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Research Paper

Stigma and its correlates among patients with Crohn's disease: A cross-sectional study in China

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ABSTRACT

Objectives: Crohn's disease is an incurable disease characterized by unpredictable intestinal symptoms, which unavoidably affect patients' lives and contribute to feelings of stigma. This study aimed to explore the status and its correlates of stigma among patients with Crohn's disease.
Methods: Using a convenience sampling, 146 hospitalized patients with Crohn's disease were recruited in a tertiary hospital in Southern China from October 2020 to March 2021. The participants were assessed by demographic and disease-related questionnaires, the Social Impact Scale (SIS), Inflammatory Bowel Disease-Self-Efficacy Scale (IBD-SES), and Social Support Rating Scale (SSRS). Multivariate linear regression analysis was conducted to explore the influencing factors of stigma among patients with Crohn's disease.
Results: The mean SIS score was 58.14 ± 10.74, representing a moderate effect of stigma, and 85.6% (125/146) of the patients experienced moderate to high levels of stigma. The multiple linear regression analysis showed that perceived public awareness of the disease, family income, age, and self-efficacy were the main influencing factors of stigma, which could explain 52% of the total variation of stigma among patients with Crohn's disease.
Conclusion: Stigma among patients with Crohn's disease is influenced by perceived public awareness of the disease, family income, age, and self-efficacy. Interventions aimed at improving self-efficacy and public awareness should be considered to alleviate the level of stigma, especially for those aged 40 years or older or low-income patients.

What is known?

- Disease-related stigma refers to an experience of inner humiliation by patients due to illness.
- Crohn's disease is considered an incurable disease, and is mostly accompanied by unpredictable intestinal symptoms, which unavoidably affect patients' mental health and contribute to feelings of stigma.
- The younger onset is one of the essential clinical manifestations of Crohn's disease.

What is new?

- Crohn's disease is a chronic disease, and the level of stigma of patients with Crohn's disease is roughly equal to that of patients with cancer.
- This research carried out an exploratory study of the relationship between stigma, self-efficacy, and social support among patients with Crohn's disease.

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- Self-efficacy is negatively related to stigma among patients with Crohn's disease.
- Age is one of the main correlates of stigma, with the stigma level among patients aged 40 years or over higher than that of patients aged 18–39.

1. Introduction

Crohn's disease, along with ulcerative colitis, is a type of inflammatory bowel disease (IBD) characterized by low mortality but incurability. It is estimated that the annual global incidence rate may reach 29.3 per 100,000 people [1]. The incidence rate shows a continuous upward trend in Eastern Europe and Asia, and the highest annual incidence has been observed in urbanized areas in China, such as Guangzhou, Hong Kong, and Macau [1]. In China, there is a lack of large-scale epidemiological studies on Crohn's disease, which was a rare disease just 20 years ago [2]; however, recent studies showed the rapid growth of the disease. The total number of IBD patients in China is expected to be 1.5 million in China by 2025, and the incidence of Crohn's disease is increasing at an even faster pace than that of ulcerative colitis [3].

The clinical manifestations of Crohn's disease include abdominal pain, diarrhea, intestinal obstruction and, less commonly, anal fistula, abscess, anal fissure, and other perianal lesions. The condition is recurrent and prolonged, and the main treatment is to relieve symptoms and promote mucosal healing [4]. The median age of onset is 31–34 years old, and the incidence rate reaches a peak between 20 and 30 years old [2]. The younger onset age, unpredictability and incurability of the disease, and perplexity of intestinal symptoms to life, such as frequent bowel movements, anxiety about incontinence in public places, urgency of defecation, and hyperactivity of bowel sounds, could unavoidably affect patients' lives and contribute to feelings of stigma [5,6].

