



## Review article

# Social support and audience engagement of lupus-related posts on social networking sites in China

Cheng Cheng<sup>a,\*</sup>, Rita Espanha<sup>b</sup><sup>a</sup> Beijing Information Science and Technology University, China<sup>b</sup> University Institute of Lisbon, Portugal

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## ABSTRACT

**Background:** Lupus, known as a chronic multisystem autoimmune disease, has become more common in China currently. Above all, most Chinese Lupus patients haven't ample knowledge and adequate understanding of this complicated chronic disease. In recent years, social networking sites have created an interactive environment in which patients can obtain health information and also can exchange personal experiences with others having similar health concerns.

**Objective:** The overall aim of this study is to develop a better understanding of the social support requested and received during the routine social media use of lupus activists and their referents. In other words, this paper seeks to explore whether the lupus-related posts disseminated on the Sina microblog platform can serve and satisfy the needs of this group.

**Methods:** Content analysis and descriptive analysis were conducted to ascertain the core topics of lupus-related posts on the Sina microblog. Chi-square tests were performed to determine the differences in types of social support between provision and request groups, as well as engaged and non-engaged groups. Finally, negative binomial regression was undertaken to investigate which types of social support generated more audience engagement.

**Results:** By analyzing 9822 lupus-related posts derived from the Sina microblog, disease description was the most prominent theme. Evidence is presented which shows that information support was requested and supplied more frequently than emotional and instrumental support. Specifically, information support was provided more than requested, while the instrumental and emotional support provisions were less numerous than the requests. Analysis revealed that posts containing information support provisions attracted more engagement than those with the other five types of social support.

**Conclusions:** Social networking sites play a critical role on disseminating lupus-related information and provide an interactive space in which users can freely communicate their health conditions and seek peer support. However, health practitioners not only have to present more communication strategies to provide emotional and instrumental support through social media, but also have to boost audience engagement.

\* Corresponding author.

E-mail addresses: [cuchelena@163.com](mailto:cuchelena@163.com) (C. Cheng), [rita.espanha@iscte-iul.pt](mailto:rita.espanha@iscte-iul.pt) (R. Espanha).

## 1. Introduction

### 1.1. Lupus patients in China

Lupus is a chronic multisystem autoimmune disease that can lead to damage of several organ systems [1]. Recent studies have demonstrated that the prevalence rate of lupus in China is around 30 to 70 per 100,000 person-years, ranking the second-highest in the world [2]. And there are significant differences in Lupus incidence between gender and age groups, for instance, Lupus occurs more frequently among reproductive-age women [3]. Because the diagnosis and treatment of this rare disease are very complicated, it has been noted that lupus patients still have numerous unmet needs due to their feelings of invisibility [4].

### 1.2. Social media use, social support and lupus

In the digital era, online social networking sites have emerged as a valuable tool to raise awareness and promote effective self-management among specific disease patients [5]. In China, Sina microblog has become the most influential microblogging platform (known as Chinese Twitter) with over 573 million monthly active users in 2022 [6]. Like Twitter, Sina microblog is also regarded as a potential outreach platform not only for chronic disease patients but also for healthcare professionals and the general public [7]. Due to the lack of enough understanding of treatment and diagnosis, lupus activists and their social referents prefer using multiple media sources to seek information, exchange disease experiences and start new relationships with peers [8,9]. In prior studies regarding lupus-related social media use, the main findings can be summarized into two aspects as follows:

Firstly, existing research recognizes the critical role played by social media use in pooling knowledge and experiences of thousands of medical professionals to disseminate all sorts of lupus-related information that can help patients enrich their understanding of disease and build awareness of their health conditions, and also contribute to balancing the doctor-patient relationship [10]. In this regard, results from earlier studies demonstrate that among the various lupus-related posts delivered through digital media, treatment, diagnosis, disease activity, lived experiences and pregnancy have become the predominant topics [11].

Secondly, according to the report released by the Chinese SLE Treatment and Research Group (CSTAR), there has a huge Lupus patient population with higher disease activity and heavy economic burden in China, and the patients with lower education levels are going to be confronting more serious symptoms. In this context, online social networking sites have scalable potential to deliver more understandable and memorable health information to hard-to-reach subpopulations by leveraging multimedia technologies that can bridge the knowledge gap, integrate medical resources and even reduce health disparities [9,12]. Similarly, as lupus commonly affects child-bearing females who are avid internet users as well, online social networking created an interactive and anonymous space where they can freely discuss social and daily life with others having similar health concerns, such as working capacity and pregnancy management [13]. Considering together, given the infrequency and chronicity of lupus, online social networking sites are rapidly becoming the most promising information sources for strengthening lupus-related health education and empowering patients and their referents by continuously offering social support [14,15].

