

CLINICAL REPORT

Illness Perception in Primary Cutaneous T-cell Lymphomas: What Patients Believe About Their Disease

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There is currently no information available on illness perception in primary cutaneous T-cell lymphomas (CTCL). The aim of this study was therefore to gather initial information on disease understanding and interpretation in patients with CTCL. Consecutive patients from a hospital-based primary cutaneous lymphoma ward completed the Revised Illness Perception Questionnaire (IPQ-R) on 2 consecutive visits. A total of 24 patients with different variants of CTCL were included in the study. Patients experienced their condition as being long-lasting, but not fundamentally affecting their lives. Patients had poor belief in personal control, but strong belief in treatment control. They did not show a good understanding of their disease, and had a moderately negative emotional response to their illness. In conclusion, the IPQ-R provides a feasible and reproducible tool for measurement and better understanding of illness perception in patients with CTCL. Knowledge of patients' attitudes towards their disease should enable optimization of the patient–physician relationship and patient care. Key words: illness perception; primary cutaneous T-cell lymphoma; Revised Illness Perception Questionnaire; disease understanding.

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Illness perception describes patients' personal beliefs about their disease and the resulting psychosocial impact. The concept of illness perception is based on Leventhal's self-regulatory model and explores the relationship between illness, illness perceptions, coping processes and health outcomes (1, 2). According to this model, patients respond to symptoms and signs of illness by developing their own cognitive and emotional representations of the disease, which provide a basis for their own coping responses (1). A tool for quantitative assessment of illness perception, the Illness Perception Questionnaire (IPQ) was developed by Weinmann et al. (3) in 1996 and revised by Moss-Morris et al. (4) in 2002 (IPQ-R). The IPQ-R

comprises several key components of illness representation: timeline – acute/chronic (how long the patient thinks it will last); timeline cyclical (whether the course of disease is constant or cyclical); consequences (of the illness on a patient's life); personal control (how much influence a patient has on his or her illness); treatment control (the influence of treatment on the illness); illness coherence (a patient's understanding of the illness); and emotional representation (the extent to which a patient is emotionally affected by the illness). The IPQ and the IPQ-R have been used not only to evaluate illness perception in a wide range of conditions (rheumatoid arthritis, psoriasis, chronic obstructive pulmonary disease, chronic fatigue syndrome and diabetes) but also to address the relationship between beliefs about illness and health-related outcomes in various diseases, including asthma, myocardial infarction (MI) and cancer (5–21).

To date there is no data exploring illness perception in primary cutaneous lymphomas (PCL), a diverse group of non-Hodgkin's lymphomas (NHL) with initial presentation in the skin and no evidence of extracutaneous disease at the time of diagnosis. The annual incidence of PCL is estimated to be 1:100,000, with cutaneous T-cell lymphomas (CTCL) counting for approximately 71–77% of PCL (22). This heterogeneous disease group consists of PCL with indolent (e.g. mycosis fungoides (MF) and CD30⁺ lymphoproliferative disorders: lymphomatoid papulosis (LyP) and primary cutaneous anaplastic large cell lymphoma (C-ALCL)) or aggressive clinical behaviour (e.g. Sézary syndrome (SS) and extranodal natural killer T-cell lymphoma, nasal type). In the majority of cases CTCL follows an indolent course with slow progression over years or sometimes decades. However, this chronicity is aggravated, with an imminent, but uncertain, potential for progression. This characteristic, together with the disfigurement associated with a chronic skin disease and with the fact that treatment can be cumbersome, protracted, and rarely results in long-lasting remissions, should make our understanding of what patients with CTCL believe about their disease and how they cope with it of specific interest. However, to our knowledge there are no previous studies focusing on illness perception in CTCL. The aim of the present study was therefore to evaluate disease understanding and interpretation and

the feasibility of using an established questionnaire for this purpose in these particular patients.

MATERIALS AND METHODS

Consecutive patients of both sexes, diagnosed with CTCL, aged >18 years, attending a hospital-based primary cutaneous lymphoma ward were asked to participate in the study. CTCL diagnosis was made according to the World Health Organization – European Organisation for Research and Treatment of Cancer (WHO-EORTC) classification for cutaneous lymphomas (22). All patients were treated by the same dedicated physician. The study was carried out from December 2012 to September 2013. Written informed consent was obtained from each patient. To assess illness perception the German version of the IPQ-R was used. The 7 core IPQ-R illness dimensions: “timeline chronic”, “timeline cyclical”, “consequences”, “personal control”, “treatment control”, “illness coherence” and “emotional representation” are assessed by 32 items rated on a 5-point Likert-type scale, ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores indicate stronger perceptions of illness chronicity, a cyclical timeframe, negative consequences and greater emotional distress; lower scores indicate low perceived personal and treatment control over the illness and less understanding of the illness. The aggregate parameter scores range from 4 to 20 or 5 to 25, depending on the number of items that constitute the aggregate parameter.

