Psychological Distress in Patients With Morphea and Eosinophilic Fasciitis

Elisabeth B. M. Kroft, MD, PhD; Elke M. G. J. de Jong, MD, PhD; Andrea W. M. Evers, PhD

Objective: To examine the level of psychological distress and factors contributing to distress in patients with morphea or eosinophilic fasciitis.

Design: Cross-sectional study.

Setting: Dermatology outpatient clinic of a university hospital.

Participants: Of 120 patients with morphea or eosinophilic fasciitis diagnosed between December 1, 1994, and July 15, 2007, who were enrolled in the study, only 74 completed questionnaires were suitable for data analysis.

Main Outcome Measures: Self-reported responses on the Impact of Chronic Skin Diseases on Daily Life scale measure psychological distress, specifically anxiety and depressed mood.

Results: Psychological functioning was generally impaired in patients with skin disease, particularly among patients with generalized morphea and eosinophilic fasciitis. Twenty-eight patients (38%) were at risk of depression or anxiety. Higher levels of psychological distress were significantly related to greater severity of skin disease; more pain and fatigue; impact of disease on daily life; more perceived stigmatization; illness cognitions of greater helplessness; and less acceptance and less perceived social support.

Conclusions: Physical and psychosocial aspects play a substantial role in the quality of life for patients with morphea. Physicians should be encouraged to assess the physical and psychosocial factors when treating patients with sclerotic skin diseases. This approach could improve quality of life and ultimately lead to improved dermatological treatment outcomes.

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In recent decades, it has often been proposed that physical and psychosocial factors have a significant role in chronic diseases, such as psoriasis and rheumatoid arthritis. However, there is a dearth of knowledge about psychosocial functioning among adult patients with morphea. Morphea, or localized scleroderma, is a primary cutaneous sclerosis and can be classified into the following main groups: plaque morphea, generalized morphea, bullous morphea, linear morphea, and deep morphea. Eosinophilic fasciitis is often seen as a deep morphea, but several classifications have defined this disease as a separate entity.

Stress-vulnerability models propose that major life events and other external stressors as well as internal vulnerability factors and personality characteristics, such as negative affectivity, could affect disease outcomes in chronic diseases. Mediating factors such as coping, illness cognitions, or social support are thought to explain the relationship between internal and external factors and disease outcomes. In contrast to relatively enduring personality characteristics and irreversible stressors, it is assumed that coping, social support, and illness cognitions can be altered via psychological treatments, and, consequently, they are the focus of many studies in patients with chronic diseases, including skin conditions.

In line with these stress-vulnerability models, various physical, psychological, and social factors have been suggested to influence the course of chronic diseases. In addition to clinical disease severity, physical symptoms of itch, pain, and fatigue are considered severe chronic stressors in patients with sclerotic skin diseases, resulting in heightened levels of psychological distress. Furthermore, perceived stigmatization and other effects of disease on daily life have been shown to be possible stressors and to contribute to psychological distress among patients with chronic skin diseases. Particular illness cognitions also have been shown to be an important predictor of psychological well-being in patients with chronic conditions. Specifically, patients who report high levels of helplessness and lower levels of acceptance with regard to their
disease, emphasize the negative aspects of their condition, and generalize them to all facets of daily life also experience worse physical and psychological functioning. Finally, social factors are known to be important among patients with chronic disease. The number of people in the social network and the qualitative aspects of this support can be expected to have a protective effect against the development of psychological distress. Increasing knowledge about the factors affecting psychological distress could improve multidisciplinary care for patients with chronic skin disease.

Sclerotic skin diseases can cause severe morbidity because of the altered appearance and reduced mobility of the skin and subcutaneous tissue, joint contractures, and serious deformities of the face and extremities. We hypothesized that psychological distress among patients with a sclerotic skin disease would be predicted primarily by increased physical symptoms of itching, pain, and fatigue; greater impact of disease on daily life; illness cognitions of greater helplessness; lower levels of acceptance and perceived benefits of the disease; and less social support.

METHODS

PATIENTS AND PROCEDURES

All patients (N = 120) with a localized sclerotic skin disease attending the outpatient’s clinic of the Department of Dermatology at Radboud University Nijmegen Medical Centre, the Netherlands, from December 1, 1994, through July 15, 2007, were enrolled in the study and sent a questionnaire through the mail. Diagnoses were confirmed by dermatological, rheumatological, and, if necessary, pathological analysis. The Medical Ethics Committee of the Radboud University Nijmegen Medical Centre determined that this study was exempt from further review.

