

# Effects of Alexithymia to Stigma of Patients with Lymphedema

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## Abstract

**BACKGROUND:** Secondary lymphedema is one of the common complications after malignant tumor surgery. It is a chronic and complex disease. Once lymphedema occurs, there will be discomfort such as limb swelling, pain, numbness and tension, which will eventually lead to changes in the appearance of the affected limb and will seriously affect the quality of life and require lifelong treatment and psychosocial support. This study investigated the current situation of stigma and alexithymia in patients with lymphedema, and discussed the impact of alexithymia on stigma in patients with lymphedema. **AIMS:** To understand the current situation of stigma and alexithymia in patients with lymphedema, and to analyze the influence of alexithymia on stigma. **METHODS:** 195 patients with lymphedema in a hospital were selected by convenient sampling. General information questionnaire, Toronto Alexithymia Scale and social impact scale were used to investigate respectively, to study the general situation, stigma and alexithymia of the respondents. **RESULTS:** The results showed that the total score of stigma in 195 patients with lymphedema was  $(60.36 \pm 11.08)$ , and the total score of alexithymia was  $(56.53 \pm 8.43)$ . Multiple linear regression analysis showed that alexithymia and family relationship were the influencing factors of stigma in patients with lymphedema. **CONCLUSIONS:** The patients with lymphedema have obvious stigma, and alexithymia and family relationship are the influencing factors.

## Keywords

Alexithymia, Lymphedema, Stigma, Influence Factor

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## 1. Introduction

Lymphedema is one of the common complications after malignant tumor surgery. It is a chronic and complex disease [1]. It affects about 20 million people around the world and brings serious psychological discomfort, quality of life and economic burden to patients [2]. The incidence of secondary lymphedema varies from study to study [3]. According to the relevant literature, the incidence of secondary lymphedema in gynecologic malignancies is 21.8%, and the incidence rate increases with the observation period: 1 years 12.9%, 5 years 20.3%, 10 years 25.4% [4]. The incidence of lymphedema in the breast cancer survivors was 10 during the past 10 years. Once lymphedema occurs, there will be discomfort such as limb swelling, pain, numbness and tension, which will eventually lead to changes in the appearance of the affected limb, and will seriously affect the quality of life and require lifelong treatment and psychosocial support [5]. Due to the long course of lymphedema, patients with lymphedema will cause psychological distress and normal movement, and then be isolated by the society [6] [7] [8] and lose intimate relationship with their partners [6], which affects the social activities and family relations of patients, reduces the quality of life of patients [9], and even fear of being found or discriminated, and fear of being excluded and marginalized by the society. There is a strong sense of stigma. Stigma refers to a negative inner stigma feeling that is labeled, alienated, avoided, belittled, discriminated and not accepted due to illness, which affects physical and mental health and disease recovery [10]. Alexithymia is an affective disorder, which is the internal factor causing individual physical and mental diseases. It makes the ability to recognize and distinguish emotions, feel low, and lack the ability to reveal external attitudes, feelings, wishes and ideas; inability to describe spiritual experiences and difficulties in properly expressing emotions. [11]. This study investigated the current situation of stigma and alexithymia in patients with lymphedema, and discussed the impact of alexithymia on stigma in patients with lymphedema, so as to provide basis for nursing intervention measures of stigma. The report is as follows.

## 2. General Information and Methods

### 2.1. General Information

Using convenient sampling method, 195 patients with lymphedema treated in a hospital in Guangzhou from June 2021 to December 2022 were selected for questionnaire survey. Inclusion criteria: ① according to the differentiation and diagnosis of lymphedema [12], all patients were patients with lymphedema and underwent comprehensive detection and treatment; ② Age  $\geq 18$  years old; ③ Normal cognitive and communication skills, able to cooperate with the investigation; ④ The patients had informed consent and were willing to participate in this study. Exclusion criteria: ① combined with other system tumors or severe liver and kidney dysfunction; ② Tumor recurrence and distant metastasis; ③ Accompanied by ascites, limb edema, serous cavity effusion, etc.; ④ People with

mental illness or personality disorder.

## 2.2. Method

### 2.2.1. Investigation Tools

General information questionnaire, literature review, the research team designed the questionnaire by itself. The content includes sociodemographic and disease-related data.