A further section of the questionnaire addresses the patients’ beliefs about disease causes comprising stress or worry, inheritance, bacterial or viral infections, diet or eating habits, chance, poor medical care in the past, own behaviour, environmental pollution, personal emotional state, family problems or worries, overwork, mental attitude, ageing, alcohol, smoking, accident or injury and altered immunity.

For reproducibility, patients were asked to complete the questionnaire on 2 consecutive visits with a 3-month interval.

Statistical analysis

The scores for the 7 aggregated variables mentioned above were calculated separately for each questionnaire. Due to the exploratory nature of our study mainly descriptive statistics were used. In addition, differences between first and second interrogation were evaluated via the paired *t*-test. When differences between groups were calculated, the unpaired *t*-test was used. For all calculations either IBM SPSS Statistics Version 22.0 or Microsoft Office 2013 were used. *p*-values <0.05 were regarded as significant. If not indicated otherwise, values are given as mean ± standard deviation (SD).

RESULTS

A total of 24 patients (12 males, 12 females) with different variants of CTCL (for details see Table I) were included in the study and completed the IPQ-R at least once. Twenty-two patients (11 males, 11 females) repeated the test a second time at the 3-month follow-up. The median disease duration at the time of the first assessment was 28 months (range 0–208 months).

At the initial investigation participants generally experienced their condition as being long-lasting (timeline acute/chronic: 19.0 ± 2.8 , range 5–25), with only little variation in perception depending on disease course (stable disease or timely variation of disease severity

Table I. Patient characteristics

Diagnosis	Sex	Age, years
	M/F (n)	Median (range)
Mycosis fungoides	8/9 (17)	63 (25–88)
Stage IA	3/2 (5)	60 (54–76)
Stage IB	1/2 (3)	67 (48–71)
Stage IIA	2/0 (2)	50, 54
Stage IIB	2/5 (7)	56 (25–85)
Sézary syndrome	0/1 (1)	87
Lymphomatoid papulosis	2/1 (3)	65 (48–77)
Primary cutaneous CD4 ⁺ small/medium pleomorphic T-cell lymphoma	2/1 (3)	52 (34–77)
Total	12/12 (24)	60 (25–88)

e.g. skin involvement) (timeline cyclical: 10.7 ± 3.4 , range 4–20) (Table II). The leading causes of CTCL as assumed by patients were: chance (67%), immunosystem changes (64%), environmental pollution (36%), personal emotional condition (27%), ageing (27%), and personal attitude (27%).

Patients did not perceive their illness as drastically affecting their lives, with little negative consequences for their daily living (consequences: 11.6 ± 5.1 , range 5–25). Concerning control, patients had poor belief in personal control (10.8 ± 3.4 , range 4–20), but a stronger belief in treatment control (13.1 ± 3.4 , range 4–20). Regarding illness coherence patients showed a moderate disease understanding (illness coherence: 11.4 ± 3.6 , range 5–25). They had moderately negative emotional response to their illness (emotional representations: 15.0 ± 4.8 , range 5–25).

For the 22 patients who completed the IPQ-R a second time no significant differences in all aggregated variables could be observed (paired *t*-test).

To initially explore for gender-related differences in illness perception a gender-specific analysis was performed. A graphical representation of the results is given in Fig. 1, showing that women perceive the disease as more chronic than men (reaching statistical significance at the time of the first visit at $p=0.021$) and that they tend to be more emotionally affected by the disease compared with men.

DISCUSSION

Studies on illness perception in cancer are sparse and the few studies available are on breast, head and neck, colorectal and lung cancer, with one paper on a mixed group of cancer patients (including a small sample of patients with not otherwise specified skin cancer) (15, 19–21, 23–30). Studies focusing on illness perception in patients with CTCL have not been performed up to now. In the present study illness perception was measured on 2 different occasions with a 3-month interval with no specific therapeutic intervention, in order to assess the feasibility and reproducibility of the IPQ-R in this population and to gather initial results on

Table II. Aggregated scores for Revised Illness Perception Questionnaire (IPQ-R) illness dimensions in primary cutaneous T-cell lymphomas at first assessment and follow-up

