

## CLINICAL REPORT

# Patients with Psoriasis Feel Stigmatized

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**Stigmatization is defined as having a discrediting mark that leads to social discrimination and alienation. The aim of this study was to estimate the level of stigmatization experienced by patients with psoriasis. A total of 102 individuals with psoriasis were recruited and was assessed using the 6-item Stigmatization Scale and the 33-item Feelings of Stigmatization Questionnaire. In addition, quality of life, stress and depression were evaluated. The majority of patients felt that they were stigmatized by psoriasis. The most bothersome aspect was that other people stared at their skin changes. According to the 33-item questionnaire, anticipation of rejection and feelings of guilt and shame were the major aspects of stigmatization, the level of which correlated significantly with pruritus intensity, stress prior to exacerbation, depressive symptoms and quality of life. In order to decrease the stigmatization level in patients with psoriasis, greater effort is needed to raise awareness in contemporary societies that psoriasis is not contagious, but is a disease like many other chronic conditions. Key words: quality of life; psoriasis; stigmatization; well-being; pruritus; stress; depression.**

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Stigmatization is defined as having a discrediting mark, which prevents the formation of normal relationships and leads to social discrimination and alienation. The stigma may be a visible physical flaw or mark, but can also be a particular feature, situation or past event, which is usually associated with negative stereotypes, leading to social discrimination (1). Stigmatization is a very old phenomenon, which was present even in ancient societies, and can relate to any type of “otherness”. Skin diseases, considering their aesthetic aspect, are frequently the cause of social rejection, which has a negative influence on the personal and social life of patients. Skin plays an important role in establishing interpersonal relationships, and thus cutaneous disorders, which have a significant impact on physical appearance, influence other people’s attitudes (2). Visible skin changes may

arouse fear, disgust, aversion or even intolerance, and other people may be afraid of the possible contagious character of the disease.

Psoriasis is one of the most common chronic skin disorders. It usually markedly influences many aspects (social, occupational, sexual and even financial) of a patient’s life. In recent years there has been increasing interest in quality of life (QoL), stress and depression in patients with psoriasis (3–5). However, data concerning the experience of stigmatization in people with psoriasis are limited. Therefore, our study was conducted to estimate the level of stigmatization experienced by patients with psoriasis and to explore relationships between feelings of stigmatization and selected clinical, demographic and psychosocial parameters.

## MATERIALS AND METHODS

A total of 102 people with psoriasis, mean age  $45.2 \pm 17.2$  years (range 16–82 years) were included in the study. The mean duration of psoriasis was  $16.4 \pm 13.8$  years (range 3 months to 55 years) and the number of hospitalizations due to psoriasis within the two most recent years ranged from 1 to 12 times (mean  $2.5 \pm 2.1$  times). Detailed clinical and demographic characteristics of the examined patients are shown in Table 1. It should be mentioned, that we have used our data previously in another paper with a focus on pruritus (6).

### Methods

The study was approved by the ethics committee of Wrocław Medical University. All patients signed a written informed consent prior to commencement of any study procedure. All patients underwent careful anamnesis and physical examination in order to complete a specially designed questionnaire about demographic and clinical data. Psoriasis Area and Severity Index (PASI) (7) was used for the evaluation of psoriasis severity. In addition, each participant was assessed according to the presence of pruritus. The severity of pruritus was determined using a 10-point visual analogue scale (VAS) and a 4-Item Itch Questionnaire used previously by our group in different studies on itching (6, 8). The scoring of pruritus severity in the 4-Item Itch Questionnaire ranges from 0 to 19 scores. In both scales the higher the score, the more severe pruritus is experienced. After completion of the physical examination each subject was asked to complete several validated questionnaires assessing their level of stigmatization, QoL, stress and symptoms of depression.