Indeed, several studies have highlighted that particularly in patients with chronic diseases, such as systemic lupus erythematosus, the primary drivers of health-related social media use are linked to social support seeking and providing, including informational support, emotional support, and instrumental support [12,16,17]. In the literature on this subject [18,19], informational support is defined as offering, inquiring, or being exposed to such information, including tips, advice, personal experiences, suggestions, and explanations. Emotional support refers to the expression of emotional states, or seeking understanding, encouragement, and empathy. And instrumental support (also known as tangible support) includes seeking or providing tangible resources and physical assistance.

Above all, it has been conclusively shown that social support information has a positive influence both on health outcomes and online engagement behaviors, such as retweets, comments, and likes [20]. As the survival rate of lupus patients is closely associated not only with the advancement of treatment and diagnosis but also with the increased levels of perceived social support, current research efforts are focused on the characteristics of the user-generated content about lupus and relevant engagement behaviors on online social networking sites [12,21]. These studies indicate that online social networking sites provide an unprecedented opportunity for helping patients conceptualize disease and also build a sense of empowerment, giving them feelings of being esteemed, loved, and cared for [22,23].

### 1.3. Knowledge gap and objectives

Thus far, despite existing research recognizing the critical roles played by online social networking sites in improving lupus patient outcomes, there is a current paucity of empirical research focusing specifically on the varieties of social support that users request and offer by generating lupus-related posts via online social networking sites in China. Moreover, what remains unclear are the prominent lupus-related themes disseminated through online social networking sites in China.

The starting point of this study is what lupus patients have been discussing on the social networking sites and whether their needs have been satisfied. The research question therefore been to investigate what they have been received, offered and asked for during the use of Sina microblog platform and whether the types of social support can motivate their engagement with lupus-related posts. Consequently, there are three central aims to this research: a) identify lupus-related themes more frequently discussed on the Sina microblog platform; b) explore which types of social support request and provision posts (informational, emotional and instrumental) are most prevalent on the Sina microblog platform; and c) examine which social support content related to lupus elicited higher engagement from receivers on the Sina microblog platform.

## 2. Methods

### 2.1. Data collection and data cleaning

Considering the overall objectives of this study, retrieval of lupus-related posts from the Sina microblog platform occurred between December 1, 2021, and December 31, 2022. In accordance with the recent studies, keywords search methods have been widely utilized to recruit heterogeneous digital text [24]. For determining the baseline of user conversation, we firstly used Sina microblog search engine to collect fifty lupus-related posts and segmented words manually. Consistent with the current studies focusing on the systemic lupus erythematosus patient information [17,21], the five most common words were “狼疮 (Lupus)”, “免疫 (Immunity)”, “药物 (Medicine)”, “不死的癌症 (Undying cancer)” and “治疗 (Treatment)”.

Consequently, a programming script was written in the Python to continuously crawl posts containing at least one of the following terms: #狼疮 (Lupus) and #不死的癌症 (Undying cancer). Generally, both data collection methods and selected keywords are in line with the previous studies, which characterized key themes of lupus-related posts or analyzed health-related posts on the Sina microblog platform [12,21,25]. In the present research, as all relevant posts were extracted from the public domain, no ethics approval was required. And all users' descriptions were removed to avoid any identification information, such as username, location, and gender.

During the study time frame, a total number of 52,395 relevant posts (including retweets) was captured. Regarding the inclusion criteria, the irrelevant posts, retweets, advertising, false information, and non-Chinese posts were excluded. Notably, the data cleansing procedure was implemented based on the consensus of two researchers. Totally, there has 9822 lupus-related posts remained.

In addition, three index numbers for each post were recorded, namely “comment frequency”, “like frequency” and “repost frequency”. Following this, a single metric was calculated by summing up the three index numbers mentioned above, in order to reflect all reactions per post [26]. For the purpose of this research, we then separated and classified all included posts into two groups based on the number of “total engagements”: a) engaged posts and b) non-engaged posts.