Exclusion criteria included severe psychiatric or mental disabilities that could severely interfere with adherence to the study protocol, age younger than 16 years, systemic sclerosis as defined by American College of Rheumatology criteria, or pseudoscleroderma/pseudosclerosis (eg, scleroderma graft vs host disease, sclerodema of Buschke, scleromyxedema, pseudosclerosis owing to genetic disorders or traumatic agents). After applying exclusion criteria, data were available for 36 patients with plaque-type morphea, 10 with linear morphea (occurring on an extremity or the face), 16 with generalised or disseminated morphea, and 12 with cosinophilic fasciitis. Generalized morphea was described as multiple sclerotic plaques, confluent or affecting more than 3 places on the body. Plaque morphea was described as 1 or more circumscribed patches of sclerotic skin in 2 or fewer sites.

MEASURES

GENERAL CHARACTERISTICS

The demographic variables of age, sex, marital status, and educational level were determined from the medical records. Educational level was measured using 7 possible responses classified as primary, secondary, and tertiary level, representing 8, 12, and 17 years of formal education, respectively. The time since diagnosis was measured in years.

Comorbidity, the presence of chronic diseases other than the sclerotic disease, was measured with the Impact of Chronic Skin Disease on Daily Life (ISDL) scale. Psychological well-being and/or distress was measured using the 10-item anxiety subscale and the 6-item negative/ depressed mood subscale of the ISDL. The validity and reliability of the ISDL have been extensively studied. Because the ISDL is a generic dermatological questionnaire for patients with chronic skin diseases, no questions required adaptation for this study group.

PHYSICAL FUNCTIONING

Severity of Skin Disease

Severity of skin disease was assessed by measuring the degree to which different parts of the body were affected with sclerosis or tightening of the skin according to the 9-item skin disease severity subscale of the ISDL. Patients indicated the degree to which 9 specific parts of the body were affected (face, head, neck, hands, arms, torso, legs, feet, and genitals/anus) via a 4-point Likert scale, with 1 being not affected and 4, totally affected. A total score was then calculated by summing the 4-point scores for each of the 9 body parts. The minimum score of 9 represented no involvement and the maximum score of 36 indicated that all 9 body parts were totally affected.

Physical Symptoms of Itching, Pain, and Fatigue

The visual analog subscales (VAS) of the ISDL were used to estimate the mean level of itching, pain, and fatigue during the previous 4 weeks on a scale of 0 to 10; 0 represented no itching, pain, or fatigue, and 10 represented maximum fatigue, pain, or itching ever experienced.

Stressors

Impact of disease on daily life was assessed using the ISDL 10-item generic subscale, which measures the effects on daily activities such as work, hobbies, sleep, sexuality, and relationships. The 6-item stigmatization subscale of the ISDL measured the extent to which patients felt stigmatized by others as a result of the sclerotic disease. Illness cognitions were measured using the ISDL 6-item helplessness, acceptance, and perceived benefits subscales. Helplessness was defined as focusing on the negative consequences of the disease and generalizing them to functions in daily life. Acceptance was defined as acknowledging being chronically ill and perceiving the ability to manage the negative consequences of the disease. Perceived benefits were defined as positive, long-term consequences of the disease (eg, becoming a stronger person).

Finally, social support was assessed by determining qualitative and quantitative aspects of social support in the past 6 months, as measured by the ISDL. The quantitative aspect was assessed by the size of the social network. Patients were asked to fill in the number of friends or family members with whom they associated. The qualitative aspect was measured with a 5-item subscale that
measured perceived availability of emotional and instrumental support.

STATISTICAL ANALYSES

Square root transformation was applied owing to skewed distributions of scores for depressed mood. Social network scores were categorized according to reference classes. The mean and standard error of the mean of the psychological distress scores (anxiety and depressed mood) for patients with morphea and eosinophilic fasciitis were compared with reference values from healthy Dutch persons described in the ISDL manual. To assess risk groups for psychological distress, the number of patients with scores for anxiety and depressed mood equal to or higher than the mean scores of psychiatric outpatients was determined by comparing their scores with mean scores of representative norm Dutch groups of psychiatric outpatients described in the manual who were considered at risk for psychological distress.

