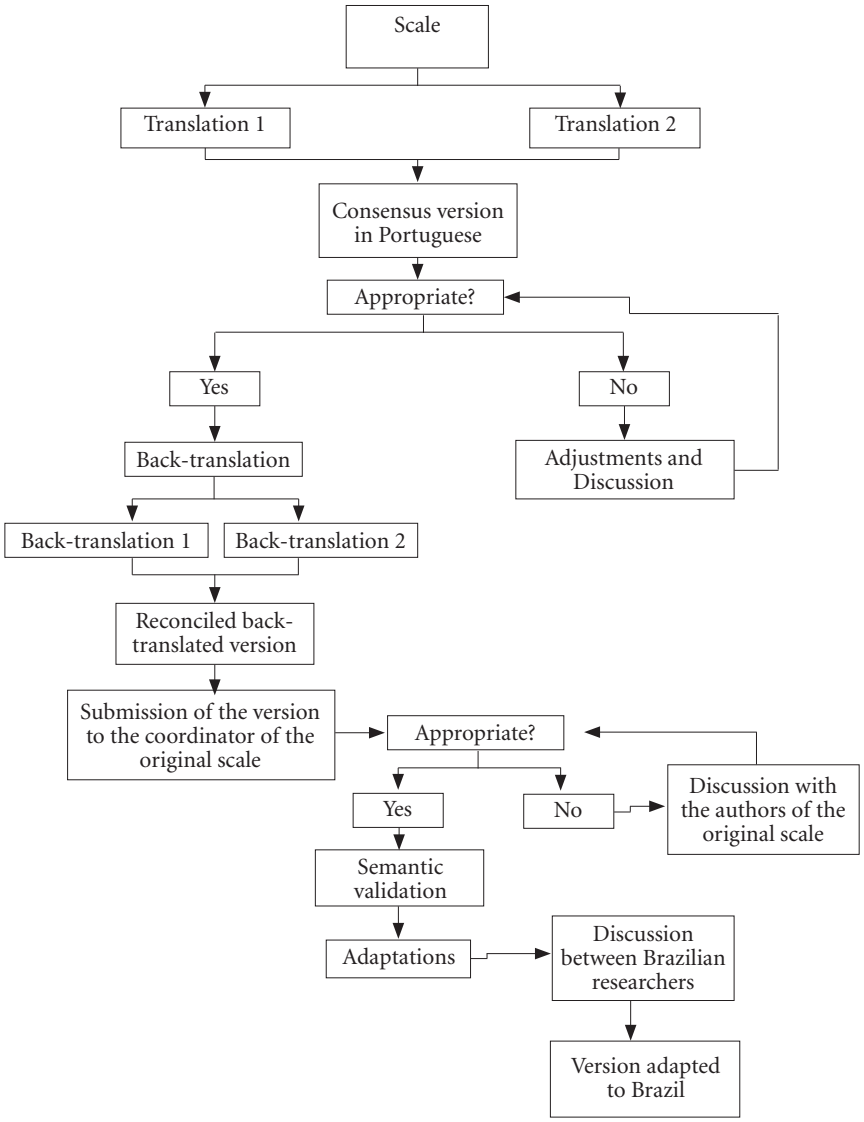

Figure 1. Flowchart of the stages of cultural adaptation of the Tuberculosis-related stigma scale to Brazil, Brazil, 2014.

Source: Adapted from Borsa et al.[17].

tory of 650.92 km²[18]. According to the Human Development Index (HDI) of 0.80, literacy rate of 3.0, and the São Paulo Social Vulnerability Index (IPVS), the city is in the group of those presenting good social and economic indicators[18,19].

In the city the care for TB patients is centralized in the reference clinics with TB Control Programs (TCP) distributed in five Health Districts (east, west, north, south, and central). These services work with specialized teams consisting of a minimum of one physician, two nursing assistants, and one nurse performing activities related to diagnosis, clinical management of cases and their contacts, medical visits, and coverage of the Directly Observed Treatment (DOT). In relation to the epidemiological situation of TB, in 2013 the incidence was of 28.17 cases per 100,000 inhabitants and 18% of TB/HIV co-infection. Re-

garding the outcomes of the treatment, in 2012 a cure rate of 77.8% was verified, 6.6% of abandonment of treatment, and 3.6% of death rate[20].