IPQ-R dimension	Score range	Baseline, mean ± SD [Median (range)]	Follow-up, mean ± SD Median (range)	p-value
Timeline–acute/chronic	5–25	19.0 ± 2.8 [19.0 (13–25)]	18.8 ± 2.5 [19.0 (13–24)]	0.680
Timeline–cyclical	4–20	10.7 ± 3.4 [11.0 (4–17)]	10.7 ± 3.2 [10.5 (4–16)]	1.000
Consequences	5–25	11.6 ± 5.1 [11.5 (5–20)]	11.3 ± 4.2 [11.0 (5–19)]	0.699
Personal control	4–20	10.8 ± 3.4 [11.0 (4–19)]	11.6 ± 3.4 [12.0 (4–19)]	0.122
Treatment control	4–20	13.1 ± 3.4 [13.5 (8–20)]	13.3 ± 2.4 [13.5 (8–18)]	0.724
Illness coherence	5–25	11.4 ± 3.6 [10.0 (7–20)]	11.6 ± 3.6 [10.5 (6–19)]	0.725
Emotional representations	5–25	15.0 ± 4.8 [16.0 (5–25)]	14.0 ± 5.6 [15.0 (5–25)]	0.193

Higher scores indicate stronger perceptions of illness chronicity, a cyclical timeframe, negative consequences and greater emotional distress; lower scores indicate low perceived personal and treatment control over the illness and less understanding of the illness. SD: standard deviation.

the specific items and dimensions determined by the test. Our results indicate that, at the beginning and at 3-month follow-up, there is no statistically significant change in any of the assessed items.

Patients with CTCL experience their illness as chronic/long-lasting. This is in partial agreement with findings of Hopman & Rijken (23), who carried out a study among a random sample of cancer patients drawn from the Netherlands Cancer registry, assessing illness perception using the IPQ-R and the Mental Adjustment to Cancer Scale including all tumour types. Patients’ views on the chronicity of cancer varied, but many believed their illness to be long-lasting. Interestingly, recently treated patients perceived their illness as more chronic. CTCL, in the majority of cases, show a mild, indolent course with slow progression over years or sometimes decades. Secondary problems, such as severe itch in mycosis fungoides and Sézary syndrome or psychosocial problems due to the illness itself or its treatment, often continue for years. Therefore most forms of CTCL are regarded as chronic conditions, as has been shown in general by Stein et al. (31) for many other cancerous diseases. The results of our study show that, in this respect, the beliefs of our patients about the chronicity of their disease are correct.

Another notable result was that patients had limited belief in personal control, but a strong belief in treatment control. This might be attributed to our sample consisting of patients with a long disease duration. Among patients with acute disease, treatment and personal control percep-

tions may be less divergent. Similar results were shown in the patient sample of Hopman & Rijken (23), where a heterogeneous sample of 325 cancer patients showed a strong belief in the efficacy of their cancer treatment. In this study, in addition to illness perception, coping strategies of cancer patients were also assessed by using the Mental Adjustment to Cancer Scale. In general, there are 2 ways of coping: adaptive coping, where patients anticipate the problem/illness; for example, by planning or showing

fighting spirit; and maladaptive coping, for example, denial, anxious avoidance and escape. Surprisingly neither perceptions of treatment control nor perceptions of personal control were related to specific ways of coping (23). On the other hand, perception of personal control over one’s own illness was significantly related to higher attendance at cardiac rehabilitation programmes after MI and better adherence to medication and self-management recommendations in patients with hypertension (32, 33). Consequently, assessment of beliefs about disease control in our patients might allow us specifically to address points of uncertainty, support patients’ self-control, and thereby improve adherence to treatment.

Our results regarding illness coherence show that patients do not have a good understanding of their condition. This may be explained by the nature of this particularly uncommon disease, which is widely unknown among the public, and emphasizes the need for improvement in patient-oriented information and education by the attending physician. Providing appropriate information upon the diagnosis of a malignant condition is always a challenging task and even more so in CTCL with its peculiar features described above, which will probably remain enigmatic to most patients (and doctors alike). Evaluation of illness perception might provide a means for healthcare professionals to provide information based on objectively verified information about each individual’s particular needs, and should be further studied in CTCL for its potential to improve