### Assessment of stigmatization

Assessment of stigmatization caused by psoriasis was performed with the validated Polish versions of the 6-item Stigmatization Scale by Lu et al. (9, 10) and the Feelings of Stigmatization

Table I. Clinical and demographic characteristics of study patients with psoriasis

| Variables                        | n (%)     |
|----------------------------------|-----------|
| Gender                           |           |
| Male                             | 64 (62.7) |
| Female                           | 38 (37.3) |
| Marital status                   |           |
| Married                          | 52 (51)   |
| Single                           | 45 (44.1) |
| Informal relationship            | 5 (4.9)   |
| Education                        |           |
| Elementary school                | 15 (14.7) |
| Secondary school                 | 25 (24.5) |
| High school                      | 45 (44.1) |
| University                       | 17 (16.7) |
| Employment                       |           |
| Employed                         | 34 (33.3) |
| Unemployed                       | 68 (66.7) |
| Place of living                  |           |
| Countryside                      | 18 (17.6) |
| Town (<100,000 citizens)         | 41 (40.2) |
| City (≥100,000 citizens)         | 43 (42.2) |
| Family history of psoriasis      |           |
| Yes                              | 37 (36.3) |
| No                               | 65 (63.7) |
| Duration of disease exacerbation |           |
| <3 months                        | 57 (55.9) |
| ≥3 months                        | 45 (44.1) |
| Pruritus                         |           |
| Absent                           | 11 (10.8) |
| Present                          | 91 (89.2) |
| Joint involvement                |           |
| Absent                           | 78 (76.5) |
| Present                          | 24 (23.5) |
| Lesions on the face              |           |
| Present                          | 60 (58.8) |
| Absent                           | 42 (41.2) |

Questionnaire by Ginsburg & Link (10, 11). Assessment of stigmatization referred to the last 2 weeks of the patient's life. In the 6-Item Stigmatization Scale patients had to answer 6 questions (Table II) using one of four possibilities scored from 0 to 3 points: "not at all", "sometimes", "very often", and "always". Higher scoring meant greater feeling of stigmatization (range 0–18). The total scoring was used for further analysis. In the Feelings of Stigmatization Questionnaire patients had to give answers to 33 items using one of 6 possibilities scored from 0 to 5: "definitely yes", "yes", "rather yes", "rather no", "no", "definitely no". The overall scoring could range from 0 to 165 points. Similarly to the 6-item Stigmatization Scale, the higher the score, the more severe the patient's feeling of stigmatization. The questions were designed to explore 6 different dimensions of the stigma: anticipation of rejection (8 items), feeling of being flawed (6 items), sensitivity to the opinions of others (5

items), guilt and shame (5 items), secretiveness (5 items), and positive attitudes (4 items) (for details: see (11)).

#### Other psychological assessments

QoL within the last 7 days prior to the study visit was evaluated according to the Polish version of Dermatology Life Quality Index (DLQI) (12, 13). The severity of depressive symptoms was rated based on the Beck's Depression Inventory (BDI) (14). The level of stress was measured within one month before disease exacerbation and was assessed according to the Holmes & Rahe Social Readjustment Rating Scale (SRRS) (15) as well as according to the Stress Self-assessment Scale (no stress, mild, moderate, severe and extremely severe stress) (16). Detailed results of QoL, depression and stress have been published elsewhere (4, 6).

#### Statistical analysis

Statistical analysis was performed using Statistica 7.0 software (Statsoft, Krakow, Poland). Means, standard deviations (SD), median values and frequencies were calculated. The differences between the groups of patients were analysed using the Student's *t*-test for independent variables, Mann-Whitney *U* test, analysis of variance (ANOVA) and multiple regression analysis, where appropriate. Correlations between analysed parameters were verified by using Spearman's rank correlation test ( $\rho$  – correlation coefficient). The results were considered statistically significant, if the *p*-value was less than 0.05.

## RESULTS

#### Level of stigmatization

The majority of studied patients were found to have feelings of stigmatization due to psoriasis. According to 6-Item Stigmatization Scale the mean level of stigmatization was  $5.0 \pm 3.7$  points. Only 10 (9.8%) patients with psoriasis had no feeling of stigmatization (0 points) and a further 19 (18.3%) were only minimally stigmatized (1–2 points). The remainder of the patients demonstrated various degrees of feelings of stigma. Analysing each question separately, the most troublesome aspect of psoriasis for studied subjects was the problem of staring at skin changes by other people (mean  $1.3 \pm 0.9$  points) followed by the fact, that other persons consider psoriasis to be a contagious disease (mean  $1.1 \pm 0.9$  points) (Table II).

The mean level of stigmatization measured with 33-item scale was  $76.3 \pm 19.2$  points. Anticipation of rejection and feelings of guilt and shame were the most important aspects of stigmatization felt by patients (Table III).