The population of the study consisted of TB patients aged over 18 years, living in the city of Ribeirão Preto, and undergoing treatment in the reference clinics for a minimum period of two weeks. Patients that did not present the minimum skills to understand the questions of the scale and those who did not feel comfortable to talk about the objectives of the investigation in the presence of the researchers were excluded.

Convenience sampling with patients undergoing TB treatment in the reference clinics of the western and northern regions of the city between September and December 2014 was performed for the semantic validation. The choice of these health services is justified as they are located in two areas that have a concentration of new cases of TB and coincide with the areas of concentration of poverty and intermediate living conditions[21]. The number of participants in this stage was established according to the method DISABKIDS, validated in six European countries and Brazil[16,22].

Two groups were formed considering the selected reference clinics. With the 23 items that make up the scale three subgroups were formed: (A) consisting of items 1 to 7 of the first dimension; (B) consisting of items 8 to 11 of the first dimension and 1 to 4 of the second dimension; (C) consisting of items 5 to 12 of the second dimension. Three patients were considered for each subgroup:

Selection of participants was performed through an initial contact with the teams in the reference clinics of western and northern districts, introduction of the research objectives, and non-participant observation of the care provided in the service, and follow-up of DOT at home.

From this local recognition the individuals eligible for the study were identified, verbal and written information on the research was provided, and the invitation to participate was made. In the event of adherence by patients, the free and informed consent form was read and signed in two copies by them.

Then the patients were requested to complete the *Tuberculosis-related stigma* scale and the general impressions form. Subsequently the participants of each subgroup answered the questions of the specific form. In addition to the quantitative data, the researcher also registered in her field notes the qualitative impressions of the individuals of the study on their understanding of the items of the scale and the experience of the stigma associated with TB. Clinical information on the condition of patients were obtained from medical records and charts available in the clinics.

Data were analyzed in the software *STATISTICA* version 12.0. Descriptive analyses were conducted in all variables. Measures of dispersion (deviation-standard – SD, minimum and maximum values), central tendency (mean and median) were calculated for continuous variables. Measures of absolute and relative frequencies were calculated for categorical variables.

The study was approved by the Ethics Committee of the School of Nursing of Ribeirão Preto of the University of São Paulo.

Results

Of the total of 26 patients undergoing treatment in the two reference clinics, 17 participated in the study. There was no refusal and one patient died. According to the reference clinics for TB diagnosis and treatment, the distribution of sociodemographic and clinical variables suggests a prevalence of male patients affected by the disease, in economically productive groups, with years of education ranging between six and nine, and presenting average family income below two minimum wages per month.

In relation to the clinical variables, it was observed that two individuals were seropositive for HIV and that there are, respectively in the western and northern districts clinics, 5 (62,5%) and 6 (66,7%) individuals with the pulmonary clinical form, most of these consisting in new cases with no previous treatment (Table 1).

The general impressions of the scale are presented in Table 2. It is possible to observe that, in general, the scale was well accepted and easily understood by most participants. It was also verified that 12 (70.6%) interviewees considered it as good, while 16 (94.1%) considered the items as very important for the assessment of the stigma associated with TB and was easy to understand.

In the specific analysis form of the *Tuberculosis-related stigma* scale the items were fully understood, except for item 1 *Some people prefer not to have someone with TB living in their community*, item 3 *Some people think people with TB are disgusting*, item 5 *Some people with TB lose friends when they share the information that they have the disease*, and item 8 *Some people with TB will choose carefully those to share the information about the disease*, which were not understood by

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Table 1. Sociodemographic and clinical characteristics of the participants of the semantic validation of the *Tuberculosis-related stigma* scale according to reference clinics, Ribeirão Preto, 2014.