Stigma refers to an attribute that is profoundly disgraceful and could be defined as a "mark" of social humiliation arising from social relations, thereby causing those who bear it to feel the loss of full social acceptance. Disease-related stigma refers to an experience of inner shame by patients due to illness, and they perceive to be labeled, discriminated against, belittled, alienated, avoided, and not understood and accepted due to their condition [7]. Although defecation and exhaust are natural physiological activities of daily life, they are regarded as "dirty" to some extent in China. An adult who is incapable of controlling their bowel movements properly may feel embarrassed and challenged in public. Unlike gastrointestinal cancer or chronic gastritis, Crohn's disease is an unfamiliar and uncommon chronic disease for people, and it is hard for patients to explain to others their "strange" disease and "embarrassing" symptoms, even their closest family members [8]. This pressure may have a significant negative impact on a patient's social life and working performance, ultimately leading to stigma. Barnes [9] also reminded scholars to pay attention to the mental health matters of Crohn's disease.

There are several variables correlated with the formation of stigma. Self-efficacy among patients with Crohn's disease could affect their persistent self-management skills and their quality of life [10]. Previous studies have reported that self-efficacy negatively predicted stigma for breast cancer survivors and lung cancer patients [11,12]. Social support has a positive effect on the clinical process [13] and is related to the well-being of patients [14]. Social support is negatively correlated with stigma among patients with other diseases, such as HIV and breast cancer [11,15]. The relationship between self-efficacy, social support, and stigma has been demonstrated in patients with Crohn's disease.

Some studies have suggested that the stigma experienced by patients has a relationship with their socio-demographic characteristics. A previous study reported that the risk of psychosocial adaptation problems faced by young patients with Crohn's disease increased [16]. The degree of stigma was related to the course of the disease and the frequency of disease attacks. The longer period of the disease may have a more significant impact on a patient's social function, ultimately leading to discriminated feelings [17]. Patients with a higher frequency of disease attacks reported higher levels of perceived stigma [18].

The feeling of stigma among patients with Crohn's disease is rarely reported, especially in the Chinese cultural context. Because of the similarity in disease characteristics, most studies often combined Crohn's disease and ulcerative colitis as IBD; however, Crohn's disease has its unique disease characteristics, and patients with Crohn's disease are more likely to be affected by mental disorders than those with ulcerative colitis [19]. A recent study in China described the correlation between stigma and self-esteem among patients with Crohn's disease [20]. Our research carried out an exploratory study of the relationship between stigma, self-efficacy, and social support, which differs from the existing research. This study may help medical professionals to realize the stigma among patients with Crohn's disease and develop individualized interventions to alleviate the stigma of patients.

2. Methods

2.1. Study design

It was a descriptive, cross-sectional study, and aimed to explore the status and its correlates of stigma among Chinese patients with Crohn's disease.

2.2. Samples

The study was conducted from October 2020 to March 2021 at a tertiary hospital in Southern China. Participants were eligible for this study if they were 18 years of age or older, diagnosed with Crohn's disease according to the IBD diagnostic criteria formulated by the IBD group of the Digestive Disease Branch of the Chinese Medical Association in 2018 and confirmed by colonoscopy, and agreed to participate in the study. Participants were excluded from this study if they had a stoma, other intestinal diseases, mental illnesses, AIDS, physical disabilities, or a malignant tumor. Using a convenience sampling, we contacted 156 patients with Crohn's disease, and ten patients with invalid questionnaires were withdrawn from the study, including six incomplete and four carelessly filled questionnaires. Finally, 146 (93.59%) patients completed the survey. There were no statistically significant differences in the distributions of age and gender between the respondents and no respondents.

2.3. Data collection

Given the sensitivity of stigma, we took measures to ensure the authenticity and integrity of the data. Before the survey, we explained the purpose and process of the study to the eligible participants and obtained their written informed consent. To ensure the anonymity and confidentiality of the survey, we presented all data research numbers without discoursing personal information. Then, the participants completed the questionnaire independently in a quiet room with standard explanations if necessary.

2.4. Measures

A multi-part survey comprising a self-designed demographic and disease-related questionnaire, the Social Impact Scale (SIS), Inflammatory Bowel Disease-Self-Efficacy Scale (IBD-SES), and Social Support Rating Scale (SSRS) were used to measure the demographic and disease-related information, stigma, self-efficacy, and social support among the patients with Crohn's disease.

2.4.1. Demographic and disease-related questionnaire

Demographic data (e.g., age, gender, educational level, marital status, employment status, place of residence, and family income) and disease-related information (e.g., course of the disease, perceived public awareness of the disease) were collected using the self-designed demographic and disease-related questionnaire.