### 2.2. Coding

In the present study, a single post is regarded as the unit of measurement. Firstly, both inductive and deductive coding approaches were adopted to identify the predominant lupus-related themes discussed among Sina microblog users. Then, coders classified the lupus-related posts into six different categories based on the varieties of social support that users offer or seek (See Table 1). All posts were independently evaluated by two coders who are native Chinese speakers by utilizing MAXQDA. If an individual post encompasses multiple types of social support, it was coded according to the most salient type [17,26]. Cohen's kappa coefficient of agreement on the thematic categories and social support types of lupus-related posts was 0.895 and 0.920, respectively, indicating an acceptable level of intercoder reliability [27].

### 2.3. Data analysis

To date, content analysis has been long established in communication research to analytically describe and categorize the textual or visual information, such as interpreting the underlying meanings, manifesting the characteristics of content and exploring the emerging hot-spot issues [28]. Considering the general objectives of this study, quantitative content analysis was employed to present a detailed analysis of lupus-related posts, including common topics and social support types. Descriptive statistics were first chosen to illustrate the most prominent lupus-related themes, as well as the number and percentage of each type of social support posts. The second stage of the analysis (Chi-square tests) evaluated differences in types of social support between request and provision. Additionally, Chi-square tests were also employed to quantitatively describe the differences in types of social support between engaged and non-engaged groups. Finally, as the single metric mentioned above used to reflect the total engagement with each lupus-related post was considered as count data and social support type was considered as a categorical independent variable, negative binomial regression was carried out to investigate the relationship of social support types and the volume of engagement. Fig. 1 displays an overview of the data processing procedure.

**Table 1**  
Coding scheme and examples of posts.

Category		Example (translated from Chinese)
<b>Request</b>	Informational support	What are the effective medications used to treat systemic lupus erythematosus?
	Emotional support	I often feel tired and frustrated, I always ask myself, “Why me?”
	Instrumental support	Donation: please help us!
<b>Provision</b>	Informational support	Existing research revealed that fatigue and hair loss are two common symptoms of lupus in women
	Emotional support	Come on! We can fight against lupus, don't give up!
	Instrumental support	Hydroxychloroquine is sold at low prices as my doctor informed me to change drugs.

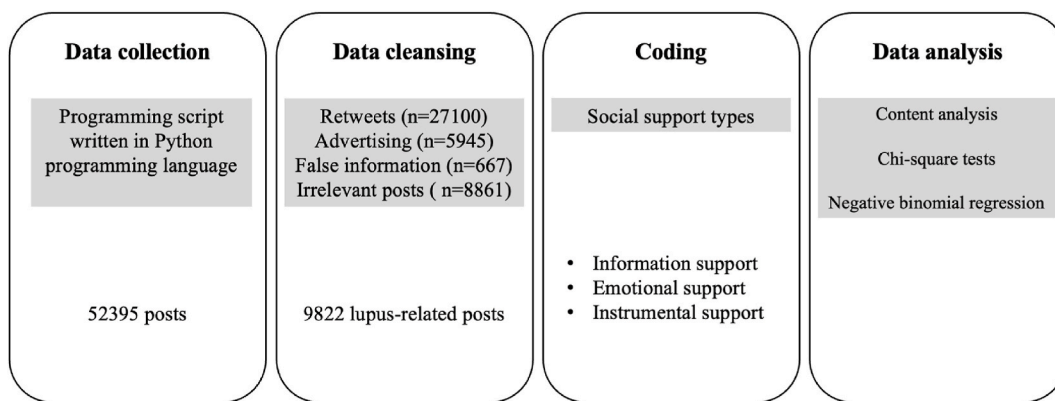


Fig. 1. The flowchart of data processing.

### 3. Results

#### 3.1. Descriptive analysis

Out of the 9822 lupus-related posts, a post that gave a brief explanation of what Lupus erythematosus is was mostly retweeted ( $n = 10,218$ ), liked ( $n = 1544$ ) and commented on ( $n = 1010$ ). By analyzing a dataset of 9822 lupus-related posts harvested from the Sina microblog platform, the content was generalized to five main themes (Disease description:  $n = 7511$ ; Living with lupus:  $n = 4158$ ; Community effects:  $n = 1251$ ; Online consultation:  $n = 314$ ; Others:  $n = 142$ ), including seventeen core topics and six subtopics. Table 2 presents the summary statistics for the total number of these topics and subtopics. What stands out is the dominance of the posts regarding lupus symptoms and personal stories. In addition, medication dosage and frequency, psychological statements, and donations have featured heavily among the selected posts.