Characteristics	Clinics (west)		Clinics (north)	
	n	%	n	%
Sociodemographic				
Sex				
Female	4	50.0	1	11.1
Male	4	50.0	8	88.9
Place of birth				
Northeast	1	12.5	0	0.0
Southeast	7	87.5	8	88.9
South	0	0.0	1	11.1
Marital Status				
Married	4	50.0	5	55.6
Unmarried	3	37.5	0	0.0
Widowed	1	12.5	0	0.0
Divorced	0	0.0	2	22.2
Other	0	0.0	2	22.2
Ethnic group				
White	6	75.0	5	55.6
Black	2	25.0	4	44.4
Occupation				
Working with a formal contract	2	25.0	1	11.1
Freelancer	2	25.0	2	22.2
Retired	1	12.5	1	11.1
Unemployed	2	25.0	5	55.6
Other	1	12.5	0	0.0
	$\bar{x}$	SD	$\bar{x}$	SD
Age (years)	40.8	20.8	46.5	11.2
Years of education	9.2	4.4	6.6	4.3
Income*	1246.7	452.2	1366.4	796.5
	n	%	n	%
Clinics				
HIV				
Negative	8	100	6	66.7
Positive	0	0.0	2	22.2
Not informed	0	0.0	1	11.1
Type of TB				
Pulmonary	5	62.5	6	66.7
Extra pulmonary	3	37.5	3	33.3
Case status				
New case with no previous treatment	7	87.5	7	77.8
New case with previous treatment and cure	0	0.0	1	11.1
Relapse after cure	0	0.0	1	11.1
Return after abandonment	1	12.5	0	0.0

*Minimum wage in force at the time of data collection was R$ 724.00.

16.7% of the individuals. However, no changes in items were suggested. Item 2 *some people keep distance from TB patients* was not found relevant for 33.4% of the individuals (Tables 3 and 4).

In relation to the reformulation of items, five individuals suggested changes to colloquial terms. After some discussion the researchers agreed with the suggestions of the participants, resulting in the version adapted for Brazil. In the analysis of registered qualitative impressions, the stigma associated with TB was represented in the following reports:

... *The unknown is always feared* [...] *especially in the early stage of the disease.* (E3)

Table 2. Results of the assessment in relation to the general impression of the *Tuberculosis-related stigma* scale according to the group of respondents, Ribeirão Preto, 2014.

Questions of the General Impression Form	n	%
In general, what do you think of our scale?		
Very good	5	29.4
Good	12	70.6
Regular	0	0.0
Are the questions understandable?		
Easy to understand	16	94.1
Hard sometimes	1	5.9
Not understandable	0	0.0
About the categories of answers Did you have any difficulties?		
No difficulty	15	88.2
Some difficulties	2	11.8
Many difficulties	0	0.0
Are the questions important to the stigma associated with TB?		
Very important	16	94.1
Sometimes important	1	5.9
Not important	0	0.0

... I see that such behavior is influenced by the lack of knowledge on TB in the community. (E3)

... Even today, it annoys me to know that I have lost friends because of this disease [...] *it is not easy, you know.* (E5)

... I was really afraid, just like my family, to tell friends and neighbors that I had the disease. (E5)

... Yes, I believe this disease still faces a certain level of discrimination and prejudice. (E10)

... In fact, this occurs and it outrages me [...] *I see respect to each other, especially when the person is sick.* (E2)

Discussion

This paper aimed at introducing the stages of the process of cultural adaptation of the Tuberculosis-related stigma scale for TB patients in Brazil. To this end, the guidelines suggested in national and international literature were followed[15,23,24].

According to authors[24], some instruments are developed considering only a given culture, while others are developed to be culturally adapted.

Table 3. Results of specific part of the semantic validation according to the first dimension – perspectives of the community in relation to TB, Ribeirão Preto, 2014.