2.4.2. Social Impact Scale (SIS)

The SIS was developed [21] in 2000 and was translated into Chinese [22] in 2007. It is widely used to examine stigma among patients with HIV/AIDS, cancer, stoma, and chronic diseases. This scale consists of 4 dimensions and contains 24 items, including social rejection (9 items), financial insecurity (3 items), internalized shame (5 items), and social isolation (7 items). The items scored from 1 (strongly agree) to 4 (strongly disagree), and scored reversely. Average item scores are classified into three levels: low (1.00–1.99), moderate (2.00–2.99), or high (3.00–4.00) stigma. The higher the score, the stronger the sense of stigma. The Cronbach's α coefficient of this scale was 0.927 in our study.

2.4.3. Inflammatory Bowel Disease-Self-Efficacy Scale (IBD-SES)

The IBD-SES was developed to measure the self-efficacy of IBD patients [10] and was translated into Chinese [23] in 2014. The Chinese version of the scale contains 29 items. It consists of 4 dimensions, including managing stress and emotions (9 items), managing medical care (8 items), managing symptoms and disease (7 items), and maintaining remission (5 items). The scale is scored from 1 (strongly unconfident) to 10 (very confident), with a possible score of 29–290. The higher the total score, the stronger the sense of self-efficacy. The Cronbach's α coefficient of this scale was 0.962 in our study.

2.4.4. Social Support Rating Scale (SSRS)

The SSRS was designed [24] in 1986 and widely used in China. It consists of 10 items, including three dimensions of subjective support, objective support, and utilization of support. The scale is graded from 1 to 4. The higher the score, the higher the level of social support. Total scores were classified into three classes: low ($\leq$22), moderate (23–44), or high ($\geq$45) social support. The Cronbach's α coefficient of this scale was 0.748 in our study.

2.5. Data analyses

All analyses were conducted using SPSS version 25.0. Demographic data and disease-related information were summarized as mean and standard deviation (*SD*), ranges for continuous variables, and frequency counts (percentages) for categorical variables. Independent samples One-way ANOVA/*t*-tests was used to describe differences in the mean stigma scores for different categorical demographic and disease-related data. Pearson's correlation analyses were used to investigate the correlations between stigma and self-efficacy and social support. Statistically significant variables in the univariate analysis were included in the multivariate analysis. We explored the main influencing factors of stigma among patients with Crohn's disease using multiple linear regressions (with stepwise variable selection). Differences was statistically significant when $P < 0.05$.

3. Results

3.1. Sample characteristics

Of the 146 study participants, most were males (102, 69.86%) (Table 1), and the mean age, mean age at diagnosis, and the mean course of the disease of the participants was 31.3 years ($SD = 8.6$), 27.7 years ($SD = 8.4$), and 3.6 years ($SD = 3.9$), respectively.

3.2. Difference of stigma among patients with Crohn's disease with different demographic data and disease characteristics

Univariate analysis was performed to identify the related factors of stigma. The results showed that age ($P < 0.05$), place of residence ($P < 0.05$), employment status ($P < 0.01$), family income ($P < 0.01$), and perceived public awareness of the disease ($P < 0.01$) were influencing factors of stigma (Table 1).

3.3. Stigma, self-efficacy, and social support level and their relationships among patients with Crohn's disease

The mean scores of stigma, self-efficacy, and social support were 58.14 ($SD = 10.74$), 197.54 ($SD = 43.43$), and 36.96 ($SD = 7.56$), respectively, and approximately 85.6% ($n = 125$) of participants reported moderate to high levels of stigma. The level of stigma by the average score of items from high to low was as follows: financial insecurity, internalized shame, social isolation, and social rejection (Table 2). The correlation analyses showed that both self-efficacy ($r = -0.54$, $P < 0.01$) and social support ($r = -0.21$, $P < 0.05$) were negatively associated with stigma.

3.4. The correlates of stigma among patients with Crohn's disease

Multiple linear regression was then used to identify the factors influencing stigma, and the independent variables assignment for multiple linear regression analysis was shown in Table 3.