Table II. Feeling of stigmatization according to 6-Item Stigmatization Scale (9)

| Question  | Not at all<br>n (%) | Sometimes<br>n (%) | Very often<br>n (%) | Always<br>n (%) | Mean ± SD     |
|---|---------------------|--------------------|---------------------|-----------------|---------------|
| 1. Others are not attracted to me due to my skin disease.               | 36 (35.3)           | 43 (42.1)          | 17 (16.7)           | 6 (5.9)         | $0.9 \pm 0.9$ |
| 2. I think that others stare at my skin disease.                        | 16 (15.7)           | 49 (48.0)          | 27 (26.5)           | 10 (9.8)        | $1.3 \pm 0.9$ |
| 3. Others feel uncomfortable touching me due to my skin disease.        | 49 (48.0)           | 37 (36.3)          | 9 (8.8)             | 7 (6.9)         | $0.7 \pm 0.9$ |
| 4. Other people think that my skin disease is contagious.               | 30 (29.4)           | 41 (40.2)          | 24 (23.5)           | 7 (6.9)         | $1.1 \pm 0.9$ |
| 5. Other people avoid me due to my skin disease.                        | 69 (67.6)           | 24 (23.5)          | 9 (8.8)             | 0 (0)           | $0.4 \pm 0.7$ |
| 6. Other people sometimes make annoying comments about my skin disease. | 65 (63.7)           | 27 (26.5)          | 6 (5.9)             | 4 (3.9)         | $0.5 \pm 0.8$ |

SD: standard deviation.

Table III. Level of stigmatization measured according to Feelings of Stigmatization Questionnaire (11)

|                                       | Items<br><i>n</i> | Scoring<br>Mean $\pm$ SD | Maximal possible<br>score, % | Scoring per question<br>Mean $\pm$ SD | Minimum | Maximum |
|---------------------------------------|-------------------|--------------------------|------------------------------|---------------------------------------|---------|---------|
| Feelings of stigmatization (total)    | 33                | 76.3 $\pm$ 19.2          | 46.3                         | 2.3 $\pm$ 0.6                         | 26      | 127     |
| Anticipation of rejection             | 8                 | 23.9 $\pm$ 6.0           | 59.6                         | 3.0 $\pm$ 0.7                         | 7       | 37      |
| Feeling of being flawed               | 6                 | 12.3 $\pm$ 5.6           | 41.1                         | 2.1 $\pm$ 0.9                         | 2       | 27      |
| Sensitivity to the opinions of others | 5                 | 10.0 $\pm$ 4.5           | 39.8                         | 2.0 $\pm$ 0.9                         | 0       | 21      |
| Guilt and shame                       | 5                 | 14.1 $\pm$ 3.9           | 56.5                         | 2.8 $\pm$ 0.8                         | 4       | 23      |
| Secretiveness                         | 5                 | 8.2 $\pm$ 4.0            | 32.6                         | 1.6 $\pm$ 0.8                         | 0       | 23      |
| Positive attitudes                    | 4                 | 7.8 $\pm$ 3.5            | 38.9                         | 1.9 $\pm$ 0.9                         | 1       | 19      |

SD: standard deviation.

The results achieved with the 6-Item Stigmatization Scale correlated highly with the Feelings of Stigmatization Questionnaire ( $\rho=0.68$ ,  $p<0.001$ ) as well as with separate dimensions of stigma (anticipation of rejection:  $\rho=0.53$ , feeling of being flawed:  $\rho=0.62$ , sensitivity to the opinions of others:  $\rho=0.67$ , secretiveness:  $\rho=0.35$ , positive attitudes:  $\rho=0.41$ ,  $p<0.001$  for all comparisons) except the dimension of “guilt and shame” ( $\rho=0.14$ ,  $p=0.16$ ). Similarly, total scoring of the Feeling of Stigmatization Questionnaire significantly correlated with all questions of 6-Item Stigmatization Scale analysed separately ( $\rho$  ranging from 0.41 to 0.61,  $p<0.001$ ).