#### 3.2. Social support requests and provisions

As reported in Table 3, the difference between the two groups was evident,  $\chi^2(2, N = 9822) = 866.623, P < .001$ , Cramer’s  $V = .297, P < .001$ . Further statistical tests indicated that the proportion of posts containing informational support provisions was considerably greater than those with information support requests. Furthermore, the frequency of emotional support requests was significantly higher than emotional support provision. Similarly, the posts regarding instrumental support seeking were more frequent than those providing instrumental support.

Table 2

The number of main themes, topics, and subtopics of lupus-related posts.

Core topics	Subtopics
Disease description (N = 7511)	Treatment (N = 3106) Medication (N = 929) Other treatment (N = 611) Adverse effect (N = 475) Test/Examination (N = 368) Professionals and hospitals (N = 363) New trials (N = 360)
Living with Lupus (N = 4158)	Symptoms (N = 2435) Diagnosis (N = 598) Lupus and Pregnancy (N = 573) Lupus and Vaccination (N = 433) Cause and Prevention (N = 366) Daily life and personal stories (N = 1223) Psychological statement (N = 798) Social referents (N = 535) Quality of life (N = 516) Social assurance (N = 382) Nutrition and Food avoiding (N = 372) Job and Education (N = 332)
Community effects (N = 1251)	Donation (N = 779) Social news and Social activities (N = 311) Support group (N = 161)
Online Consultation (N = 314)	

**Table 3**

Chi-square tests on the types of social support between provision and request groups.

	Informational	Emotional	Instrumental	Chi-square	df	p
Provision	5926 (84.3 %)	690 (9.8 %)	410 (5.8 %)	866.623	2	0.000
(Expected count)	5373.6 (29.1)	1102.3 (-25.3)	550.1 (-11.7)			
Request	1586 (56.7 %)	851 (30.4 %)	359 (12.8 %)			
(Expected count)	2138.4 (-29.1)	438.7 (25.3)	218.9 (11.7)			

### 3.3. Social support type and engagement

Results of Chi-square tests revealed that there was a significant difference in types of social support (provision vs request) between engaged and non-engaged groups,  $\chi^2(1, N = 9822) = 264.514, P < .001, \phi = .164, P < .001$ . In other words, the lupus-related posts regarding social support requests were more prevalent among engaged posts than among non-engaged posts (Table 4). As shown in Table 5, the posts relevant to informational and instrumental support requests were more recurrent in the engaged group, while the posts containing informational and instrumental provisions were more frequent among non-engaged posts,  $\chi^2(5, N = 9822) = 372.379, P < .001, Cramer's V = .195, P < .001$ .

Furthermore, the results of negative binomial regression revealed that the type of social support was a significant predictor of the volume of engagement on the Sina microblog platform, Wald  $\chi^2(df = 5) = 346.813, P < .001$ . In particular, the posts relevant to instrumental support provisions ( $N_{engagement} = 534, Mean = 1.93$ ), informational support requests ( $N_{engagement} = 16,225, Mean = 12.7$ ) and instrumental support requests ( $N_{engagement} = 1014, Mean = 3.24$ ) generated 94.2 % ( $P < .001$ ), 54.3 % ( $P < .001$ ) and 87.4 % ( $P < .001$ ) less engagement than posts containing informational support provisions ( $N_{engagement} = 132,746, Mean = 38.66$ ), respectively.

## 4. Discussion

### 4.1. A wide range of lupus-related topics and social support

Consistent with the literature, the most common themes relevant to lupus that spread on the Sina microblog were disease description, followed by living with lupus and community effects [21]. Besides discussing the symptoms of the disease and exchanging personal stories, users represented their concerns about the COVID-19 vaccine during the unprecedented health emergency, in keeping with the previous empirical studies focusing on the topic modeling for COVID-19-related discussions of social media users [20,29].