Item	Is this important to your situation? (%)			Do you have difficulty in understanding these questions? (%)		Are the options of answers clear and in accordance with the questions? (%)	
No. The answers are repeated: totally disagree / disagree/agree/totally agree	Yes	Sometimes	No	No	Yes	Yes	No
1. Some people prefer not to have individuals with TB living in their community	83.3	16.7	0.0	83.3	16.7	100	0.0
2. Some people keep distance from TB patients	66.6	0.0	33.4	100	0.0	100	0.0
3. Some people think people with TB are disgusting	83.3	0.0	16.7	83.3	16.7	100	0.0
4. Some people feel uncomfortable when they are close to a person with TB	83.3	0.0	16.7	100	0.0	100	0.0
5. Some people do not want people with TB playing with their children	83.3	0.0	16.7	100	0.0	100	0.0
6. Some people do not want to talk with those who have TB	83.3	0.0	16.7	100	0.0	100	0.0
7. If a person has TB, some members of the community will behave differently in relation to that person for the rest of their lives	83.3	0.0	16.7	100	0.0	100	0.0
8. Some people may not want to eat or drink with friends that have TB	80.0	20.0	0.0	100	0.0	100	0.0
9. Some people avoid touching people with TB	100	0.0	0.0	100	0.0	100	0.0
10. Some people may not want to eat or drink with family members that have TB	100	0.0	0.0	100	0.0	100	0.0
11. Some people fear those who have TB	100	0.0	0.0	100	0.0	100	0.0

Table 4. Results of specific part of the semantic validation according to the second dimension – perspectives of the patient in relation to TB, Ribeirão Preto, 2014.

Item	Is this important to your situation? (%)			Do you have difficulty in understanding these questions? (%)		Are the options of answers clear and in accordance with the questions? (%)	
No. The answers are repeated: totally disagree /disagree/ agree/totally agree	**Sim**	**Sometimes**	**No**	**No**	**Yes**	**Yes**	**No**
1. Some people with TB feel guilty because their family carries the burden of taking care of them	100	0.0	0.0	100	0.0	100	0.0
2. Some people with TB keep distance from other people in order to avoid the transmission of TB germs	100	0.0	0.0	100	0.0	100	0.0
3. Some people that have TB feel lonely	100	0.0	0.0	100	0.0	100	0.0
4. Some people with TB feel hurt with the way other people react when they learn that they have TB	100	0.0	0.0	100	0.0	100	0.0
5. Some people with TB lose friends when they share the information that they have the disease	100	0.0	0.0	83.3	16.7	100	0.0
6. Some people with TB are worried about the possibility of having AIDS too	100	0.0	0.0	100	0.0	100	0.0
7. Some people with TB fear telling people out their families that they have the disease	100	0.0	0.0	100	0.0	100	0.0
8. Some people with TB will carefully choose those who they will inform about their condition	100	0.0	0.0	83.3	16.7	100	0.0
9. Some people with TB fear going to TB clinics because other people may see them there	66.6	16.7	16.7	100	0.0	100	0.0
10. Some people with TB fear telling their families that they have the disease	100	0.0	0.0	100	0.0	100	0.0
11. Some people with TB fear telling other people about their condition because other people may think they have AIDS too	83.3	16.7	0.0	100	0.0	100	0.0
12. Some people feel guilty as they may have been affected by TB due to the habit of smoking, drinking alcohol, and not taking care of themselves	100	0.0	0.0	100	0.0	100	0.0

The translation of the scale from the source language to the target language required a series of careful steps in order to minimize the linguistic, cultural, theoretical, and practical biases in the Brazilian context.

In this process the formal expressions were replaced by others that can be easily understood, such as the term "insulted" by "hurt". Another criterion discussed by researchers and translators refers to replacing the verb "to have" by "to be", considering the transient nature of the disease through the proper treatment and achievement of cure, as well as the connotation used in the Brazilian culture.

Pedroso et al.[25] suggest that the most significant problem caused by the use of an inappropriate method of translation and cultural adaptation consists in a misrepresented measurement of what is intended to be calculated. Therefore, submitting the reconciled back-translation of the scale to the project coordinator in Southern Thailand and her approval for the final version in Brazilian Portuguese contributed to the semantic equivalence of the versions.

However, due to the possibility of failures and limitations, the translation of the scale alone is not a procedure that ensures its applicability. The methodological strictness of the cultural adaptation does not exclude the need to verify the understanding of the items by the target-audience through the scale face, semantic, and conceptual validation. If an item remains incomprehensible or behaves in a different way than expected by the researchers, it must be reviewed and adapted[24].

Descriptive analyses of the semantic validation evidenced the understanding and acceptance of the items resulting from the translation process. A total of 94.1% of the interviewed patients considered the items as very important in the assessment of stigma associated with TB, they were easy to understand, with appropriate categories of answers that were easily answerable.

