CLINICAL REPORT

Illness Perception and Psychological Distress in Persons with Porphyria Cutanea Tarda

Janice ANDERSEN[1,2], Karin NORDIN[1,3] and Sverre SANDBERG[1,2]
[1]Department of Global Health and Primary Health Care, University of Bergen, [2]Norwegian Porphyria Centre (NAPOS), Laboratory for Clinical Biochemistry, Haukeland University Hospital, Bergen, Norway, and [3]Department of Public Health and Caring Sciences, Uppsala University, Sweden

Porphyria cutanea tarda (PCT) requires long-term treatment and follow-up, although many patients experience life-long remission. The aim of this cross-sectional postal survey was to describe and investigate the association between illness perception, health complaints, self-reported symptoms and distress in persons with PCT. The participants perceived PCT as a chronic condition with high levels of personal and treatment control. Persons who reported active symptoms scored higher on perceived illness threat, total health complaints and psychological distress compared with those in remission or latent phases. However, a higher perception of illness threat and the total burden of health complaints were more closely associated with psychological distress than were perceived PCT symptoms activity. This has implications for clinical consultation; dermatologists should be attentive to symptoms activity, but also recognize that patients in remission with a high perceived illness threat and multiple health complaints might be especially vulnerable to psychological distress with regards to PCT. ***Key words: porphyria cutanea tarda; illness perception; psychological distress; subjective health complaints; psychosocial*.**

Accepted Jan 14, 2016; Epub ahead of print Jan 18, 2016

Acta Derm Venereol 2016; 96: 674–678.

Janice Andersen, Department of Global Health and Primary Health Care, University of Bergen P.b. 7804, NO-5020 Bergen, Norway. E-mail: jan004@igs.uib.no, jacd@helse-bergen.no

Porphyria cutanea tarda (PCT) is the most common form of the porphyrias, a group of rare and mainly inherited metabolic diseases caused by reduced enzyme activity in the haem synthetic pathway (1). The prevalence is estimated at 1 in 10,000 (2), and approximately 50% of cases in Norway are hereditary, with a 10% penetrance (3). PCT symptoms usually present in late adulthood as skin fragility, blistering, milia, hypertrichosis and increased pigmentation on sun-exposed areas, and can be triggered by iron overload, hepatic conditions, oestrogens and high alcohol intake. Treatment includes avoidance of precipitating factors, phlebotomy and/or administration of chloroquine (1, 4). Complete clinical remission can take up to 6–12 months (5, 6), but the prognosis is good, and lifelong remission is common. Guidelines suggest that urinary porphyrin concentration, iron and liver function should be assessed annually in order to detect relapses (1, 4). Patients in biochemical remission have normal tolerance for sunlight.

Very little is known about the subjective experiences of PCT and, to our knowledge, only 2 previous research reports have focused on the psychosocial aspects of PCT. Jong et al. (7) found that PCT had less impact on quality of life (QoL) than did other cutaneous porphyrias and photodermatoses in general. However, only 12 persons with PCT participated in the study, and the results should therefore be interpreted with caution. In contrast, a previous qualitative study found that PCT symptoms at their worst could be very dramatic and have a large psychosocial impact. The participants had a perception of the condition as systemic and chronic, and had a tendency to attribute a range of health problems to PCT. There were also reports of over-treatment, and frequent controls for patients in long-term remission (8). PCT patients are a heterogeneous group, comprising persons with active symptoms, those in remission and asymptomatic mutation carriers (latent PCT), and they require various degrees of treatment and long-term follow-up. To optimize patient care it is, therefore, important to expand our understanding of how PCT is perceived and experienced by the patients themselves.

The aims of the present study were: (*i*) to describe and compare illness perception, self-reported health complaints and psychological distress in persons with various activity of PCT; and (*ii*) to examine the associations between illness perception, self-reported health complaints, PCT symptoms, and psychological distress.

PATIENTS AND METHODS

Design

A cross-sectional survey comprising a battery of self-evaluative questionnaires was posted to all persons older than 18 years with PCT registered at the Norwegian Porphyria Centre (NAPOS). The study was approved by the Norwegian Regional Ethics Committee (2010/1140) and complies with the Declaration of Helsinki.