Toronto Alexithymia Scale, revised by Bagby and Taylor based on the defects of TAS-26, has higher reliability and validity [13]. It consists of 3 dimensions and 20 entries. Lack of ability to recognize emotion (1, 3, 6, 7, 9, 13, 14); Lack of ability to describe emotions (2, 4, 11, 12, 17); Extraversion thinking (5, 8, 10, 15, 16, 18, 19, 20). The items of the scale adopt the link scoring method, in which 5 items such as 4, 5, 10, 18 and 19 are scored in reverse. The higher the total score, the heavier the degree of alexithymia. According to Bagby, if the score is  $\geq 61$ , it means there is alexithymia, if the score is  $\leq 51$ , it means there is no alexithymia, and if the score is between 51 and 61, it means there is alexithymia tendency. In this study, the total coefficient of cronbach's  $\alpha$  is 0.816.

Social impact scale, it is a [14] developed by Fife and Wright. It is used to evaluate the level of stigma in cancer and AIDS patients. The table includes 24 items, which are divided into 4 dimensions, including social exclusion (2, 5, 6, 7, 11, 17, 19, 20), economic discrimination (8, 9, 10, 15, 18, 22, 24), internal stigma (12, 13, 14), and social isolation (1, 3, 4, 16, 21, 23). Pan *et al.* [15] translated into Chinese (Taiwan region) version. The score adopts a 1 - 4 point system, which is reverse scoring. 4 points mean "extremely agree", 3 points mean "agree", 2 points mean "disagree", and 1 point means "extremely disagree". The total score of the scale is 96 points, which is obtained by adding the scores of the four dimensions. The higher the score, the heavier the degree of stigma of the patient. Cronbach's  $\alpha$  coefficient is 0.85 - 0.90. In this study, the total coefficient of cronbach's  $\alpha$  is 0.945.

### 2.2.2. Data Collection Method

This study was approved by the hospital ethics committee (approval No.: gyx2020-002). Questionnaire survey method was adopted, which was jointly completed by the lymphedema treatment team. Adopt unified guidelines, first do a good job in communication and communication with patients with lymphedema, actively communicate and obtain consent, support and cooperation. For those who meet the inclusion criteria, a unified questionnaire will be issued after obtaining the informed consent of the patients. Explain the purpose, significance, precautions and confidentiality principle of this study to them; Answer their questions and eliminate their concerns. On site distribution and on-site recycling; check and make up deficiencies in time to ensure its authenticity. The last two people input and review the data to ensure the accuracy of the data.

### 2.2.3. Statistical Methods

This study uses spss25 0 statistical software for statistical analysis of the entered data. The frequency and composition were compared to describe the general data

of patients. The scores of relevant variables were expressed by mean and standard deviation, and T/F test was used for comparison between groups. According to the difference of patients' general data, single factor ANOVA test was carried out. In order to further clarify and predict the influencing factors of relevant variables of the research object, multiple linear regression analysis was carried out. Pearson correlation analysis was used to explore the correlation between alexithymia and stigma in patients with lymphedema.  $P < 0.05$  means statistically significant.

### 3. Results

#### 3.1. Questionnaire Distribution and Recovery

In this study, 200 questionnaires were distributed and 195 valid questionnaires were recovered, with an effective recovery rate of 97.5%.

#### 3.2. Stigma Score of Patients with Lymphedema

The total score of stigma was ( $60.36 \pm 11.08$ ). The results showed that the score of social exclusion was the highest ( $21.07 \pm 3.80$ ), followed by economic discrimination ( $15.65 \pm 3.94$ ), social isolation ( $15.56 \pm 3.05$ ), and internal stigma ( $8.09 \pm 1.86$ ). See **Table 1**.

#### 3.3. Stigma Analysis of Patients with Lymphedema with Different Demographic Characteristics

According to the difference of patients' general data, single factor ANOVA test was carried out. The results showed that family monthly income, personality and family relationship had an impact on the level of stigma in patients with lymphedema. The difference was statistically significant ( $P < 0.05$ ). Among them, the family with low monthly income has a high score of stigma, and the introverted personality and family relationship are poor or the general score of stigma is high. See **Table 2**.