The relationship between the predictors (skin severity, physical symptoms, impact of disease on daily life, illness cognitions, social support, demographic variables, and time since diagnosis) and psychological distress (anxiety and depressed mood) was explored by calculating Pearson correlation coefficients for all patients with sclerotic skin disease. Sequential regression analyses were performed to study the relative contribution of the physical and psychosocial factors to psychological distress. Anxiety and depressed mood were used as indicators of psychological distress and were the dependent variables. The different predictors were entered in consecutive steps in the regression analyses to test their additional contribution in terms of significant F-change, after having taken into account the variance explained by the other predictors. The grouping of variables in a step and the entry order of the steps were determined a priori by the stress-vulnerability model by first entering disease-related predictors (eg, indicators of severity of skin disease and physical symptoms were entered before psychosocial factors of disease-related stressors, illness cognitions, and social support). The strength of the β value (standardized regression coefficient) and the accompanying t test were used as an indicator for the relative contribution of a predictor compared with all other predictors tested in the model, independent of entry order. Differences were considered statistically significant at P < .05. Statistical analysis was performed using SPSS statistical software, version 14 (SPSS Inc, Chicago, Illinois).

RESULTS

SAMPLE CHARACTERISTICS

Of 120 patient questionnaires, 81 (67.5%) were returned. Because of missing answers, only 74 questionnaires (61.7%) were suitable for analysis. No significant differences were found between responders and nonresponders with regard to sex, age, educational level, severity of skin disease, time since diagnosis, and morphea subtype. The mean (SEM) age of all patients was 47.0 (2.2) years (Table 1). Twenty-two of 74 patients (29.7%) experienced comorbidities.

LEVELS AND PREDICTORS OF PSYCHOLOGICAL DISTRESS

In general, mean anxiety and depressed mood scores were higher for patients with sclerotic skin diseases than healthy Dutch persons. Patients with eosinophilic fasciitis and generalized morphea reported the highest degree of psychological distress (Table 1). Finally, 28 patients (38%) with a localized sclerotic skin disease had scores equal to or higher than those of psychiatric outpatients and could be considered to be psychologically at risk.

Correlation between predictors (skin severity, physical symptoms, stressors, illness cognitions, and social support) and psychological distress (depressed mood and anxiety) are presented in Table 2. As expected, there was a strong correlation between higher levels of psychological distress and a more severe skin disease, increased pain and fatigue, greater disease effects on daily life, more stigmatization, illness cognitions of greater helplessness, and less acceptance and social support. Depressed mood was related to itching, and anxiety was related to expressing fewer perceived benefits.

We controlled for the influence of demographic variables by calculating correlations between sex, age, educational level, comorbidity, duration of sclerotic disease, and levels of psychological distress. Because no correlations were significant, these variables were not included in the regression analyses.

Multiple regression analyses were performed to examine the relative contribution of the study variables to psychological distress level (Table 3). Severity of skin disease explained 7% of the variance, and physical symptoms of itching, pain, and fatigue explained 15% of the variance in anxiety levels (F-change = 3.39; P < .05). Disease effects on daily life and stigmatization explained 31% of the variance in depressed mood (F-change = 14.18; P < .001) and 16% of the variance in anxiety levels (F-change = 6.29; P < .01). Illness cognitions explained another 8% of the variance in depressed mood (F-change = 2.87; P < .05) and 14% in anxiety levels (F-change = 4.74; P < .01). Finally, social support explained 14% of the variance in anxiety levels (F-change = 9.24; P < .001).

When the relative contribution of predictors was compared, β coefficients for the entire model indicated partly corresponding predictors for depressed mood and anxiety, ie, illness cognition of less acceptance significantly predicted psychological distress in patients with a sclerotic skin disease (acceptance: t = −2.09; P < .05 for depressed mood and t = −2.60; P < .05 for anxiety). In addition, more itching (t = −2.09; P < .05) and more perceived stigmatization (t = 2.14; P < .05) also predicted greater depressed mood, whereas impact of disease on daily life (t = −2.18; P < .05) and more helplessness (t = 2.09, P < .05), as well as less perceived social support (t = −4.26; P < .001), additionally predicted higher anxiety levels in patients with a sclerotic skin disease.
In the present study, psychological distress and contributing factors were examined in adult patients with morphea or eosinophilic fasciitis. Of patients with a localized sclerotic skin disease, 28 (38%) showed levels of anxiety or depressed mood comparable to those of psychiatric outpatients and could be considered psychologically at risk. Of all patients, those with generalized morphea and eosinophilic fasciitis reported the highest degree of distress and heightened levels of anxiety and depressed mood.12,13