Sample and recruitment

NAPOS conducts nationwide diagnostics based on biochemical and DNA analysis in addition to predictive genetic testing. Almost all persons with a known porphyria diagnosis in Norway are regis-

doi: 10.2340/00015555-2339

tered at NAPOS. Participants were recruited by NAPOS in May 2010. Follow-up reminders were sent to non-responders in June and October the same year. Diagnosis was based on analysis of urinary and faecal porphyrins in addition to plasma fluorescence scanning and uroporphyrogen decarboxylase (UROD) DNA analysis according to established criteria (9). "Sporadic" PCT patients, for whom porphyria analysis had not been performed in the past 10 years, were excluded from the study, based on the assumption that they had not experienced any PCT symptoms in the past 10 years.

Participants were categorized as having active PCT (porphyria symptoms in the day or week of the survey), PCT in remission (previous symptoms, but not at present) or latent PCT (mutation carriers who had never experienced PCT symptoms). Categorization was based on self-reports and was assessed by the following question in the questionnaire: "Have you had any porphyria-related complaints/symptoms?" followed by the answer categories: 1, never; 2, previously; and 3, have today/this week.

Measures

Socio-demographic characteristics. The socio-demographic variables included sex, age, work status, educational level, cohabitation status and having children.

Patient-reported outcome measures

Illness perception. The Brief Illness Perception Questionnaire (BIPQ) (10, 11) assesses the illness representations as adapted from the common sense model of Leventhal et al. (12) and has satisfactory validity and reliability. The questionnaire comprises 8 items measuring different dimensions of illness perception: consequences, timeline, personal control, treatment control, identity concern, emotions and coherence (illness comprehensibility). Identity refers to the symptoms a person views as part of the disease. Responses are measured on a 0–10-point scale. An overall score was computed by summing across the 8 items. Higher scores reflect a higher perceived threat associated with the condition (13).

Self-reported health complaints. The Subjective Health Complaints (SHC) inventory measures self-reported health complaints during the past 30 days on a 0–3 point Likert scale and without mapping the diagnosis or symptom attributions. The instrument is a 29-item scoring system that is categorized into 5 factors: musculoskeletal, pseudoneurology, gastrointestinal, allergy, and influenza complaints (14, 15). The instrument has satisfactory reliability and validity (15). In the present study, only the mean total sum score was assessed.

Porphyria-related psychological distress. The Impact of Events Scale (IES) measures psychological distress defined as the degree of impact of a specific event experienced at present, in this instance, porphyria. The responses are measured on 2 subscales: intrusion and avoidance. Intrusion is characterized by unbidden thoughts and strong waves of feelings, and avoidance includes denial of the meanings and consequences of the event. The scale comprises 15 items: 7 on intrusion and 8 on avoidance. The responses are assessed on a 0–5-point Likert scale. The psychometric properties have been found to be satisfactory (16, 17).

Statistical analysis

Statistical analyses were performed using IBM SPSS Statistics Version 22.0 (Armonk, NY, USA). Most analyses were based on the 3 subgroups: active, remission and latent PCT. If more than 50% of the items were missing, the sum scores were not calculated for the IES subscales and the SHC inventory total (15). When calculating the overall score on the BIPQ, items 3, 4 and 7 were reversed according to the manual. If any items were missing on the BIPQ, the overall score was not calculated (13).

Differences in socio-demographic variables were investigated using Pearson's χ^2 test for independence for categorical variables. Separate 1-way Welch analysis of variance (ANOVA) was used to determine whether the scores on the BIPQ, SHC and IES subscales differed between the 3 PCT subgroups. There were some outliers and non-normality. As a sensitivity test we used a Kruskal–Wallis non-parametric test, which identified the same significant outcome measures as the ANOVA.