**Table 1.** Stigma score ( $n = 195$ ,  $\bar{X} \pm S$ ).

| Variable                | Ntries No. | Score range | $\bar{X} \pm S$   |
|-------------------------|------------|-------------|-------------------|
| Total score of stigma   | 24         | 32 - 96     | $60.36 \pm 11.08$ |
| Social exclusion        | 9          | 11 - 32     | $21.07 \pm 3.80$  |
| Economic discrimination | 3          | 7 - 28      | $15.65 \pm 3.94$  |
| Internal stigma         | 5          | 3 - 12      | $8.09 \pm 1.86$   |
| Social isolation        | 7          | 8 - 24      | $15.56 \pm 3.05$  |

**Table 2.** Univariate analysis of stigma in patients with lymphedema ( $n = 195$ ,  $\bar{X} \pm S$ ).

| Variable    | Group   | $\bar{X} \pm S$   | t/F  | P    | LSD | Variable                       | Group       | $\bar{X} \pm S$   | t/F  | P    | LSD   |
|-------------|---------|-------------------|------|------|-----|--------------------------------|-------------|-------------------|------|------|-------|
| Age (years) | ≤40     | $60.96 \pm 13.44$ | 0.17 | 0.95 |     | Live place                     | City        | $59.46 \pm 11.16$ | 1.81 | 0.17 |       |
|             | 41 - 50 | $60.33 \pm 10.62$ |      |      |     |                                | Town        | $61.85 \pm 11.26$ |      |      |       |
|             | 51-60   | $60.98 \pm 11.98$ |      |      |     |                                | Countryside | $63.70 \pm 9.80$  |      |      |       |
|             | 61 - 70 | $59.23 \pm 9.53$  |      |      |     | Monthly household income (RMB) | ① < 1000    | $62.74 \pm 12.89$ | 4.17 | 0.01 | ③ > ④ |

## Continued

|                     |                       |               |      |      |                    |                    |               |               |       |       |
|---------------------|-----------------------|---------------|------|------|--------------------|--------------------|---------------|---------------|-------|-------|
| Gender              | >70                   | 58.71 ± 7.76  |      |      | ② 1000 - 2999      | 64.96 ± 12.30      |               |               | ① > ④ |       |
|                     | Male                  | 62.33 ± 1.53  | 0.1  | 0.76 | ③ 3000 - 4999      | 62.63 ± 10.43      |               |               | ① > ③ |       |
|                     | Female                | 60.33 ± 11.16 |      |      | ④ ≥ 5000           | 57.98 ± 10.21      |               |               |       |       |
| Education           | Primary and below     | 59.78 ± 11.75 | 1.4  | 0.25 | Time of lymphedema | <3 months          | 56.35 ± 9.23  | 2.32          | 0.08  |       |
|                     | Junior high school    | 63.05 ± 8.97  |      |      |                    | 3 - 6 months       | 61.44 ± 9.32  |               |       |       |
|                     | High school           | 61.32 ± 11.59 |      |      |                    | 6 - 12 months      | 63.68 ± 15.96 |               |       |       |
|                     | Junior college and up | 58.98 ± 11.44 |      |      |                    | >12 months         | 60.39 ± 10.22 |               |       |       |
| Marital Status      | Unmarried             | 55.63 ± 12.63 | 0.58 | 0.63 | character          | Extroversion       | 59.08 ± 11.53 | 3.85          | 0.02  | ② > ③ |
|                     | Married               | 60.64 ± 11.21 |      |      |                    | Introvert          | 64.56 ± 12.89 |               |       | ① > ① |
|                     | Divorced              | 60.33 ± 7.55  |      |      |                    | Mide               | 59.40 ± 9.11  |               |       | ③ > ① |
|                     | Widowed               | 58.00 ± 9.59  |      |      |                    | Main activity mode | In house      | 63.34 ± 11.09 | 2.97  | 0.05  |
| Occupational status | Retirement            | 59.81 ± 10.78 | 1.85 | 0.14 | Sometimes outside  |                    | 60.16 ± 10.64 |               |       |       |
|                     | On the job            | 59.38 ± 11.30 |      |      | Often outside      |                    | 57.92 ± 11.50 |               |       |       |
|                     | Unemployed            | 59.44 ± 11.38 |      |      | Family relations   |                    | Good          | 58.64 ± 10.39 | 13.48 | 0     |
| Mode of residence   | Unemployment          | 64.61 ± 10.53 |      |      |                    | OK                 | 69.17 ± 9.58  |               |       | ② > ① |
|                     | Live alone            | 62.86 ± 14.15 | 0.56 | 0.65 |                    | Not good           | 68.67 ± 20.03 |               |       |       |
|                     | With spouse           | 59.76 ± 11.15 |      |      |                    |                    |               |               |       |       |
|                     | With children         | 61.50 ± 9.90  |      |      |                    |                    |               |               |       |       |
|                     | With parents          | 59.13 ± 11.43 |      |      |                    |                    |               |               |       |       |