Multiple linear regression revealed that perceived public awareness of the disease, age, family income, and self-efficacy were the main correlates of stigma among patients with Crohn's disease ($P < 0.001$). These variables explained 52% (R^2) of the total variation of stigma (Table 4).

4. Discussion

4.1. Patients with Crohn's disease have a moderate level of stigma

The mean stigma score was 58.14 ± 10.74, representing a moderate level of stigma. The mean score of stigma in our study was lower than that of patients with a stoma (69.65 ± 13.18) [25] and roughly equal to patients with lung cancer (57.18 ± 10.89) [12] and breast cancer (55.20 ± 12.15) [11]. Unlike patients with a stoma, whose stigma results from noticeable body image loss, Crohn's disease seems to be more concealed. Although patients with Crohn's disease do not face acute lethality like cancer patients, the endless suffering of Crohn's disease affects all aspects of their social life and quality of life. Crohn's disease has the nickname "green cancer" because it has some features similar to cancer as its sustained alternation of periods of flares and remissions [26]. A qualitative research synthesis also confirmed that IBD patients experienced stigma [27]. Most patients with Crohn's disease (85.6%) in our study reported moderate to high levels of stigma, and

Table 1
Summary of the associations between demographic and disease-related characteristics and stigma ($n = 146$).

Characteristics	*n* (%)	Stigma (*Mean* ± *SD*)	*t*/*F*	*P*
Gender			−0.44	0.664
Male	102 (69.9)	57.88 ± 10.74		
Female	44 (30.1)	58.73 ± 10.84		
Age (years)			−2.14	0.034
18–39	118 (80.8)	57.22 ± 10.63		
≥40	28 (19.2)	62.00 ± 10.50		
Educational level			2.77	0.066
High school and below	49 (33.6)	61.04 ± 11.48		
Junior college	40 (27.4)	56.55 ± 10.77		
Undergraduate and above	57 (39.0)	56.75 ± 9.68		
Place of residence			3.24	0.024
Provincial capital	40 (27.4)	55.53 ± 9.01		
Prefecture-level city	45 (30.8)	56.73 ± 10.23		
County-level city	26 (17.8)	58.54 ± 12.98		
Village	35 (24.0)	62.63 ± 10.38		
Payment method for medical expenses			0.44	0.643
All at state expenses or by insurance company	6 (4.1)	58.50 ± 11.13		
Partial expense	124 (84.9)	57.81 ± 10.54		
All at their own expense	16 (11.0)	60.50 ± 12.45		
Marital status			−0.57	0.568
Unmarried	66 (45.2)	57.58 ± 10.87		
Married	80 (54.8)	58.60 ± 10.67		
Employment status			4.92	0.009
Full-time	106 (72.6)	56.47 ± 9.61		
Part-time	12 (8.2)	62.17 ± 13.67		
Unemployed	28 (19.2)	62.71 ± 12.01		
Family income (CNY per person per month, equivalent to US$)			4.29	0.006
≤5,000 ($783)	83 (56.8)	60.81 ± 10.95		
5,001–8,000 ($783–1,253)	29 (19.9)	54.97 ± 10.22		
8,001–10,000 ($1,253–1,566)	14 (9.6)	55.00 ± 7.87		
≥10,001 ($1,566)	20 (13.7)	53.85 ± 9.65		
Course of the disease (years)			0.59	0.620
<1	32 (21.9)	56.03 ± 8.79		
1–5	77 (52.8)	59.00 ± 10.94		
6–10	26 (17.8)	58.46 ± 12.02		
>10	11 (7.5)	57.45 ± 11.91		
Perceived public awareness of the disease			30.75	<0.001
Not at all	28 (19.2)	68.21 ± 10.64		
A little	99 (67.8)	57.31 ± 8.46		
Very well	19 (13.0)	47.58 ± 9.48		

Table 2
Stigma scale scores among patients with Crohn's disease ($n = 146$).