To investigate the associations between illness perceptions, self-reported health complaints and porphyria-related psychological distress, 2 separate multiple linear regression analyses were conducted. The IES subscales intrusion and avoidance were the dependent variables and age, sex, SHC inventory total score, BIPQ total score and perceived PCT symptoms were entered as the predictors in the models. PCT symptoms were dichotomized into present symptoms (active PCT) or not present symptoms (remission and latent PCT). Twenty and 27% of the participants scored a total of 0 on the intrusion and avoidance subscales, respectively, thus creating a "floor effect". To meet the assumption of normality, those participants scoring a total of 0 on the IES subscales were removed from the multiple linear regression analysis. This resulted in a total of 185 (IES intrusion subscale) and 168 (IES avoidance subscale) for the regression analysis. Those scoring 0 on the subscales were distributed as follows: intrusion: active symptoms, $n=6$, not active symptoms, $n=51$; avoidance: active symptoms, $n=7$, not active symptoms, $n=61$. The assumptions of linearity, independence of errors, homoscedasticity and extreme outliers were met. Violation of the assumption of normality of residuals was addressed through logarithmic transformation of the outcome measure variables.

To investigate the likelihood of scoring 0 or >0 on the IES subscales, logistic regression analyses were performed, using the same predictors and dependent variables as were specified in the multiple linear regression analyses.

RESULTS

A total of 484 persons registered with PCT were sent a postal questionnaire, and 272 were returned (56%). Nine participants were excluded from further analysis because of a missing response to the question categorizing participants into having active PCT, PCT in remission or latent PCT. A total of 263 (54%) questionnaires were eligible for further analysis.

Socio-demographic characteristics

Of the 263 respondents, 57 reported having present active PCT, 172 had PCT in remission and 34 reported latent PCT. For the total sample, the mean age was 59 years (range 25–88 years). Significant socio-demographic differences were found between the groups with regards to sex, age, and occupational and educational status. The active PCT group had more men than women, and the latent group had considerably more women. The mean age was >10 years younger in the latent PCT group than in the remission and active groups. For occupational status, 70% of the latent group reported being employed compared with 33% of the active group. Higher percentages of the active and remission groups than the latent group claimed disability benefits or were retired (Table I).

Table I. Socio-demographic characteristics of the sample

	Porphyria cutanea tarda; *n* (%) or mean (range)				
	Total *n* = 259–263	Active *n* = 57 (22)	In remission *n* = 172 (65)	Latent *n* = 34 (13)	*p*-value
Sex					
Male	121 (47)	34 (60)	78 (46)	9 (27)	
Female	141 (53)	23 (40)	93 (54)	25 (73)	0.01*
Age, years	59 (25–88)	61 (29–87)	60 (25–88)	49 (31–87)	< 0.01*
Occupational status					
Working	117 (44)	19 (33)	74 (43)	24 (70)	
Retired	77 (30)	18 (32)	56 (33)	3 (9)	
Disability pension	54 (20)	14 (25)	36 (21)	4 (12)	
Other	15 (6)	6 (10)	6 (3)	3 (9)	< 0.01*
Educational status					
Secondary school	58 (23)	10 (18)	45 (27)	3 (8)	
High school	117 (45)	32 (56)	71 (42)	14 (41)	
College/university	84 (32)	15 (26)	52 (31)	17 (50)	0.03*
Cohabitation					
Living alone	66 (25)	16 (29)	43 (25)	7 (21)	
Cohabitant	196 (75)	40 (71)	129 (75)	27 (79)	0.70
Children					
Yes	232 (89)	54 (96)	146 (85)	32 (94)	
No	30 (11)	2 (4)	26 (15)	2 (6)	0.51

**p*-value < 0.05. For categorical variables, *p*-values were calculated with χ^2 test for independence or Fisher's exact test when expected cell frequencies were < 5. *p*-value calculated with one-way analysis of variance (ANOVA) for continuous variables (age). Tukey's *post-hoc* test showed that there were no significant differences between active and remission groups, but between latent and both remission and active sub-groups.

Patient-reported outcome measures

The total sample scored > 8 on the timeline item on the BIPQ, indicating a high belief in the condition being chronic. The active PCT group had significantly higher perceived illness threat compared with the other PCT subgroups. They also had considerably higher mean scores on the identity item, meaning that they believed more symptoms were caused by PCT compared with remission and latent PCT. The total sample had a relatively high perception of coherence and personal control. On the treatment control item, the total sample scored even higher; although the remission group scored highest.