**Table 3.** Alexithymia scores in patients with lymphedema (n = 195,  $\bar{X} \pm S$ ).

| Variable                              | Number of entries | Score range | $\bar{X} \pm S$ |
|---------------------------------------|-------------------|-------------|-----------------|
| Total alexithymia score               | 20                | 26 - 79     | 56.53 ± 8.43    |
| Lack of ability to recognize emotions | 7                 | 7 - 32      | 20.02 ± 4.57    |
| Lack of ability to describe emotions  | 5                 | 5 - 21      | 13.80 ± 2.55    |
| Externally oriented thinking          | 8                 | 9 - 30      | 22.71 ± 3.03    |

**3.4. Alexithymia Score of Patients with Lymphedema**

The total score of alexithymia was (56.53 ± 8.43). The results showed that the score of extraversion thinking was the highest (22.71 ± 3.03), followed by the score of lack of ability to recognize emotion (20.02 ± 4.57), and the score of lack of ability to describe emotion was the lowest (13.80 ± 2.55). See **Table 3**.

**3.5. Multiple Linear Regression Analysis of Influencing Factors of Stigma in Patients with Lymphedema**

In order to further clarify and predict the influencing factors of stigma, the total score of stigma was taken as the dependent variable, and the family monthly income, personality, family relationship and alexithymia with statistical differences in single factor analysis were analyzed by multiple linear regression. The independent

**Table 4.** Multiple linear regression analysis of stigma in patients with lymphedema (n = 195).

| Predictive variable            | Non standardized coefficient $\beta$ | Standard error | Standardization coefficient beta | t      | P     |
|--------------------------------|--------------------------------------|----------------|----------------------------------|--------|-------|
| (Constant)                     | 101.568                              | 5.817          |                                  | 17.460 | 0.000 |
| Monthly Household income (RMB) | 0.661                                | 0.663          | 0.060                            | 0.998  | 0.320 |
| Character Family Relations     | 0.575                                | 0.728          | 0.046                            | 0.789  | 0.430 |
| Alexithymia                    | -8.026                               | 1.528          | -0.306                           | -5.252 | 0.000 |
|                                | -0.633                               | 0.080          | -0.481                           | -7.936 | 0.000 |

Note: R = 0.360, R<sup>2</sup> = 0.347.

**Table 5.** Correlation analysis between alexithymia and stigma in patients with lymphedema (r).

|                         | Alexithymia | Lack of emotion recognition | Lack of emotional description | Externally oriented thinking |
|-------------------------|-------------|-----------------------------|-------------------------------|------------------------------|
| Stigma                  | 0.510**     | 0.544**                     | 0.438**                       | 0.232**                      |
| Social exclusion        | 0.401**     | 0.451**                     | 0.320**                       | 0.167*                       |
| Economic discrimination | 0.534**     | 0.546**                     | 0.483**                       | 0.255**                      |
| Inner stigma            | 0.302**     | 0.345**                     | 0.274**                       | 0.09                         |
| Social isolation        | 0.479**     | 0.496**                     | 0.399**                       | 0.248**                      |

\*\* At the level of 0.01, the correlation is significant. \* At the level of 0.05, the correlation is significant.

variables entering the equation are alexithymia and family relationship. ANOVA test results  $f = 26.722$ ,  $P = 0.000$ , indicating that the proposed regression equation model has statistical significance. The independent variables (alexithymia, family relationship) explained 34.7% of the variation of the dependent variable (stigma). The results are shown in **Table 4**.