On the question of social support provisions and requests, this study found that a continuous stream of lupus-related posts containing informational, emotional and instrumental support has been disseminated via Sina microblog platforms by different communicators, such as lupus patients and their referents, medical professionals, health authorities and non-governmental organizations. In general, these findings support that social networking sites have created a virtual, anonymous and interactive environment, and more importantly, provided a sense of connectedness for chronic patients that they show greater willingness to communicate health issues, seek instrumental support for unemployment and economic problems, and share thoughts with others [8,12,14]. And these results might further indicate that recent advances in the development and popularization of social media platforms also provide prolific sources of data for medical professionals to capture the voices of lupus patients, including their needs, symptoms, treatment adherence and lived experiences, thereby reducing knowledge gap, raising awareness, influencing health behaviors and promoting health outcomes [11,30].

### 4.2. More prevalent: information support

In line with the present results, prior studies have demonstrated that information support was requested and supplied more frequently than emotional and instrumental support on the Sina microblog platform [19]. Moreover, the current study revealed that the lupus-related posts containing information support provisions were more prevalent than the posts with information support requests. To a certain extent, the higher proportion of posts relevant to information support seeking is likely to be related to individuals' uncertainty and confusion caused by the infrequency of the disease and by the tense relationship between doctors and patients in China [3,31]. Certainly, these results indicated that social networking sites have served as primary health information sources for making patients or their referents more informed of the complexity of invisible diseases not only by converging all sorts of topics and leveraging multimedia technologies but also by mobilizing and integrating social resources in China [31,32].

However, it is worth noting that the increasing accessibility of widespread digital information exerts not only a positive role in

**Table 4**

Chi-square tests on types of social support (provision vs request) between engaged and non-engaged group.

	Provision	Request	Chi-square	df	p
Engaged	4163 (66 %)	2143 (34 %)	264.514	1	0.000
(Expected count)	4511.8 (-16.3)	1794.2 (16.3)			
Non-engaged	2863 (81.5 %)	653 (18.5 %)			
(Expected count)	2519.2 (16.3)	1001.8 (-16.3)			

**Table 5**  
Chi-square tests on types of social support (informational vs emotional vs instrumental) between engaged and non-engaged group.

	Information		Emotional		Instrumental		Chi-square	df	p
	Provision	Request	Provision	Request	Provision	Request			
Engaged	3434 (54.5 %)	1279 (20.3 %)	453 (7.2 %)	551 (8.7 %)	276 (4.4 %)	313 (5 %)	372.379	5	0.000
(Expected count)	3804.7 (-15.9)	1018.3 (14.9)	444.3 (0.8)	546.4 (0.3)	263.2 (1.3)	230.5 (9.3)			
Non-engaged	2492 (70.9 %)	307 (8.7 %)	237 (6.7 %)	300 (8.5 %)	134 (3.8 %)	46 (1.3 %)			
(Expected count)	2121.3 (15.9)	567.7 (-14.9)	247 (-0.8)	304.6 (-0.3)	146.8 (-1.3)	128.5 (-9.3)			

enriching the knowledge of users living with lupus and raising their awareness but also a negative one that the patient trust in medical professions and treatment adherence might be decreased [5,15,31]. Additionally, these findings must be interpreted with caution because the current study was not specifically designed to evaluate whether the thematic categories of lupus-related posts provided are consistent with the main themes of user requirements.

#### 4.3. Supply-demand imbalance: instrumental and emotional support

Noticeably, another important finding was that the instrumental and emotional support provisions were not matched by the requests. Above all, this result highlights that the primary motivation of chronic patients for accessing social networking sites is expressing their sentiments and looking for encouragement or understanding [15,33]. And the explanation for these unmet needs can be summarized by the following two points: a) high demands of lupus patients and b) low supply from the physicians and social referents. On the one hand, previous studies have established that emotion-focused coping mechanisms have been commonly required among lupus patients due to the high relapse rate and the complicated clinical presentations [3,34]. It has been conclusively shown that productivity loss, limited medical resources, and high cost of treatment also put heavy illness, psychological and economic burdens on lupus patients and their families in China [5,9]. In addition, data from several studies have identified the high prevalence of anxiety disorders among systemic lupus erythematosus patients [35]. On the other hand, the present study raises the possibility that lupus patients have dissatisfied with emotional and instrumental support from both online and offline interpersonal communication [4,17]. It seems possible that this result may be due to the severe shortage of rheumatologists and uneven distribution of medical resources in China over the years [9]. From this perspective, the combination of findings highlights the critical roles of lupus-related interventions and education delivered through various social networking sites in China in providing emotional and instrumental support, thereby improving the psychological well-being and life satisfaction of lupus patients [9,36]. In this regard, there is abundant room for further progress in determining the impact of social media use intensity on fatigue, depression, and subjective well-being of patients living with lupus.