#### Stigmatization and socio-demographic and clinical parameters

No significant relationship was found between the level of stigmatization and clinical and demographic parameters such as age, gender, marital status, education level, employment, place of living, disease duration, duration of last exacerbation, psoriasis severity, presence of pruritus, joint involvement, presence of skin lesions on the face or number of hospitalizations (data not shown). However, the level of stigmatization measured with the 33-item scale was significantly higher in patients with no family history of psoriasis than in subjects whose family members had psoriasis (79.8  $\pm$  18.7 vs. 70.2  $\pm$  18.7 points,  $p=0.01$ ). Individuals with no family history of psoriasis also significantly more strongly expressed anticipation of rejection (24.8  $\pm$  5.6 vs. 22.3  $\pm$  6.3 points,  $p<0.05$ ), feelings of being flawed (13.4  $\pm$  5.9 vs. 10.4  $\pm$  4.5 points,  $p=0.01$ ) and sensitivity

to the opinions of others (10.7  $\pm$  4.4 vs. 8.6  $\pm$  4.5 points,  $p=0.02$ ). No significant differences concerning other dimensions of stigma or the stigmatization level assessed by the 6-Item Stigmatization Scale were found regarding family history of psoriasis.

Although the presence of pruritus did not markedly affect the level of stigmatization, in subjects with pruritus the severity of pruritus measured with the VAS correlated with the level of stigmatization evaluated both with the 6-item ( $\rho=0.21$ ,  $p=0.03$ ) and 33-item scales ( $\rho=0.2$ ,  $p<0.05$ ), although correlations were weak. Similarly, a correlation was found between the severity of pruritus assessed with the 4-Item Itch Questionnaire and the level of stigmatization (6-Item Stigmatization Scale:  $\rho=0.26$ ,  $p=0.01$ ; Feelings of Stigmatization Questionnaire:  $\rho=0.37$ ,  $p<0.001$ ). There were also positive correlations between VAS scores and the following dimensions of stigma: “feeling of being flawed” ( $\rho=0.3$ ,  $p=0.003$ ) and “secretiveness” ( $\rho=0.21$ ,  $p=0.04$ ). Positive correlations were also observed between itch severity according to 4-Item Itch Questionnaire and “anticipation of rejection” ( $\rho=0.33$ ,  $p=0.001$ ), “feeling of being flawed” ( $\rho=0.4$ ,  $p<0.001$ ), “sensitivity to other’s attitudes” ( $\rho=0.32$ ,  $p=0.002$ ) and “secretiveness” ( $\rho=0.25$ ,  $p=0.02$ ). Multiple regression analysis confirmed pruritus severity as an important variable only for the “anticipation of rejection” (data not shown).

#### Stigmatization and psychosocial estimates

The level of stigmatization, assessed by both the 6-Item Stigmatization Scale and the Feelings of Stigmatization

Table IV. Correlations between the level of stigmatization and other psychological parameters

|  | DLQI   | BDI  | SRRS   | Stress Self-assessment Scale                           |
|--|--|--|--|--|
| 6-Item Stigmatization Scale              | <b><math>\rho=0.6</math>, <math>p&lt;0.001</math></b>  | <b><math>\rho=0.46</math>, <math>p&lt;0.001</math></b> | <b><math>\rho=0.24</math>, <math>p=0.02</math></b> | <b><math>\rho=0.47</math>, <math>p&lt;0.001</math></b> |
| Feelings of Stigmatization Questionnaire | <b><math>\rho=0.55</math>, <math>p&lt;0.001</math></b> | <b><math>\rho=0.55</math>, <math>p&lt;0.001</math></b> | $\rho=0.1$ , $p=0.34$                              | $\rho=0.36$ , $p<0.001$                                |
| Anticipation of rejection                | <b><math>\rho=0.55</math>, <math>p&lt;0.001</math></b> | <b><math>\rho=0.34</math>, <math>p&lt;0.001</math></b> | $\rho=0.07$ , $p=0.48$                             | $\rho=0.23$ , $p=0.02$                                 |
| Feeling of being flawed                  | <b><math>\rho=0.48</math>, <math>p&lt;0.001</math></b> | <b><math>\rho=0.53</math>, <math>p&lt;0.001</math></b> | $\rho=0.05$ , $p=0.62$                             | <b><math>\rho=0.28</math>, <math>p&lt;0.01</math></b>  |
| Sensitivity to the opinions of others    | <b><math>\rho=0.46</math>, <math>p&lt;0.001</math></b> | <b><math>\rho=0.55</math>, <math>p&lt;0.001</math></b> | $\rho=0.14$ , $p=0.16$                             | <b><math>\rho=0.33</math>, <math>p&lt;0.001</math></b> |
| Guilt and shame                          | $\rho=0.15$ , $p=0.13$                                 | $\rho=0.16$ , $p=0.11$                                 | $\rho=-0.01$ , $p=0.96$                            | $\rho=0.04$ , $p=0.7$                                  |
| Secretiveness                            | <b><math>\rho=0.32</math>, <math>p=0.001</math></b>    | <b><math>\rho=0.34</math>, <math>p&lt;0.001</math></b> | $\rho=0.14$ , $p=0.17$                             | $\rho=0.25$ , $p=0.01$                                 |
| Positive attitudes                       | $\rho=0.29$ , $p<0.01$                                 | <b><math>\rho=0.35</math>, <math>p&lt;0.001</math></b> | $\rho=0.06$ , $p=0.57$                             | <b><math>\rho=0.31</math>, <math>p=0.002</math></b>    |