### 3.6. Correlation between Alexithymia and Stigma in Patients with Lymphedema

The results showed that alexithymia was positively correlated with stigma ( $r = 0.510$ ,  $P < 0.01$ ). See **Table 5**.

## 4. Discussion

### 4.1. Patients with Lymphedema have Alexithymia, Which Is Above the Middle Level

Alexithymia has a serious impact on the treatment, physical and mental health and quality of life of cancer patients. It is often manifested in physical symptoms. Patients with lymphedema are one of the common complications after malignant tumor surgery. At present, lymphedema cannot be cured, which brings significant mental stimulation and psychological trauma to patients. However, clinical medical staff ignore the impact of alexithymia on the occur-

rence, development, treatment effect and prognosis of lymphedema to some extent. The results of this survey show that the total score of alexithymia is ( $56.53 \pm 8.43$ ), of which the score of extraversion thinking is the highest, which is ( $22.71 \pm 3.03$ ), followed by the score of lack of ability to identify emotion, which is ( $20.02 \pm 4.57$ ), and the score of lack of ability to describe emotion is the lowest, which is ( $13.80 \pm 2.55$ ). The total score is basically consistent with the score ( $57.07 \pm 9.50$ ) of alexithymia in cancer patients less than 3 months after operation by Gritti [16], indicating that alexithymia in patients with lymphedema is obvious and at the upper middle level. The reason may be that cancer and surgery have a serious impact on the body and mind of patients. Postoperative lymphedema disease, abnormal swelling of affected limbs, changes in life, worry about other people's views, affect social interaction, affect self-esteem, and fear of being discriminated against, so as to close themselves, suppress their feelings and not express them to the outside world. Some patients also need radiotherapy and chemotherapy after operation. Multiple stress makes it difficult for patients to identify between physical discomfort and psychological discomfort. They are more sensitive to their own diseases, worry about losing family and love, and can not truly express their feelings.

Patients with lymphedema also face the psychological challenge of long-term adherence to treatment and the comprehensive treatment of the original disease after operation. If they cannot adjust and deal with it in time, they are prone to negative emotions and affect their physical and mental health. It shows that medical staff should timely understand the current situation of alexithymia in patients with lymphedema and intervene in time to reduce alexithymia and improve their physical and mental health.

#### 4.2. Patients with Lymphedema Have a High Level of Stigma

The results showed that the total score of stigma was ( $60.36 \pm 11.08$ ). The score of social exclusion was the highest ( $21.07 \pm 3.80$ ), followed by economic discrimination ( $15.65 \pm 3.94$ ) and social isolation ( $15.56 \pm 3.05$ ), and the score of internal stigma was the lowest ( $8.09 \pm 1.86$ ). It is basically consistent with the systematic review and research of Reynolds LM *et al.* [17] on the stigma of cancer patients after physical and mental trauma. Possible reasons for the highest score of social exclusion in this study: most of the patients in this study are women and in-service personnel, who pay too much attention to the external image, because the treatment of lymphedema requires bandage compression and bandage, which is exposed and cannot be concealed, which affects social and work, and the stability of work is impacted and challenged. The second highest score is economic discrimination and social segregation. For patients with lymphedema, it is a protracted battle to insist on self-treatment every day. When limb lymphedema occurs, they have to use compressed clothes or pressure treatment. Patients say they feel constantly reminding themselves of cancer and causing a sense of stigma [18]. For the exposed bandage, I feel a stigma and guilty. I feel that I am labeled with a different label. I am too sensitive, exaggerate the social



view of myself, reduce social interaction, and lead to social isolation. Therefore, the sense of stigma affects the social activities of patients with lymphedema. In addition, the reason for economic discrimination may be that the treatment materials required by patients with lymphedema need to be used for a long time. At present, the treatment materials and treatment expenses have not been included in the scope of medical insurance reimbursement, and patients need to pay at their own expense. The economic pressure caused may cause negative emotions of patients.