The active PCT group had a significantly higher mean score on total intensity and frequency of subjective health complaints compared with the remission and latent PCT subgroups. The active PCT group had a higher mean value on reported psychological distress (intrusion and avoidance) than the remission subgroup, which had a higher mean score than the latent group (Table II).

Associations between illness perception, health complaints, self-reported porphyria cutanea tarda symptoms and psychological distress

When investigating the associations between illness perception, health complaints, self-reported PCT symptoms and psychological distress, we found that illness perception and total score on subjective health complaints were significantly associated with a higher score on the intrusive scale and that the total model explained 30% of the variance. The same predictors were also significantly associated with the avoidance score and explained 20% of the variance. The self-reported presence of PCT symptoms were not significantly associated with psychological distress related to porphyria (Table III). This means that although participants reporting active PCT scored higher on perceived illness threat, total health complaints and porphyria-related psychological distress, PCT symptoms activity was not significantly associated with psychological distress.

We used the same predictors to investigate the probability of scoring > 0 on the IES avoidance and intrusion scales. Logistic regression analysis produced a significant model that confirmed that a higher score on total illness perception and more self-reported health complaints were significantly associated with scoring > 0 on porphyria-related psychological distress.

Table II. Scores on the Brief Illness Perception Questionnaire, Subjective Health Complaints Inventory and Impact of Events Scale (IES)

Patient-reported outcome measures	All participants Mean (95% CI)	Active PCT Mean (95% CI)	PCT in remission Mean (95% CI)	Latent PCT Mean (95% CI)	*p*-value	Cronbach's α
Brief Illness Perception Questionnaire (0–10)	(*n* = 235–261)	(*n* = 51–57)	(*n* = 156–170)	(*n* = 28–34)		
Consequences	3.2 (2.9–3.5)	4.9 (4.1–5.7)	2.9 (2.5–3.3)	1.6 (1.0–2.2)	< 0.01*	
Timeline	8.1 (7.7–8.5)	8.8 (8.2–9.4)	8.0 (7.5–8.4)	7.3 (5.8–8.8)	0.05*	
Personal control	5.8 (5.5–6.2)	5.4 (4.7–6.2)	6.2 (5.7–6.6)	4.9 (3.4–6.3)	0.9	
Treatment control	7.5 (7.1–7.8)	7.6 (6.9–8.4)	7.7 (7.2–8.1)	6.1 (5.2–7.1)	0.02*	
Identity	2.9 (2.6–3.3)	5.8 (5.2–6.5)	2.6 (2.2–2.9)	0.2 (0.0–0.3)	< 0.01*	
Concern	3.4 (3.0–3.7)	4.8 (4.0–5.6)	3.2 (2.8–3.6)	1.9 (1.2–2.7)	< 0.01*	
Coherence	5.6 (5.2–6.0)	5.9 (5.2–6.6)	5.7 (5.2–6.1)	4.7 (3.7–5.7)	0.12	
Emotional response	2.9 (2.5–3.2)	4.4 (3.6–5.3)	2.7 (2.3–3.0)	1.3 (0.7–1.9)	< 0.01*	
Overall score	31.5 (29.9–33.2)	39.6 (35.8–43.4)	29.7 (27.9–31.5)	27.2 (23.3–31.1)	< 0.01*	0.67
Subjective health complaints	(*n* = 255)	(*n* = 56)	(*n* = 166)	(*n* = 33)		
Total sum score	15.1 (13.6–16.7)	20.5 (16.7–24.2)	14.1 (12.4–15.8)	10.7 (7.7–13.7)	< 0.1*	0.88
Impact of Events Scale	(*n* = 258)	(*n* = 57)	(*n* = 169)	(*n* = 32)		
Intrusion (0–35)	7.0 (6.0–7.9)	11.7 (9.1–14.3)	6.1 (5.1–7.1)	3.0 (1.6–4.4)	< 0.01*	0.93
Avoidance (0–40)	7.2 (6.2–8.1)	12.1 (9.5–14.7)	6.1 (5.1–7.1)	4.3 (2.2–6.4)	< 0.01*	0.85
Score above 0 on IES	(*n* = 206/189)	(*n* = 51/50)	(*n* = 136/120)	(*n* = 19)		
Intrusion	8.7 (7.7–9.7)	13.1 (10.5–15.8)	7.6 (6.5–8.6)	5.1 (3.1–7.0)	< 0.01*	
Avoidance	9.8 (8.7–10.9)	13.8 (11.1–16.4)	8.6 (7.5–9.7)	7.3 (4.4–10.1)	< 0.01*	