Significant results are shown in **bold**.

DLQI: Dermatology Life Quality Index; BDI: Beck’s Depression Inventory; SRRS: Social Readjustment Rating Scale.

Questionnaire, correlated significantly with QoL level assessed by DLQI, the severity of depressive symptoms assessed by BDI, and the degree of stress experienced shortly before disease exacerbation measured with a Stress Self-assessment Scale (Table IV). All these psychological parameters also correlated significantly with various dimensions of stigma, except for “guilt and shame”. On the other hand, SRRS scoring demonstrated a relevant relationship only with stigmatization level assessed by the 6-Item Stigmatization Scale (Table IV).

## DISCUSSION

Reports concerning the social consequences of psoriasis first appeared in the 1970s (17). Jobling (17) found, that more than 80% of patients with psoriasis considered troubles in establishing social relationships to be the most difficult aspect of their disease. Subsequently, the interest in QoL and psychosocial well-being of patients with psoriasis has rapidly increased. In line with the studies of psychological problems in psoriasis, our current data clearly indicate that feelings of stigmatization is an important concern for a majority of patients with psoriasis.

Similar findings were obtained by Ginsburg & Link (18), who showed that almost all psoriatic individuals (99 subjects out of 100 included in the study) experienced stigmatic events in their lives, starting with subtle ones, such as avoiding touching or staring at skin lesions, up to serious ones, such as asking to leave the place. Another study has reported that 57% of patients with psoriasis felt that people stare at their skin changes and consider them contagious (19). Lu et al. (9), using the same 6-item scale as in our study, found that 79% of patients experienced at least one of the events described in the questionnaire and 35% experienced all of them.

We performed analysis concerning the level of stigmatization in the context of selected clinical and demographic parameters and, surprisingly, found no significant relationship with the majority of studied characteristics. It was surprising to find that the presence of psoriasis on the face had no influence on patients' feelings of stigma, even though patients with facial lesions had significantly more severe psoriasis and the face is the most visible area of our body. It may be explained, at least in part, by the fact, that the remaining patients had lesions on other visible skin areas, such as the hands. However, it could be also suggested that feelings of stigmatization might be largely attributed to the fact of having psoriasis, rather than to its degree of severity or other demographic and social factors (20, 21). This suggestion could be supported by the results of Ludwig et al. (22), who showed that the location of skin diseases has little influence on the feeling of embarrassment, probably, as suggested by these authors, because

in any intimate approach there is always some sort of exposure involved. On the other hand, Schmid-Ott et al. (23) reported that the genital region is especially relevant for the stigmatization experience. The only important clinical parameters found in our study were the family history of psoriasis and pruritus severity. We can expect that patients whose family members also have psoriasis, may have better understanding about being ill and may be able to obtain more support from their families. As a consequence, they may cope better with psoriasis. Interestingly, the severity of pruritus was another important factor influencing the level of stigmatization, which is in agreement with results obtained by Lu et al. (9). In addition, Ginsburg & Link (11) assumed that the presence of excoriations and bleeding is a significant factor predisposing to higher stigmatization. It could be suggested that excessive scratching may additionally draw people's attention, and bleeding may lead to an unaesthetic appearance and can arouse fear or disgust.