### **4.3. Analysis of Influencing Factors of Stigma in Patients with Lymphedema Sociodemographic Characteristics**

In order to further clarify the influencing factors of stigma, the total score of stigma was taken as the dependent variable, the statistically significant ones in univariate analysis and the statistically different family monthly income, personality, family relationship and alexithymia in univariate analysis were taken as the independent variables for regression analysis. The results of this study showed that alexithymia and family relationship were the main influencing factors of stigma in patients with lymphedema. The treatment of lymphedema is a long-term process. Girgis *et al.* [18] showed that patients with lymphedema hope to obtain information about lymphedema and its related treatment and care during the treatment process. For the treatment of patients with lymphedema, lymphedema therapists focus more on how to heal the patient's mind and improve the patient's social cognition. Long-term bandage makes the patient reduce social contact. Patients often choose to avoid and can't carry out good self-management, resulting in the further aggravation of lymphedema symptoms. Therefore, the high cost and the lack of social role also directly affect family relations and social support. Therefore, professional lymphedema therapists are needed. We should adjust the mentality in time, reduce the occurrence of negative emotions, help patients improve their self-treatment and nursing skills at home, overcome psychological obstacles, do their own emotional management, and eliminate or slow down their sense of stigma. Encourage patients to communicate with each other and greet each day with a positive attitude. Family participation can timely understand the psychological needs of patients, so as to alleviate the psychological stigma, which plays a positive role.

### **4.4. Alexithymia in Patients with Lymphedema Is Directly Proportional to the Sense of Stigma**

The results of this study show that alexithymia is an influencing factor in patients with lymphedema. Alexithymia was positively correlated with the total score of stigma. The higher the level of alexithymia, the stronger the sense of stigma. Multi layer bandage compression bandage is one of the important steps in the comprehensive detumescence treatment of lymphedema. Although it can reduce or control the symptoms of lymphedema, it also brings physical and mental effects and social adaptation to patients. With the guidance and help of



professional lymphedema therapists and the support of family members, we can provide patients with a comprehensive way of rehabilitation; Improve physical function, provide regular follow-up and psychological adjustment, help patients recover physically and mentally, and eliminate the sense of stigma. The emergence of lymphedema is undoubtedly worse for patients, and they are worried about cancer recurrence. They will have a negative attitude towards themselves and deny their own value. Worry about becoming a burden on family members and social exclusion, which affects social activities [1]. This study further confirmed the correlation between alexithymia and stigma, suggesting that lymphedema therapists should take appropriate psychological counseling to reduce the degree of stigma. Therefore, medical staff should provide a follow-up platform for patients with malignant tumors after operation, conduct regular follow-up, timely psychological adjustment, guide them out of negative mood, help patients choose their own lifestyle and work mode, and reflect their social value.

### 5. Limitations of This Study

The scope of the study was small, and only the patients with lymphedema in a hospital were investigated. In the future, we can further expand the region or hospitals at different levels to select a larger sample size; The secondary lymphedema caused by different age, lymphedema stage and different diseases were investigated and analyzed; To provide a deeper and more effective basis for clinical exploration.

### 6. Conclusions

All patients with lymphedema had alexithymia and moderate stigma. Alexithymia was positively correlated with stigma.

The main influencing factors of stigma in patients with lymphedema were alexithymia and family relationship. Suwankhong and Liamptong [19] showed that physical changes (hair loss, scars, etc.) of patients may lead to a sense of social isolation and reduced sexual activity; and fear of being seen as suffering from “disgusting” diseases. Long-term negative emotion will reduce the emotional expression of patients. Due to the fact that all patients with lymphedema in this study were malignant tumor patients who underwent comprehensive postoperative treatment, some patients may experience a dual sense of shame. Especially for patients with lymphedema, because of the inconvenience of life caused by long-term adherence to bandage, the sense of shame will further worsen. They have inferiority complex and are unwilling to describe their inner feelings with others, which affects the relationship between husband and wife and family life, resulting in an enhanced sense of stigma. It is suggested that medical staff should communicate with patients in time. Family participation and social support can avoid the occurrence of more negative emotions of patients and guide patients to properly vent their emotions, so as to reduce the degree of stigma.

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## Core Tip

Patients with lymphedema exhibited alexithymia and moderate stigma, with a positive correlation between alexithymia and stigma. The primary influencing factors of stigma in these patients were alexithymia and family relationships.

## Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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