p-values for differences between means calculated using the Welch analysis of variance (ANOVA). **p*-value ≤ 0.05. PCT: porphyria cutanea tarda.

Table III. Multiple linear regression analysis with Impact of Events Score (IES) as the outcome measure

	Intrusion ($n = 185$)			Avoidance ($n = 168$)		
Variable	B	95% CI	*p*-value	B	95% CI	*p*-value
Constant	2.25	1.14–4.57	0.02	2.37	1.12–5.01	0.02
Age	0.99	0.98–1.00	0.11	1.00	0.99–1.01	0.87
Sex	1.09	0.86–1.34	0.44	1.13	0.86–1.47	0.38
SHC total	1.02	1.01–1.03	< 0.01*	1.02	1.01–1.04	< 0.01*
BIPQ total	1.03	1.01–1.04	< 0.01*	1.01	1.00–1.32	0.04*
PCT symptoms	1.24	0.92–1.68	0.15	1.31	0.94–1.81	0.11
Adjusted R^2			0.30			0.20

*$p \leq 0.05$. The total model was significant ($p < 0.001$). Analysis was performed on log-transformed outcome variables. The estimates and confidence intervals (CI) presented in the table were back-transformed to the original units of measure. Participants scoring 0 on the IES subscales (Intrusion $n = 57$ and Avoidance $n = 68$) were removed from the regression analysis. SHC: Subjective Health Complaints; BIPQ: Brief Illness Perception Questionnaire.

DISCUSSION

The current study found a trend towards higher perceived illness threat, more self-reported health complaints and more porphyria-related psychological distress in participants reporting active PCT compared with those reporting latent PCT or PCT in remission. However, the regression analysis did not support an association between PCT symptoms and higher scores on porphyria-related distress. By contrast, perceived illness threat and total health complaints were associated with greater porphyria-related distress.

The finding that perceived illness threat, and not reported symptoms activity, was associated with porphyria-related distress suggests that, although PCT symptoms can be dramatic, PCT in remission can also be challenging for patients. Exactly what it is that makes some patients view PCT as a threatening disease cannot be answered by the present study. In view of the results showing that total health complaints are associated with PCT-distress, and that our previous study (8) showed that PCT patients can find it difficult to separate PCT from other conditions, a possible explanation might be that health complaints other than skin symptoms are also thought to be caused by PCT, and this is contributing to patients reporting higher psychological distress. Others have shown that the perception of disease is associated with psychological distress and QoL in dermatological disorders (18–20), and despite the diverse aetiology, photodermatosis (21) can have a major impact on QoL (7), psychological well-being and lifestyle (22), which suggests that the management of photosensitivity disorders requires a biopsychosocial approach (18, 23) and that further studies are warranted investigating how PCT in both active and remission phases impacts QoL.

In agreement with the findings of our previous study using focus groups (8), we found an overall high belief in the condition being chronic. This can be viewed as positive, in that it might increase compliance with the guidelines for control and preventive measures. Annual assessment of urinary porphyrin excretion, iron metabolism and liver function are recommended (1). On the other hand, many patients with PCT are expected to experience life-long remission, and a high degree of perceived chronicity and illness threat can entail an ethically challenging situation with a potential for medicalization of this group. Our previous study found evidence of overtreatment; for example, frequent blood samples (every 2 weeks and every month) in patients in remission (8).