During the interviews, the expressions of stigmatizing behaviors and attitudes described in the items included the elements of the construct with varied levels of difficulty. The replacement of colloquial terms suggested by individuals with low educational level is pointed out by Pasquali[26] as a strength, because if these group of individuals understands the item, it is expected that the group with higher levels of education will also understand it.

It was observed that some individuals presented a certain level of difficulty in understanding four of the items of the scale, requiring more time to answer the questionnaires. The difficulty in understanding such items may be associated with the levels of stigma and its impact on the social relations and self-esteem of these individuals. According to authors[27,28], the process may occur more subtly for some people, because being labeled as belonging to a given stigmatized condition leads to expectations of discrimination and devaluation.

Therefore, besides facing the negative experiences resulting from the symptoms of their own health condition, TB patients often have to deal with negative attitudes and behaviors by society. According to Corrigan and Watson[10], this subjective process occurs when members of a stigmatized group accept the prejudice associated with their condition and apply these negative attitudes and beliefs to themselves, affecting their quality of life.

The individual tends to anticipate the rejection, devaluation, and discrimination from other people and begins to develop strategies to prevent these experiences, avoiding social interactions and hiding their health condition and treatment history[29]. Informal reports on low levels of satisfaction in relation to important spheres of life, including work, family, and relationships with friends were presented during the interviews with patients that were undergoing TB treatment for less than a month. Equivalence between experiences of stigma reported by patients undergoing TB treatment in Southern Thailand[4] and patients in Brazil was observed.

Although the use of scales represents a challenge in the assessment of the social stigma of TB, it is possible to explain why this factor represents a predictor of delay of diagnosis and non-adherence to treatment in certain contexts and not in others. These scales consist of tools for the assessment and channeling of resources to strengthen social support networks that include intersectoral actions of TB treatment in the health services[11].

There is evidence that a good social support may represent a protective factor and that a poor social network may contribute to the vulnerability and internalization of stigmatizing attitudes[30]. It is observed that the intersectoral action in health services involves the creation of spaces for communication and overcoming of conflicts leading to accumulation of strengths, creation of individuality, and the discovery of the possible course of actions[31]. In the course of providing intersectoral health services, it is necessary to establish the paradigm for the social production of health and provide tools to deal with the impact of the stigma in the health of TB patients.

Regarding the limitations of the study, it is important to take into account that Brazil is a large country, with cultural, historical, and social differences that may affect the processes of cultural adaptation and validation of scales of subjective assessment like the *Tuberculosis-related stigma* scale.

The need of application of the scale by interviewers may have impacted the choices of the respondents. However, this is the most appropriate method of data collection when the subjects present difficulties such as the ability to write reliably, illiteracy, or people with low educational levels and low income. This limitation was also pointed out by researchers in the process of validation of the stigma tool in Nicaragua[12].

The interaction of TB patients with people reveal discriminatory behavior and their devaluation in family, society, and health services. The investigation of this interaction and its implications in the control of the disease requires new approaches, producing theoretical and methodological challenges for researchers.

Preliminary results of the scale indicate adequacy of the equivalence between the original and the Brazilian versions, considering the assessed linguistic and cultural variations. However, the scale validation process is in progress and the analyses of future psychometric properties will test the reliability and validity of the scale in the Brazilian context in order to complement the presented cultural adaptation.

According to disclosed publications about the impact of stigma associated with TB and the

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practical experience in the process of cultural adaptation of the scale, a scarcity of assessments of stigma related to TB in comparison with other health conditions was verified. Adapted, validated scales may contribute in the study of populations affected by the stigma of TB and support interventions of actions on this disease that will reflect the experience of living with people affected by this disease.

Making the *Tuberculosis-related stigma* scale available in Brazil may enable the comparison of the results of research between two countries and foster discussions on strategies to reduce stigma in different social realities.

Collaborators

JA Crispim worked in the conception of the study, analysis and interpretation of data, and writing of the article; MM Touso and M Yamamura in the analysis and interpretation of data and writing of the article; MP Popolin and MCC Garcia in the critical review of the article; CB Santos, PF Palha, and RA Arcêncio in the conception of the study, interpretation of data, critical review of the article, and approval of the version to be published.

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