Higher levels of psychological distress (depressed mood and anxiety) were significantly related to having more severe skin disease; more pain, fatigue, stigmatization, and helplessness; greater disease effects on daily life; and less acceptance and social support. When comparing the relative contributions of different predictors, less acceptance of illness most consistently predicted psychological distress in patients with a sclerotic skin disease. In addition, more itching and more stigmatization also predicted greater depressed mood. Finally, greater impact of disease on daily life, more helplessness, and lower perceived support also predicted higher anxiety levels among patients with a sclerotic skin disease.

A comprehensive set of physical, psychological, and social factors were relevant to psychological distress in patients with a sclerotic skin disease. In interpreting these findings, it is important to realize that the questionnaires were distributed at a random point in time, when only a few patients were actively being treated for skin disease. Therefore, the present study might have underestimated the presence and severity of psychological distress among patients.6 Other limitations of the study are the absence of a control group and the small sample size, which limit opportunities for comparison. In addition, explorative assessments of comorbidities indicate the need for further research. Disease severity was assessed by patients rather than physicians. Other psychological factors shown to be possibly relevant in patients with a chronic disease, such as coping strategies and personality characteristics,7,14-17 should be taken into account in...
any further studies. Furthermore, the strength of the correlations between psychological distress and self-reported disease severity, determined by the ISDL severity score and physical symptoms of pain, itch, and fatigue were moderate, suggesting that the severity of skin disease and physical burden of the condition partly contribute to patients’ distress but that other factors, such as perceived stigmatization and acceptance of the diseases, are of equal importance. However, this study is the first, to our knowledge, to describe the level of psychological distress and its contribution in patients with a localized sclerotic skin disease.

The ISDL is a validated self-report instrument for patients with atopic dermatitis and psoriasis, and most subscales have also previously been validated in studies of other chronic diseases, such as rheumatic conditions or multiple sclerosis.\(^4\,7,10\) However, in the present study, these factors were studied for the first time in patients with sclerotic skin diseases. The results of this study are comparable to the findings in studies of other chronic skin diseases, such as psoriasis and atopic dermatitis,\(^4,10\) as well as to those in studies of chronic skin disease using other instruments, such as the Skindex or the Impact of Rheumatic Diseases on General Health and Lifestyle scale, to measure quality of life.\(^18\)

Consistent with biopsychosocial models of chronic diseases and related models for skin conditions,\(^10,19\) researchers are increasingly considering the general and dermatological implications of chronic skin diseases. The ISDL is a reliable and valid self-report inventory that gauges the effects of a condition on daily living by assessing common generic health and dermatological aspects of chronic skin diseases. An additional advantage of the ISDL is that the generic scales used (eg, psychological distress, illness cognitions) have already been tested in patients with other chronic physical conditions, which has yielded reference ranges for patients with rheumatoid arthritis, fibromyalgia, and multiple sclerosis, among other populations.\(^10,20\) Results of the present study show that levels of psychological distress and its predictors are comparable to those in patients with other chronic diseases\(^7,21\) as well as to findings from other widely used quality-of-life scales, such as the Dermatology Life Quality Index or the Skindex.\(^10,20,22\)

### Table 2. Correlating Depressed Mood and Anxiety With ISDL Subscales

<table>
<thead>
<tr>
<th>ISDL Subscale</th>
<th>Depressed Mood</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning (0.26(^b))</td>
<td>0.27(^b)</td>
<td></td>
</tr>
<tr>
<td>Skin disease severity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical symptoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Itch (0.44(^c))</td>
<td>0.15</td>
<td></td>
</tr>
<tr>
<td>Pain (0.24(^b))</td>
<td>0.25(^b)</td>
<td></td>
</tr>
<tr>
<td>Fatigue (0.38(^c))</td>
<td>0.44(^c)</td>
<td></td>
</tr>
<tr>
<td>Stressors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact of disease on daily life (0.41(^c))</td>
<td>0.32(^c)</td>
<td></td>
</tr>
<tr>
<td>Stigmatization (0.48(^c))</td>
<td>0.40(^c)</td>
<td></td>
</tr>
<tr>
<td>Illness cognition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helplessness (0.49(^c))</td>
<td>0.40(^c)</td>
<td></td>
</tr>
<tr>
<td>Acceptance</td>
<td>-0.64(^c)</td>
<td>-0.67(^c)</td>
</tr>
<tr>
<td>Perceived benefits</td>
<td>-0.17</td>
<td>-0.29(^b)</td>
</tr>
<tr>
<td>Social support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived support</td>
<td>-0.35(^c)</td>
<td>-0.55(^c)</td>
</tr>
<tr>
<td>Social network</td>
<td>-0.36(^c)</td>
<td>-0.27(^b)</td>
</tr>
</tbody>
</table>