Participants with active PCT scored significantly higher on total self-reported health complaints compared with the remission and latent PCT groups. Various hepatic conditions, haemochromatosis and lifestyle factors, such as high alcohol intake and smoking, are associated with active PCT (1, 4, 24) and might contribute to explaining this finding in patients reporting active PCT. The finding that PCT is associated with other diseases may also have impacted on illness perception. Although data about this (i.e. alcoholism, hepatitis, etc.) was not investigated in the present study, the illness perception measurement (BIPQ) was porphyria specific and is expected to reflect the perception of PCT independent of other conditions.

The socio-demographic differences between the PCT groups might also explain some of the observed differences. Although there were more men than women in the active PCT group, women are generally known to report more substantial health complaints (25). An alternative explanation is that attribution of health complaints to PCT could have resulted in a "false" self-reported classification of PCT activity, which is consistent with the findings of our earlier study in which participants reported experiencing PCT as a systemic disease suspected to cause a range of health complaints (8). The active PCT group also scored significantly higher on the identity item, indicating that this group attributed more symptoms to PCT.

Whether or not PCT is a distress-causing life-event, is debatable. Previous findings have, however, shown that PCT could certainly have a large negative psychosocial impact for some (8). In the present study, we did not use individual cut-off values to differentiate between distress and no distress, but rather tried to identify the factors associated with higher distress scores. Individual scores > 9 on the IES subscales have been used as an indication of distress of a moderate character (26). Others have suggested a total sum score of ≥ 40 as signifying a stressful event (27). Although these cut-off values are intended for assessment on an individual level, it is interesting to note that, as a group, those reporting active PCT had a mean score on the intrusion and avoidance subscales in the "moderate distress" category.

A positive finding was that the total PCT sample reported relatively high scores on coherence (understanding of the condition) and personal control. A high belief in treatment control was also reported, and the remission group reported the greatest belief in treatment, which indicates that they experienced their treatment as adequate and effective, which fits well with previous findings (8).

Compared with the personal control scores in those with contact dermatitis (mean 3.5) (19), the PCT patients had a greater belief in their own control of the condition.

The classification of participants into active PCT, PCT in remission, and latent PCT was based on self-reported information. Although this study was aimed specifically at exploring the subjective experiences of the participants and their own interpretation of their situation with regards to PCT, a dermatology-specific instrument and objective evaluation of symptoms could have strengthened the study. A response rate of 54% is somewhat low and can be viewed as a limitation in terms of representability.

In the present study, PCT was perceived as a chronic condition with a high degree of treatment control. Although persons reporting active PCT had more health complaints and perceived PCT as more threatening compared with those reporting latent PCT or PCT in remission, psychological distress was more closely associated with a higher perception of illness threat and the total burden of health complaints than were perceived PCT symptoms. This has implications for clinical consultations with this patient group. It seems evident that PCT patients need clear and concise information and guidance with regards to what health complaints are caused by PCT.

ACKNOWLEDGEMENTS

This study was funded by research grants from the Western Norwegian Regional Health Authorities. The authors would like to thank Karl Ove Hufthammer for valuable assistance with statistical analyses, and Egil Støle and Jørild Haugen for extensive assistance in recruitment of participants to the study.