Variables	Score (*Mean* ± *SD*)	Item mean score (*Mean* ± *SD*)	*n* (%)		
			Low level	Moderate level	High level
Stigma	58.14 ± 10.74	2.42 ± 0.45	21 (14.4)	110 (75.3)	15 (10.3)
Internalized shame	12.76 ± 2.55	2.55 ± 0.51	8 (5.5)	108 (74.0)	30 (20.5)
Social isolation	16.85 ± 3.84	2.41 ± 0.55	21 (14.4)	100 (68.5)	25 (17.1)
Financial insecurity	8.81 ± 1.87	2.94 ± 0.62	2 (1.4)	67 (45.9)	77 (52.7)
Social rejection	19.72 ± 4.38	2.19 ± 0.49	35 (24.0)	103 (70.5)	8 (5.5)

Table 3
Independent variables assignment for multiple linear regression analysis.

Variables	Value description
Gender	Male = 1; Female = 2
Age (years)	18–39 = 1; ≥40 = 2
Educational level	High school and below = 1; Junior College = 2; Undergraduate and above = 3
Place of residence	Provincial capital = 1; Prefecture-level city = 2; County-level city = 3; Village = 4
Payment method for medical expenses	All at state expenses or by insurance company = 1; Partial expense = 2; All at their own expense = 3
Marital status	Unmarried = 1; Married = 2
Employment status	Full-time = 1; Part-time = 2; Unemployed = 3
Family income (CNY per person per month)	≤5,000 = 1; 5,001–8,000 = 2; 8,001–10,000 = 3; ≥10,001 = 4
Course of disease (years)	< 1 = 1; 1–5 = 2; 6–10 = 3; > 10 = 4
Perceived public awareness of the disease	Not at all = 1; A little = 2; Very well = 3

Table 4
Factors influencing stigma among patients with Crohn's disease by multiple linear regression model tests ($n = 146$).

Variables	*B*	*SE*	*β*	*t*	*p*	95% CI for *B*	
Perceived public awareness of the disease	−7.86	1.17	−0.41	−6.70	< 0.001	−10.18	−5.54
Family income	−1.59	0.59	−0.16	−2.69	0.008	−2.77	−0.42
Age	5.45	1.60	0.20	3.41	0.001	2.29	8.60
Self-efficacy	−0.10	0.02	−0.39	−6.15	< 0.001	−0.13	−0.07

Notes: $F = 37.51$, $R^2 = 0.52$.

the proportion was higher than the 40% reported among IBD patients in a previous study [28]. This result suggests that the level of stigma among patients with Crohn's disease may be higher than that of ulcerative colitis. Previous studies also found that patients with Crohn's disease showed higher levels of psychological distress, such as insecurity and depression, than patients with ulcerative colitis [19].

China's unique cultural characteristics may have a bearing on the stigma of patients with Crohn's disease. Most Chinese people are influenced by Confucian culture. People with severe diseases usually rationalize that the cause of their illness or the derangement of their recovery is their sin, and they tend to have self-blame responses [29]. Furthermore, Chinese people care a lot about face ("mian zi" in Chinese), and they may strive to make themselves look respectable. Unfortunately, as an adult, it means "losing face" for patients with Crohn's disease not to be able to deal with their own exhaust and defecation problems, especially in public places.

4.2. Self-efficacy is negatively related to stigma

Self-efficacy was an important influencing factor of stigma among patients with Crohn's disease. Consistent with the findings from breast cancer survivors, lung cancer, and colostomy patients, stigma among Crohn's disease was negatively correlated with self-efficacy [11,12,25]. Self-efficacy beliefs regulate human functioning through cognitive, motivational, affective, and decision-making processes. Through various means, confidence in one's capability to exercise some measure of control in the face of stressors promotes resilience [30]. Self-efficacy was a key driving factor for patients with Crohn's disease to respond positively to self-management of the disease, and patients with higher self-efficacy were more likely to exhibit adaptive behavior [31]. Some scholars [32] suggested that there may be a specific relationship between self-efficacy and stigma in patients with Crohn's disease. Interventions increasing self-efficacy may help to alleviate the negative impact of stigma on physical health [33]. To alleviate the stigma, medical professionals should improve the patient's self-efficacy by communicating with patients and answering their questions promptly, encouraging disease information disclosure, enhancing disease acceptance, and fully mobilizing the patient's social support networks [11,12].