Abbreviation: ISDL, Impact of Chronic Skin Disease on Daily Life scale.
\(^a\) A positive correlation indicated that anxiety or depressed mood is related to having a more extensive skin disease; more itching, pain, or fatigue; greater impact of disease on daily life; more stigmatization or helplessness; and less acceptance, less perceived disease benefits, and less social support.

\(^b\) \(P < .05\).
\(^c\) \(P < .01\).

### Table 3. Multiple Regression Analysis Predicting Psychological Distress in Patients With a Sclerotic Skin Disease

<table>
<thead>
<tr>
<th>ISDL Subscale</th>
<th>Depressed Mood (R^2)^b</th>
<th>Anxiety (R^2)^b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning (NS)</td>
<td>0.06</td>
<td>NS</td>
</tr>
<tr>
<td>Skin disease severity</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Physical symptoms (0.08)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Itch (0.30(^c))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain (NS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue (NS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stressors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact of disease on daily life (0.31(^d))</td>
<td>0.46(^c)</td>
<td></td>
</tr>
<tr>
<td>Stigmatization (0.31(^c))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness cognition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helplessness (NS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acceptance (0.08(^c))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived benefits (NS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived support (NS)</td>
<td>-0.38(^c)</td>
<td>-0.42(^c)</td>
</tr>
<tr>
<td>Social network</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (R^2)^d</td>
<td>...</td>
<td>0.57(^d)</td>
</tr>
</tbody>
</table>

Abbreviations: ellipses, not applicable; ISDL, Impact of Chronic Skin Disease on Daily Life scale; NS, not significant.
\(^a\) Standardized \(\beta\) and \(t\) tests indicate the significant predictors when comparing all predictors in the regression model.
\(^b\) Percentages explained variance in the different steps of the regression model (\(F\)-change).
\(^c\) \(P < .05\).
\(^d\) \(P < .001\).
\(^e\) \(P < .01\).
Previously, no information was available regarding psychological well-being in patients with morphea or eosinophilic fasciitis. Health care providers should be aware that more than a third of patients with a localized sclerotic skin disease (localized scleroderma and eosinophilic fasciitis) had anxiety or depressed mood levels comparable to those of psychiatric outpatients and could be considered psychologically at risk. Knowledge about psychological well-being is important, whereas impaired psychological well-being has been shown to have an unfavorable effect on dermatological treatment outcomes, and therefore on disease severity. Consequently, it is important to know which contributors most effectively predict psychological distress.

Assessment of the physical symptoms of fatigue and pain, impact of disease on daily life, the illness cognitions of helplessness and acceptance, and level of social support can give additional information about patients with sclerotic skin disease at risk of psychological distress. Therefore, this assessment can be used to design better treatment plans for such patients. In practice, patients with a sclerotic skin disease could potentially benefit from multidisciplinary treatment options that focus on reducing fatigue and pain (eg, focusing on sleep disturbances, rest-activity balance, and providing patients with adequate medication against pain), changing perceived stigmatization and helpless attitudes about the disease (eg, social anxiety training, cognitive restructuring of depressogenic cognitions), and promoting social support (eg, mobilizing social support from significant others).

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Correspondence: Elisabeth B. M. Kroft, MD, PhD, Radboud University Nijmegen Medical Centre, PO Box 9101, NL-6500 HB Nijmegen, the Netherlands (i.kroft@rug.nl).
Author Contributions: Drs Kroft and de Jong had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: Kroft, de Jong, and Evers. Acquisition of data: Kroft and de Jong. Analysis and interpretation of data: Kroft, de Jong, and Evers. Drafting of the manuscript: Kroft and de Jong. Critical revision of the manuscript for important intellectual content: Kroft, de Jong, and Evers. Administrative, technical, or material support: Kroft. Study supervision: Kroft, de Jong, and Evers.
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