REFERENCES

1. Puy H, Gouya L, Deybach JC. Porphyrias. Lancet 2010; 375: 924–937.
2. Mykletun M, Aarsand AK, Stole E, Villanger JH, Tollanes MC, Baravelli C, et al. Porphyrias in Norway. Tidsskr Nor Laegeforen 2014; 134: 831–835.
3. Aarsand AK, Boman H, Sandberg S. Familial and sporadic porphyria cutanea tarda: characterization and diagnostic strategies. Clin Chem 2009; 55: 795–803.
4. Kauppinen R. Porphyrias. Lancet 2005; 365: 241–252.
5. Frank J, Poblete-Gutierrez P. Porphyria cutanea tarda – when skin meets liver. Best Pract Res Cl Ga 2010; 24: 735–745.
6. Sarkany RP. The management of porphyria cutanea tarda. Clin Exp Dermatol 2001; 26: 225–232.
7. Jong CT, Finlay AY, Pearse AD, Kerr AC, Ferguson J, Benton EC, et al. The quality of life of 790 patients with photodermatoses. Br J Dermatol 2008; 159: 192–197.
8. Andersen J, Gjengedal E, Sandberg S, Raheim M. A skin disease, a blood disease or something in between? An exploratory focus group study of patients' experiences with porphyria cutanea tarda. Br J Dermatol 2015; 172: 223–229.
9. Badminton MN, Whatley SD, Deacon AC, Elder GH. The porphyrias and other disorders of porphyrin metabolism. In: Burtis CA, Ashwood ER, Bruns DE, editors. Clinical chemistry and molecular diagnostics. 5th edn. New York: Elsevier Saunders; 2012. p. 1031–1054.
10. Broadbent E, Petrie KJ, Main J, Weinman J. The Brief Illness Perception Questionnaire. J Psychosom Res 2006; 60: 631–637.
11. Broadbent E. BIPQ Norwegian version http://www.uib.no/ipq/html/citing.html. [accessed 03 Feb 2015]. Available from: http://www.uib.no/ipq/html/citing.html.
12. Leventhal H, Nerenz DR, Steele DJ. Illness representations and coping with health threats. Handbook of psychology and health IV. NJ Erlbaum: Hillsdale; 1984. p. 219–252.
13. Broadbent E. The Brief Illness Perception Questionnaire Scoring instructions http://uib.no./ipq. [accessed 03 Feb 2015]. Available from: http://uib.no./ipq.
14. Eriksen HR, Ihlebaek C. Subjective health complaints. Scand J Psychol 2002; 43: 101–103.
15. Eriksen HR, Ihlebaek C, Ursin H. A scoring system for subjective health complaints (SHC). Scand J Public Health 1999; 27: 63–72.
16. Sundin EC, Horowitz MJ. Impact of event scale: psychometric properties. Br J Psychiat 2002; 180: 205–209.
17. Sundin EC, Horowitz MJ. Horowitz's impact of event scale evaluation of 20 years of use. Psychosom Med 2003; 65: 870–876.
18. Richards HL, Ling TC, Evangelou G, Brooke RC, Huber K, Gibbs NK, et al. Psychologic distress in polymorphous light eruption and its relationship to patients' beliefs about their condition. J Am Acad Dermatol 2007;56: 426–431.
19. Benyamini Y, Goner-Shilo D, Lazarov A. Illness perception and quality of life in patients with contact dermatitis. Contact Dermatitis 2012; 67: 193–199.
20. Cartwright T, Endean N, Porter A. Illness perceptions, coping and quality of life in patients with alopecia. Br J Dermatol 2009; 160: 1034–1039.
21. Bylaite M, Grigaitiene J, Lapinskaite GS. Photodermatoses: classification, evaluation and management. Br J Dermatol 2009; 161 Suppl 3: 61–68.
22. Stafford R, Farrar MD, Kift R, Durkin MT, Berry JL, Webb AR, et al. The impact of photosensitivity disorders on aspects of lifestyle. Br J Dermatol 2010; 163: 817–822.
23. Rizwan M, Reddick CL, Bundy C, Unsworth R, Richards HL, Rhodes LE. Photodermatoses: environmentally induced conditions with high psychological impact. Photochem Photobio Sci 2013; 12: 182–189.
24. Darwich E, To-Figueras J, Molina-Lopez RA, Deulofeu R, Olbina G, Westerman M, et al. Increased serum hepcidin levels in patients with porphyria cutanea tarda. J Eur Acad Dermatol 2013; 27: e68–74.
25. Ihlebaek C, Eriksen HR, Ursin H. Prevalence of subjective health complaints (SHC) in Norway. Scand J Public Health 2002; 30: 20–29.
26. Joseph S. Psychometric evaluation of Horowitz's Impact of Event Scale: a review. J Trauma Stress 2000; 13: 101–113.
27. Thewes B, Meiser B, Hickie IB. Psychometric properties of the Impact of Event Scale amongst women at increased risk for hereditary breast cancer. Psychooncology 2001; 10: 459–468.