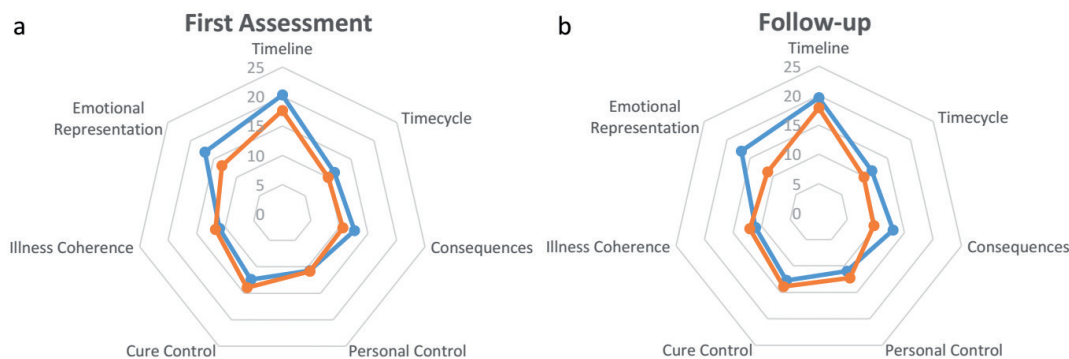


Fig. 1. Spider chart of Revised Illness Perception Questionnaire scores in women (blue) and men (orange) across the 7 dimensions. (a) At the time of initial assessment. (b) At the follow-up visit 3 months later. Values represent mean aggregated scores.

patient education with the goal of improving treatment adherence, as it has been shown by Iskandarsyah et al. (34) in breast cancer that negative illness perceptions were associated with non-adherence.

Furthermore, illness perception and its assessment might not only be useful to guide routine patient care, but might also be a target for specific interventions. Modifying patients' illness perception by psychological therapy has been shown to improve patients' illness-related behaviours and outcomes. Increasing evidence from different diseases, including cancer, indicates that various interventions can be effective in changing illness perceptions, for example 10-week cognitive-behavioural stress management group intervention in patients with prostate carcinoma showed greater improvements in emotional well-being relative to control participants (35). A trial of a psychological family-based intervention to change illness perceptions in patients with poorly controlled type 2 diabetes showed significant changes in illness perceptions and improvement in HbA1c in the intervention group (36). Furthermore, early intervention after MI resulted in improved perceived illness coherence, higher intentions to attend rehabilitation, reduced anxiety, and a faster rate of return to work. The intervention consisted of 4 half-hour in-hospital individual patient sessions with a health psychologist (37). Petrie et al. (38) showed an improvement in recovery following MI by an early intervention (3 sessions explaining the pathophysiology of MI, exploring patients' beliefs about MI and developing a plan to minimize future risk factors).

Illness representations are thus a potential and important target, not only for scientific research, but also for intervention to improve patient outcomes. The use of illness perception assessments in CTCL, if based on evidence from future studies for which we provide a basis here, may assist in identifying those patients who would benefit from interventions particularly aimed at improving illness coherence and strengthening the perception of personal control.

An interesting and widely neglected aspect is the influence of gender on illness perception. In our study sample we could show trends toward a difference between men and women in beliefs about the chronicity of illness and in emotional representation. Obviously it is worthwhile and of great interest in future studies to focus more specifically on gender-specific differences in illness perception. Beyond that, it is also highly likely that cultural, educational, and other social differences influence disease understanding and, although no intercultural comparison studies are available, it has to be assumed that the results described here cannot be extrapolated to other populations.

Some limitations of this study have to be mentioned: (i) this protocol was planned as a pilot/feasibility study and all correlations of the results obtained with disease subtype and other patient characteristics will remain

hypothetical until confirmed in further studies. (ii) Although performed at 2 consecutive visits, this is not a longitudinal, but rather a cross-sectional study, and no conclusion as to the time course of illness perception in CTCL is possible.

The present study demonstrates how patients with CTCL perceive their illness and that the IPQ-R is a feasible tool for assessing illness perception in CTCL. Healthcare professionals need to be aware of patients' individual attitudes and perceptions regarding their disease in order to identify issues that can be addressed and used as a starting point for adequate communication. Although the experienced and skilful doctor might argue that he or she is able to achieve this goal without the need for a quantitative tool, systematic assessment of illness perception allows, and is necessary for, a more scientific generally applicable approach. Future studies investigating illness perception and coping strategies of these patients are warranted to determine whether specific interventions could help to reduce distress and emotional problems with the expected associated benefits in outcome, as described above. Furthermore, implementation of these questionnaires in study protocols, as it is already routinely performed with Quality of Life (QoL) questionnaires, might add valuable comparative information about the impact of new treatments and other study parameters on specific aspects of the patients' view on their disease that is likely to prove clinically useful. Illness representations are thus a potentially important target for both scientific research and clinical practice, with the goal of improving patient outcomes.

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