4.3. Other influencing factors of stigma

Perceived public awareness of the disease finally entered into the regression model of stigma. The finding that greater awareness among the general population of the nature and symptoms of Crohn's disease positively correlated to decreased stigma was consistent with previous studies [34,35]. Our study further confirmed that regaining normality in society among patients with Crohn's disease is critical to avoid loneliness and alienation [36]. However, a survey of general populations showed that public awareness of Crohn's disease was inferior, and the patients were quickly labeled as "heterogeneous" [37]. Meanwhile, to avoid negative impacts on their work performance, patients often choose to conceal their disease and maintain the working image of being "normal people" [34]. But while hiding the reality of the illness, patients put themselves in a constant state of tension, which aggravates their psychological burden and leads to stigma [38]. These results urge us to develop a nationwide awareness campaign for Crohn's disease. Through active and effective disease knowledge dissemination, the public would gradually form a correct understanding of Crohn's disease, reduce discrimination and prejudice, and provide more support to patients. Social media is the easiest and quickest way to disseminate information nowadays. However, previous findings indicated that the people who were most often involved in producing social media content knew little about Crohn's disease, which may have dangerous and adverse effects on patients [37]. It is urgent to establish an online publicity campaign championed by medical professionals to reduce misunderstandings.

Age also entered into the regression model of stigma, with the stigma level among patients aged 40 years or over higher than that of patients aged 18–39. This finding was consistent with a similar study [20] recently published in China but was opposite to the results of previous studies that age was a protective factor of stigma for patients with stoma and lung cancer [12,25]. Different from lung cancer, Crohn's disease primarily affects a relatively younger population [39]. The older they are, the greater the financial and care burden that they feel bringing to their families, and patients often experience a sense of inferiority and gradually increase their stigma [20].

Family income was also an influencing factor of stigma, as patients with lower incomes experienced higher stigma. Our finding may indicate a relationship between low stigma and a person's ability to establish and maintain well-paid employment, and low-income patients and their families may have a more intense economic and psychological pressure response to treatment. The unpredictable and long treatment process of the disease may result in a substantial economic burden for patients and their families, and produce enormous psychological challenges, including guilty, burdensome feelings, and stigma [14].

4.4. Limitations

There are three major limitations in this study that could be addressed in future research. First, this was a small-sized and single-center study, and studies with large scale and multiple centers are needed in the future. Additionally, Guangzhou is a relatively developed city in China, which may affect the stigma levels of patients. In addition, although we assured them that their information would remain confidential and anonymous, stigma is a sensitive topic, and some patients may have concealed their real feelings unconsciously or tried to adapt to social expectations or norms, which may have caused deviations in the right level of stigma felt among patients with Crohn's disease.

5. Conclusion

This study showed that the factors influencing the stigma of

patients of Crohn's disease included perceived public awareness of the disease, family income, age, and self-efficacy. Medical professionals should pay more attention to the stigma level among patients with Crohn's disease who are over 40 years old, have lower family income and self-efficacy, and perceive less public awareness of the disease. Furthermore, the research provides a reference to develop to alleviate stigma of patients with Crohn's disease by promoting science popularization to increase public awareness and knowledge about Crohn's disease, and strengthening the patients' self-efficacy of coping with it.

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Nothing to declare.

Data availability statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethical statement

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the Ethics Committee of the Sixth Affiliated Hospital of Sun Yat-sen University (NO.2021ZSLYEC-110). Informed consents were signed by patients before questionnaire collection.

CRediT authorship contribution statement

Dandan He: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing, Project administration. **Lanzhen He:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing - review & editing. **Yijuan Yuan:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - review & editing. **Lingli Huang:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Writing - review & editing. **Qi Xiao:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Writing - review & editing. **Xinmei Ye:** Conceptualization, Methodology, Validation, Formal analysis, Writing - review & editing, Supervision. **Jun-E Zhang:** Conceptualization, Methodology, Validation, Formal analysis, Writing - review & editing, Supervision, Project administration.

Declaration of competing interest

The authors declare that they have no competing interests.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijnss.2023.06.012.

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