



# Management of chronic pruritus: from the dermatological office to the specialized itch center: a review

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## Abstract

Patient care for those affected by chronic pruritus is remarkably complex due to its high prevalence and multifactorial nature. It requires a comprehensive assessment of the patient's medical history, extensive diagnostic procedures, and long treatment duration, including management of possible accompanying disorders such as sleep disturbances and mental distress. It is important to prioritize patient's needs when developing a therapeutic treatment plan. Standardized questionnaires and scales should be used to better analyze the patient history, quality of life, symptom intensity, and course of treatment. These can be distributed via digital platforms, allowing for more effective communication between the treating agents and gathering of large volumes of data in central databases. In today's health care system, it is essential for physicians with itch-related specializations and specialized itch centers to cooperate. It is thus crucial to focus efforts on the further development of specialized treatment centers and training courses for medical practitioners. There are, however, various regulatory and economic barriers to overcome in the modern health care system before patients with chronic pruritus can be offered the best possible care. Accordingly, health care authorities should be made aware of the difficulties associated with the management of chronic pruritus and of the high individual and societal burden it represents.

**Keywords:** Chronic pruritus, Prurigo nodularis, Therapy, Health care, Patient Benefit Index, Itch clinics

Chronic pruritus (CP) is a burdensome symptom affecting approximately one-fifth of the global population<sup>[1]</sup> that leads to an impairment of quality of life<sup>[2]</sup>. The Global Burden of Disease study has determined that pruritus is one of the world's 50 most common interdisciplinary disorders and that it demonstrates an especially high burden on the elderly<sup>[3]</sup>. Because of the multifactorial nature of this symptom and its multitude of possible origins, a diagnostic workup and therapeutic approach are of high complexity<sup>[4]</sup>. Multimodal medical and nursing care is required, including the identification and treatment of the

underlying cause, a symptomatic antipruritic therapy, treatment of the skin lesions arising from chronic scratching, and management of secondary sleep disorders, if any are present<sup>[5,6]</sup>. In addition, affected individuals often develop psychological disorders, such as anxiety and depression, or deprive themselves of social contact due to shame from incontrollable scratching or visible skin lesions<sup>[7]</sup>. Adjuvant psychological or psychiatric management may thus be necessary. Because of the complexity of the symptom, as well as the multidisciplinary requirements for its management, it is imperative to maintain a well-structured network of care providers from both dermatological offices and specialized itch centers to achieve optimal care. This article aims to define the needs and priorities of CP management, analyze obstacles in the care of these patients, and highlight possible improvements in treatment approaches.

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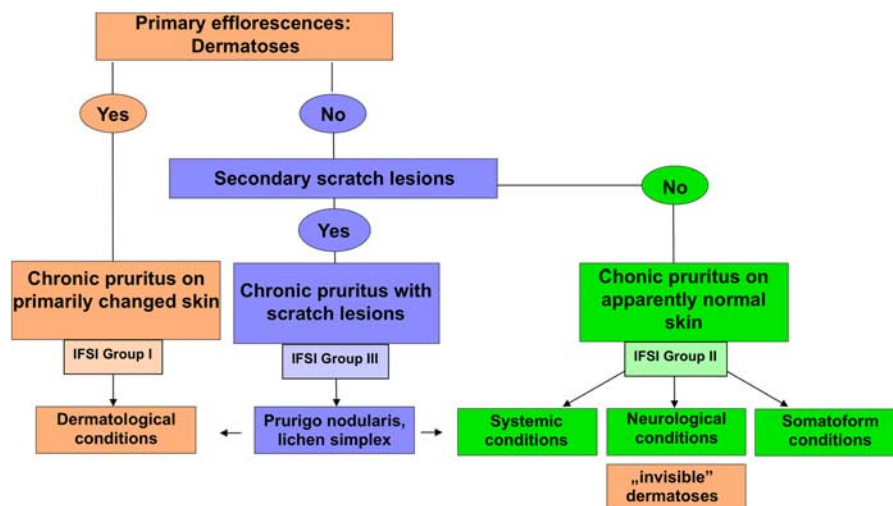
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## Patients with CP: who are they?

CP is a multifactorial, heterogenous condition affecting patients of all backgrounds. When considering larger cohorts of patients with CP, it becomes clear that there is no uniform profile for the affected patients. The patient population is highly heterogenous in terms of age, patient groups (children, pregnant women, adults, and seniors), medical history, skin lesions, cause for the pruritus, and sensory pruritus characteristics<sup>[4]</sup>. CP can develop in association with several diseases. To better assist in the categorization of CP, the International Forum for the Study of Itch (IFSI) has proposed a classification system based on the clinical presentation and underlying disease. Patients are divided into 3 clinical groups, namely those with an inflammatory skin condition (IFSI I), those with pruritus without skin alterations (IFSI II),



**Figure 1.** