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# Stigma and illness uncertainty among patients with visible burn scars: A cross-sectional study

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ABSTRACT

The purpose of this research was to understand the current status of stigma and illness uncertainty in patients with visible burns and explore the correlation between them. Measures to help patients alleviate shame and uncertainty in illness are also discussed. A cross-sectional study was conducted in a tertiary hospital from November 2020 to March 2021 for patients with burns on exposed parts of the face, neck, or limbs. The scales used in this study include demographic data questionnaires, the Social Impact Scale (SIS), and the Mishel Uncertainty in Illness Scale for Adults (MUIS-A). A two-tailed independent *t*-test was used to evaluate the differences in the respondents' sociodemographic characteristics, stigma, and illness uncertainty. The total stigma and illness uncertainty scores of 146 patients were 57.03 ± 6.762 and 68.59 ± 12.901, respectively. Spearman correlation analysis showed that stigma was positively correlated with illness uncertainty ($r = 0.398$, $p < 0.01$). Multiple regression analysis showed a relationship between stigma and uncertainty of illness (B = 0.215, $p = 0.000$), itching (B = 2.555, $p = 0.01$), residence (B = 2.545, $p = 0.029$), and age (B = 0.074, $p = 0.037$). The stigma level of patients with visible burns increased with increasing uncertainty regarding illness. Therefore, reducing the patients' uncertainty in illness is a way to intervene in stigma.



## 1. Introduction

Burns are one of the most severe public health problems globally, with the high morbidity and mortality [1,2]. According to a WHO report, in 2004, approximately 11 million people worldwide needed medical treatment due to burn injuries, ranking fourth among all damages and totaling even higher than the combined number of tuberculosis and AIDS infections [3]. After traffic accidents, burns were the second leading cause of accidental injury death in China [4]. Burns are a common injury in daily life, and 66.7% of burn patients in Turkey do not go to the hospital for medical treatment [5]. Even in China, only 5% of burn patients are hospitalized to treat their wounds, and most burns are treated at home or in outpatient clinics [6].

As an emergencies, burns may have a considerable impact via burn injuries [7]. Especially in severe burn patients, even after a long time, the impact of the accident cannot be eliminated. Wigs, masks, hats, sunglasses, scarves, gloves, and

*Abbreviations:* SIS, MUIS-A.

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long skirts up to the ankles are frequently used to cover up the exposed differences, but this has no good effect. Studies have shown that visible burns are more psychologically harmful than burns hidden under clothing [8]. Burns that occur on visible parts of the body may cause unusual attention from others; thus, special attention must be paid to people with such burns. Traditional Chinese culture emphasizes the theory of body and mind as a whole; physical defects may be related to moral defects, therefore, burns on exposed body parts may cause stigma and illness uncertainty [9].

Stigma refers to the process by which patients with stigma are subjected to negative evaluations and stereotypes from the outside world. They will develop a series of beliefs, feelings, or behaviors, such as shame, feelings of iniquity and worthlessness, and try to conceal these characteristics that cause shame [10–12]. Stigma impacts the physical and mental health of people who are stigmatized, which can be proven by the incidence of stress-related diseases (depression and hypertension) [13]. Most research on stigma has focused on mental illness, HIV, obesity, and cancer [14–22]. Regardless of the severity of the disease, the stigma will increase worries about the illness and destructive emotions, thus hindering the patients' recovery [23]. Many qualitative interviews have been used to explore the psychological experience, coping strategies, and social regression of patients after burns [3,24–27]. Some studies have been carried out on burns victims in China, but the number is far from sufficient.

Michel proposed the uncertainty in illness in 1988, and it originated from the concept of uncertainty in illness theory, which proposes that insufficient knowledge related to disease will cause patients to experience uncertainty [28]. Studies have shown that the patient's uncertainty in illness impacts their physical health, psychological health, and quality of life [29–31].

Previous studies have explored the relationship between stigma and uncertainty in illness; for example, the level of stigma in sickle cell patients was affected by uncertainty in illness [32]. To the best of our knowledge, no study has quantitatively explored whether uncertainty in illness affects the level of stigma in burn patients. Therefore, a cross-sectional study was carried out in a tertiary hospital in Guangzhou, China.

The primary purpose of this study was to:

(1) Understand the experience of stigma and uncertainty in illness when the visible parts of the body are burned.
(2) Verify the correlation between stigma and illness uncertainty.
(3) Examine the societal effects related to the stigma associated with burn patients' demographic factors and disease-related factors.

The concept of this research was guided by the stigma-induced identity threat model [12]. The degree of uncertainty is related to personal characteristics, and people with higher stigma facing uncertain situations are more likely to judge things as threats. In other words, uncertainty as a unique traits is one of the factors influencing stigma. As part of the collective representations, the concept of the unity of body and mind in traditional Chinese culture also participates in stigma.

According to previous research results, we assume a positive correlation between stigma and uncertainty in illness. The level of illness uncertainty, some demographic data, and disease-related data influence stigma. Our research will help burn patients in all aspects of physical, psychological, and social rehabilitation.

## 2. Methods and measures

### 2.1. Participants

A cross-sectional study was conducted in the burn department or ward of a tertiary hospital from November 2020 to March 2021. We recruited adult (≥18 years old) patients with primary school education or above treated in the burn department of a tertiary hospital in Guangzhou with burns on the exposed body parts (face, neck, or limbs). Patients with severe systemic infection or combined severe inhalation injury were excluded from this study. Simultaneously, the presence of cognitive dysfunction or previous mental illness were also ruled out.

### 2.2. Investigation

A cross-sectional study was conducted in the burn department or ward of a tertiary hospital from November 2020 to March 2021 for patients with burns on exposed parts of the face, neck, or limbs. The scales used in this study include demographic data questionnaires, the Social Impact Scale (SIS), and the Mishel Uncertainty in Illness Scale for Adults (MUIS-A). The Ethics Committee of the Third Affiliated Hospital of Sun Yat-sen University approved this study ([2021]02-036-01). In total, 170 patients in the burn clinic or ward were selected as potential subjects, and 146 (85.9%) completed the patient questionnaire data. Six patients refused to participate in this survey, and 18 questionnaires were invalid.

### 2.3. Social demographic variables and clinical variables

Social demographic variables include sex, age, education level, residence, living status, occupation, mode of payment for medical expenses, per capita monthly family income, marital status, and working status. Disease-related information included the burn type, stage, area, cause, time, and site; itching; and pain.

### 2.4. The Social Impact Scale (SIS)

The Social Impact Scale (SIS) was compiled by Fife [33] in 2000 and translated into Chinese by Pan [34] in Taiwan in 2007. It includes 24 items and four dimensions. In this study, the internal consistency of the scale was 0.805. The four dimensions were social exclusion, economic discrimination, internal shame, and social isolation. Social exclusion is used to assess the individual's feelings of being discriminated against in social and life. Economic discrimination can lead to self-discrimination, which in turn is related to poor interpersonal relationships. Inherent shame is the result of disease factors and financial insecurity, which may be the reason why individuals conceal burns. Social isolation refers to feelings

of loneliness, inferiority, and uselessness. Each item used a 4-level scoring method and reverse scoring, in which 4 represented 'strongly agree', 3 represented 'agree', 2 represented 'disagree', and 1 represented 'strongly disagree'. The sum of the scores of the four dimensions was the total score of the scale, which ranged between 24–96 points. The higher the score, the more significant the social impact, and the stronger the stigma. The Cronbach's alpha value of this scale was 0.805. In particular, the application of the scale in the Chinese burn patient population has been verified in Wen Yu's research [35].

### 2.5. *The Mishel Uncertainty in Illness Scale for Adults (MUIS-A)*

The Mishel Uncertainty in Illness Scale for Adults (MUIS-A) is a self-assessment scale developed by Mishel [36] and translated into Chinese by Professor Shulian Xu [37] from Taiwan. The internal consistency of the scale in this study was 0.835. The scale includes 25 items and two dimensions (uncertainty and complexity). Each item used the Likert 5-level scoring method, with 1, 2, 3, 4, and 5 points indicating 'strongly disagree', 'disagree', 'uncertain', 'agree', and 'strongly agree', respectively, for a total score ranging from 25 to 125 points. A higher score indicates a higher level of uncertainty in the individual's illness. This scale has been widely used in the medical field among the Chinese population. Cronbach's alpha for the scale was 0.835.

### 2.6. *Sample size*

The method of calculating the sample size based on the total number of proportional sizes was applied [38].We needed to expand the maximum number of dimensions by more than ten times to provide a sufficient sample size. The empirical formula was sample size = [Max (dimension degree) × (10–20)] × [1 + (10%–15%)]. In this study, SIS had the largest number of dimensions (four dimensions); thus, the dimensions of this scale were used as the sample size for benchmark measurements. Taking into account the need to eliminate invalid questionnaires, this study finally set the required minimum sample size as 92 (4 × 20 × 1.15 = 92) patients.

### 2.7. *Quality control*

Before the study began, relevant training of researchers was carried out. For patients who could not read the paper questionnaire, the researchers relayed the scale contents one by one, and the patients gave corresponding answers without intervention. All participants signed the informed consent statement.

The data from each questionnaire were transcribed into a computer program. Invalid questionnaires (questions with less than 70% of the total number of entries answered) were deleted, and two independent researchers entered the data. At the end of data entry, a 10% random check of data consistency was conducted, and the consistency of this study was 100%.

### 2.8. *Statistical data analysis*

The data were entered in an Excel spreadsheet in a timely manner and analyzed in SPSS version 25. According to the data type, the general demographic data and disease-related data of the surveyed persons were described in different ways. Continuous variables were described as the mean ± standard deviation. Numbers and percentages were used to describe categorical variables. An independent *t*-test or one-way analysis of variance was used to compare continuous variables. Spearman correlation analysis was used to study the correlation between stigma and disease uncertainty. Multiple linear regression was used to explore the main factors that affect the stigma of visual burn patients. Statistical inferences were performed using a two-sided test, and $p < 0.05$ indicated that the results were statistically significant.

## 3. Results

### 3.1. *Demographic*

Table 1 is a report of sociodemographic data. A total of 146 patients completed the survey, of which 60.3% were male, and 39.7% were female. The mean age of the patients was 36.50 ± 13.88 years, and most patients were 21–30 years old (31.5%). Most patients were married (61.6%), lived with others (82.2%), lived in provincial capital cities (76.0%), used medical insurance to pay bills (63.0%), and were working (58.9%).

A total of 83.6% of patients' had burn areas that covered less than 30% of the total body surface area, and most patients had itching (56.2%) and pain (69.2%). Burns that occurred in the family were the primary cause (63.7%). A total of 67.1% of patients had single-site burns (mostly burns on limbs). The majority (80.8%) of the respondents stated that the accident had occurred within one month prior. Among the respondents, residence, household per capita monthly income, occupation, burned area, itching, and burn location were the influencing factors of stigma ($p < 0.05$).

### 3.2. *Stigma and illness uncertainty*

The overall stigma score was 57.03 ± 6.762, including 2.7% have a mild stigma, 66.4% with moderate stigma, and 30.8% with severe stigma (Table 2).

As shown in Table 3, the average scores of the SIS subdimensions were as follow. The social rejection dimension (mean score = 21.72) had the highest score, followed by social isolation (mean score = 15.77), internalized shame (mean score = 11.91), and financial insecurity (mean score = 7.57). The MUIS-A total mean score was 68.59 ± 12.901, ambiguity (mean score = 40.33), and complexity (mean score = 28.26).

In Table 4, regarding the correlation between stigma and uncertainty in illness, a significant positive correlation was present ($r = 0.398$).

### 3.3. *Multivariate analysis*

With the variables in the univariate analysis and correlation analysis as independent variables, and stigma as the dependent variable, a multiple linear regression model was established (Table 5). A stepwise logic multivariate

**Table 1 – Univariate analysis of demographic and clinical variables (N = 146).**

| Variable | Item | Number(%) | *p* |
|---|---|---|---|
| Sex | Male | 88(60.3%) | 0.212 |
| | Female | 58(39.7%) | |
| Age (years) | 18–20 | 16(11.0%) | 0.321 |
| | 21–30 | 46(31.5%) | |
| | 31–40 | 33(22.6%) | |
| | 41–50 | 22(15.1%) | |
| | 51–60 | 20(13.7%) | |
| | 61–70 | 9(6.2%) | |
| Residence | Capital city | 111(76.0%) | 0.002 |
| | Noncapital city | 35(24.0%) | |
| Payment method for medical expenses | At their own expense | 54(37.0%) | 0.314 |
| | Medical insurance | 92(63.0%) | |
| Educational level | Junior high school and below | 52(35.6%) | 0.092 |
| | High school/technical secondary school | 46(31.5%) | |
| | College degree and above | 48(32.9%) | |
| Per capita monthly income (yuan) | ≤2000 | 11(7.5%) | 0.017 |
| | 2001–4000 | 40(27.4%) | |
| | 4001–6000 | 47(32.2%) | |
| | 6001–8000 | 13(8.9%) | |
| | 8001–10,000 | 3(2.1%) | |
| | >10,000 | 32(21.9%) | |
| Marital status | Unmarried | 56(38.4%) | 0.804 |
| | Married | 90(61.6%) | |
| Living condition | Live alone | 26(17.8%) | 0.952 |
| | Live with others | 120(82.2%) | |
| Occupation | Workers | 44(30.1%) | 0.015 |
| | Farmers | 11(7.5%) | |
| | Administrative officer | 6(4.1%) | |
| | Technology/medical/teacher | 5(3.4%) | |
| | Individuals businessmen/enterprises/government | 42(28.8%) | |
| | Other | 38(26.0%) | |
| Working status | On-the-job | 86(58.9%) | 0.224 |
| | Retirement | 14(9.6%) | |
| | Unemployed | 46(31.5%) | |
| Cause of burn | Thermal burns | 133(91.1%) | 0.405 |
| | Nonthermal burn | 13(8.9%) | |
| Burn staging | Mild burns | 78(53.4%) | 0.136 |
| | Moderate burn | 44(30.1%) | |
| | Severe burns | 20(13.7%) | |
| | Very severe burns | 4(2.7%) | |
| Percentage of body burned | <30% | 122(83.6%) | 0.042 |
| | 30–50% | 18(12.3%) | |
| | >50% | 6(4.1%) | |
| Itching | No | 64(43.8%) | 0.014 |
| | Yes | 82(56.2%) | |
| Pain | No | 45(30.8%) | 0.842 |
| | Yes | 101(69.2%) | |
| Causes of burns | Work-related injure | 40(27.4%) | 0.786 |
| | Family accident | 93(63.7%) | |
| | Other | 13(8.9%) | |
| Number of days of burns | 1–3 days | 22(15.1%) | 0.073 |
| | 4–7 days | 51(34.9%) | |
| | 8–28 days | 45(30.8%) | |
| | >28 days | 28(19.2%) | |
| Burn location | Single-site burn | 98(67.1%) | 0.011 |
| | Multiple burns | 48(32.9%) | |

analysis method was used. The results showed that the MUIS-A total score (B = 0.215, $p = 0.00$), itching (B = 2.555, $p = 0.01$), residence (B = 2.545, $p = 0.029$), and age (B = 0.074, $p = 0.037$) were the main factors affecting the stigma of visible burn patients. Moreover, the 26.5% of the variability could be explained.

## 4. Discussion

We conducted a cross-sectional study of 146 patients with burns on exposed sites and found that their stigma was at a moderate level. Multiple regression analysis showed a high

**Table 2 – Level of stigma among burn patients (N = 146).**

| Level of stigma | | Frequency | Percent(%) |
|---|---|---|---|
| Mild stigma | (20–39) | 4 | 2.7 |
| Moderate stigma | (40–59) | 97 | 66.4 |
| Severe stigma | (60–80) | 45 | 30.8 |

**Table 3 – Outcome scales and subscales (N = 146).**

| Variables | Mean | Standard deviation |
|---|---|---|
| Stigma | 57.03 | 6.762 |
| Social rejection | 21.72 | 3.003 |
| Financial insecurity | 7.57 | 1.107 |
| Internalized shame | 11.91 | 1.73 |
| Social isolation | 15.77 | 2.384 |
| MUIS-A | 68.59 | 12.901 |
| Ambiguity | 40.33 | 8.508 |
| Complexity | 28.26 | 5.166 |

correlation between uncertainty in illness, itching, residence, age, and stigma. The staff of medical institutions can use the results of this study to promote the recovery of burn patients.

Disagreement regarding whether the stigma level of burn patients is different from that of ordinary people is present. A Brazilian study showed that the stigma level of burn survivors is no different from that of the general population [39]. This was not the same as the conclusion of Yanfei Li's research in China. Vast differences in social and cultural backgrounds and cognitive behaviors may be the reason for the varying results. In the identity threat model, the cultural background as part of the collective representation affects everyone's awareness and evaluation of stigma-related sobriety. The scars leftover from burns in Chinese cultural stereotypes indicate poor conduct and moral corruption [3]. Therefore, burns at exposed body put patients under tremendous pressure, including social-moral pressure, which may be a reliable explanation for the higher severity of stigma compared to Brazil. This reminds us that the impact of cultural differences needs to be considered when providing health guidance to patients with burns on exposed parts of the body.

The first goal of this study was to understand the status quo of stigma and disease uncertainty in people with burns on exposed sites. The stigma score in this survey was 26–74, with an average of 57.03 ± 6.762, indicating that the-population experienced a moderate level of stigma. This

**Table 5 – Variables that are independently associated with stigma in the regression analysis (N = 146).**

| | B | Std. Error | Beta | t | p |
|---|---|---|---|---|---|
| MUSI-A | 0.215 | 0.038 | 0.41 | 5.621 | 0.00* |
| Itching | 2.555 | 0.975 | 0.188 | 2.62 | 0.01* |
| Residence | 2.545 | 1.155 | 0.161 | 2.203 | 0.029* |
| Age | 0.074 | 0.035 | 0.151 | 2.104 | 0.037* |

*Bold numbers are statistically significant ($p < 0.05$).

was consistent with Yanfei Li's results, in which the stigma score (57.18 ± 8.08) of burn patients in Qingdao, China, was higher than those of lung cancer and urinary incontinence patients [40]. Among the four dimensions of SIS, social exclusion and social isolation were most often reported, compared to internal shame and economic insecurity. This may be related to the high proportion of male patients in this study, of whom nearly one-third indicated that they were unemployed. Men are the primary source of family finances in China, and patients hospitalized for illness or working with bandages may receive strange looks that increase their psychological burden. This was somewhat different from Wen Yu's study, which focused on female patients, who scored the highest in the intrinsic shame dimension [35]. Women pay more attention to appearance than men, and an abnormal appearance is usually associated with shame [41]. The uncertainty in the illness of burn patients was moderate, and the ambiguity dimension score was higher than the complexity. This suggests confusion about the patients' symptoms of the disease, complications, treatment programs, and rehabilitation training. More communication is expected between patients, patients, medical staff, patients, and the community [42]. Strengthening communication with burn patients, whether male or female, with burns on exposed parts of the body would be a meaningful measure to reduce the level of stigma and disease uncertainty.

The second objective of the study was to examine the relationship between stigma and uncertainty in illness. All dimensions of the SIS and MUIS-A were statistically correlated in this study. The results of this study show a positive correlation between stigma and uncertainty in illness. Furthermore, regression analysis further proved that uncertainty in illness was an independent predictor of stigma. The conclusion of this study is consistent with that of Alphanso Blake's team [32]. Itching is not uncommon in patients after burns. As itching is another independent predictor of stigma, more attention should be given to this symptom in the future.

**Table 4 – Correlation between stigma and illness uncertainty (N = 146).**

| | Social rejection | Financial insecurity | Internalized shame | Social isolation | Stigma |
|---|---|---|---|---|---|
| Ambiguity | .316[b] | .453[b] | .216[b] | .470[b] | .416[b] |
| Complexity | .253[b] | .341[b] | .176[a] | .350[b] | .304[b] |
| MUIS-A | .318[b] | .438[b] | .207[a] | .452[b] | .398[b] |

[a] Correlation is significant at the 0.05 level (2-tailed).
[b] Correlation is significant at the 0.01 level (2-tailed).

In the conceptual model of adult chronic itching, stigma is mentioned as an essential concept [43]. The degree of itching is correlated with the level of stigma, which is consistent with Hrehorow's research [44]. Age had a mitigating effect on stigma in many studies [45]. However, in this study, age had a positive effect on the prediction of stigma, which may have been affected by the characteristics of the survey population (most of the respondents were middle-aged). The impact of the living environment on stigma should also be considered. People in rural settings were more likely to report more adverse speech and discrimination experiences [46]. In general, uncertainty in illness, as a factor in which medical staff can more easily intervene, should receive more effort than to improving the prejudice of the population in the place of residence. For patients with itching and elderly patients, we should also pay attention to their particular needs and take acceptable measures to meet them.

The third objective of the study was to identify the factors associated with stigma. Social demographic variables (residence, monthly household income per capita, and housing status) were significantly related to stigma. Regarding the approved clinical data, burn area, itching, and the burn site were significantly associated with stigma. This study also found that, different from the study of Wen Yu (focusing on female patients with deep burns) and Yang Ping (studying facial burn patients), the age, sex, education level, marital status, payment method of medical expenses, burn location, burn time, and pain were not associated with the level of stigma [35,47]. Male sex was identified as a protective factor in another study [41]. Therefore, whether sex affects the stigma of burn patients still needs more research. The time after burn does not affect the patient's stigma level, which suggests that we need to implement social and psychological activities to interfere with the profound impact of burns on the population [48]. The characteristics of the population under investigation may be one of the main reasons for the observed difference. In general, more attention needs to be given to burn patients who live alone in noneconomically developed areas and have low per capita household incomes.

It is worth mentioning that burn scars are not uncommon as sequelae [49]. Scars after burns may be stigmatized by the general public in places other than China. Burned women in India are even considered impure in religious or moral meaning [50]. In ancient China, ink punishment was used to tattoo the face of criminals to humiliate and punish them [51]. Therefore, abnormalities of visible body parts will bring great mental pressure to individuals. The mental health of such people should be given special care. Implementing a continuous care plan after burns may be an excellent way to promote health and may even have a positive impact on quality of life [52]. In addition, medical staff should promote the public's awareness and attention to scars and alleviate the shame of patients and the public.

## 5. Conclusions

Our research indicated that patients with burns on exposed sites had a moderate degree of stigma, and were found a positive correlation between the level of stigma and uncertainty in illness. Multiple regression analysis showed that uncertainty in illness, itching, place of residence, and age were significant factors that affected patients' level of stigma.

## 6. Strengths and limitations

To the best of our knowledge, this is the first study to evaluate the correlation between stigma and uncertainty in illness in the Chinese cultural context. The findings of this study have some implications. First, the stigma level of patients with burn on exposed body parts is relatively high, as influenced by the residence, education level, occupation, burn area, itching, and burn location. Second, the patients showed a certain degree of illness uncertainty, and illness uncertainty, itching, place of residence, and age are important factors for predicting stigma. Finally, this study suggests that medical staff can start with changing the uncertainty in the disease to intervene in the stigma. Further research is needed to determine which intervention method has a better effect on improving stigma.

Due to some limitations, the results of this study should be interpreted with caution.

(1) Participants in this study were recruited through convenience sampling at the burn clinic of a general hospital in a capital city in southern China.
(2) Most of the patients selected in this study were selected within one week of the burn, so the long-term stigma level of the burned population is still unknown.
(3) The sample size of this study is limited, and more research is needed.

## Author contributions

Xiaoxue Wu contributed to the manuscript writing, survey design, data collection and analysis and interpretation, and article writing; participated in the manuscript writing, and finally approved the upcoming version.

Yueyun Hu participated in the critical revision of the manuscript and finally approved the version to be published.

Ailing Hu participated in the critical revision of the manuscript and finally approved the version to be published.

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## Conflict of interest statement

The authors declare no known conflict of interest associated with this publication and no significant financial support for this work that could have influenced its outcome.

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