#### 4.4. Types of social support influence users' engagement

It has been conclusively shown that productivity loss, limited medical resources, and high cost of treatment also put heavy illness, psychological and economic burdens on lupus patients and their families in China [5,9]. In addition, data from several studies have identified the high prevalence of anxiety disorders among systemic lupus erythematosus patients [35]. On the other hand, the present study raises the possibility that lupus patients are dissatisfied with emotional and instrumental support from both online and offline interpersonal communication [4,17]. It seems possible that this result may be due to the severe shortage of rheumatologists and uneven distribution of medical resources in China over the years [9]. From this perspective, the combination of findings highlights the critical roles of lupus-related interventions and education delivered through various social networking sites in China in providing emotional and instrumental support, thereby improving the psychological well-being and life satisfaction of lupus patients [9,36]. In this regard, there is abundant room for further progress in determining the impact of social media use intensity on fatigue, depression, and subjective well-being of patients living with lupus.

#### 4.5. Brief strategies

Considering these elements together, we can observe that communication features of social media platforms should be harnessed more than ever to foster desirable health attitudes and improve quality of life among individuals with similar health concerns [37].

In this regard, for instance, posting features can contribute to building a sense of agency that facilitates knowledge translation, and social interaction features, such as comments, retweets, and other reactions, can help to create a supportive atmosphere which can promote a sense of community, thereby achieving positive health outcomes, especially among patients living with lupus [16,17,38]. Consequently, firstly, health practitioners have to leverage the advantages of social media to create a favorable information environment by delivering accurate, timely, and prompt knowledge, to decrease the uncertainty of users living with lupus. Secondly, more effective peer support should be provided by integrating online and offline communication between medical professionals and patients. In other words, harnessing social media as a delivery system not only for satisfying different types of information needs but also for giving emotional and instrumental support, has obvious advantages, such as maintaining physician-patient relationships, alleviating anxiety of lupus patients, and enhancing treatment compliance. Thirdly, health practitioners in China are encouraged to track the engagement metrics, comments, and content of posts delivered by lupus patients on social media platforms which is valuable for



exploring the unmet needs of patients, mobilizing medical resources, and building patient-centered environments.

## 5. Conclusion

As previously mentioned, this study has characterized the lupus-related posts disseminated on the Sina microblog in terms of thematic categories, social support requests, and provisions, as well as engagement metrics. One of the strengths of this study is that it shows a comprehensive overview of lupus-related posts released during the whole year of 2022. Furthermore, the relevant posts were grouped into informational, emotional, and instrumental categories, expanding our understanding of the volume characteristics of social support provided and requested by users. To our knowledge, the analysis undertaken here has been one of the first attempts to focus specifically on lupus-related posts delivered through social networking sites in China, as well as examining the associations between engagement level and the varieties of social support. The present study confirms previous findings about the critical roles of social media platforms on chronic patient education and contributes additional evidence that suggests effective communication strategies must be tailored to boost more engagement on lupus posts containing emotional and instrumental support. All these findings are relevant to both lupus patients and health practitioners in China.

Several limitations to this study need to be acknowledged. Firstly, the present investigation was not designed to figure out the characteristics of lupus-related posts in communicator types and media types. Secondly, an issue that was not addressed in this study was whether engagement behaviors can contribute to positive health behaviors among lupus patients. Thirdly, these findings are limited by the fact that the current research has only considered the use of the Sina microblog platform so would tend to miss people who never use it. In terms of directions for future research, it will be important to explore the relationships between the communication behaviors of social media users living with lupus and their health outcomes, such as treatment compliance, mental health, and self-reported health status. Additionally, more research is required to determine which core lupus-related topics generated higher engagement on popular social media platforms in China.

## CRedit authorship contribution statement

**Cheng Cheng:** Writing – original draft, Visualization, Validation, Software, Methodology, Investigation, Formal analysis, Conceptualization. **Rita Espanha:** Writing – review & editing, Supervision, Methodology, Investigation, Funding acquisition.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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