Although most authors also did not find any difference in the level of stigmatization between genders (9, 24, 25), Ginsburg & Link (11) noticed that women experienced greater distress due to psoriasis and were more sensitive to stigmatization than their male counterparts. In addition, Perrot et al. (26) reported that women experienced guilt and shame significantly more severely than men. On the other hand, Gupta & Gupta (27) reported that male patients were more afraid of losing their job because of psoriasis. They also were more sensitive to unpleasant comments at school or in the workplace, and required more medical involvement. One of the explanations of the differences between our results and previous studies may be related to the different time-periods that were assessed by patients in respect of the feeling of stigmatization. In our study patients were asked to rate the experience of stigmatization in the previous 2 weeks, as we thought it would be the most reliable time-period regarding the patients' memory. However, as this is rather short period, it might not sufficiently cover all experiences of being stigmatized. Therefore, it would be of interest to analyse stigmatization over a longer period of study in order to reliably assess how the feelings of stigmatization change over time in subjects with psoriasis.

Although our current study did not provide evidence for the correlation between the feeling of stigmatization and age, many authors suggested that the negative influence of skin diseases on QoL is particularly strong in young adults (9, 27–29). Physical appearance is usually of great importance for them, as this group of patients is starting their careers, establishing interpersonal relationships and leading a busy social life. Furthermore, marital status may be another aspect with some influence on stigmatization, despite the fact that we, similarly to Perrott et al. (26), were not able to find such a relation-

ship. According to Ginsburg & Link (11), patients who had never been married were more sensitive to other people's opinion. Moreover, Lu et al. (9) observed that single people experienced significantly higher levels of stigmatization.

Employment is another interesting topic in relation to the impact of psoriasis on a patient's life. In one study (30), nearly 60% of patients reported frequent absences from work due to psoriasis and approximately one-third of unemployed patients reported that being jobless was a consequence of their disease. In one of our previous studies (31) we found that psoriasis negatively influences work ability in a significant subgroup of patients with psoriasis, and thus psoriasis should be considered as a disease that not only decreases the patient's QoL, but also has the potential to lower the productivity of subjects with psoriasis. Regarding the stigmatization, we did not observe a significant correlation between feelings of stigmatization and employment; however, Ginsburg & Link (11) found that employed patients had a lower level of stigmatization: they had lower anticipation of rejection, feelings of guilt and shame and were less sensitive to others' attitudes.

Of note is a significant relationship between stigmatization level and other psychological assessments. These findings clearly indicate that stigmatization is an important element of how patients perceive their disease, and what impact psoriasis has on their daily life. Thus, stigmatization may determine the degree of QoL impairment or even depression. Higher incidence of depression in psoriasis is well documented (32–36) and a close relationship between stigmatization and depression has already been mentioned by Gupta et al. (37). These authors report that patients with psoriasis who experienced avoidance of touch by other people had significantly higher levels of depression (37). Our study also demonstrated a positive correlation between stigmatization and the level of experienced stress. Stress in patients with psoriasis was caused not only by real discrimination, but also by the fear of being discriminated against. Stress poses a very complex problem in psoriasis as, on the one hand, psoriasis may cause stress and depression, and, on the other hand, stress and anxiety may worsen the skin condition (16). However, patients may differ in their reactivity to stressful life events and the related psychological response to stress, which subsequently may influence the disease-related outcome. It could be suggested, that subjects who are more sensitive to stigmatization can be also more sensitive to stress. Persistent worry, a common response to disease, has been reported to prolong stress-related affective and physiological activation of endocrine and immune systems, negatively influencing disease severity, especially in subjects with high levels of worry (38, 39). It is of note that Ginsburg & Link (18) reported that patients who felt rejected or who were very sensitive to

other's attitudes significantly more often had problems in the workplace, more often sought psychological or psychiatric help, and reported higher alcohol intake.

In conclusion, psoriasis is not only a problem in terms of skin treatment, but also presents a significant psychological burden for patients and their relatives. Stigmatization is an important aspect of psoriasis that is frequently experienced by patients and it may significantly worsen patient's QoL or even cause depression. Therefore, our attempts to help people with psoriasis should focus not only on improving anti-psoriatic treatments, but also on raising awareness in contemporary societies that psoriasis is not contagious and is a disease like many other chronic conditions.

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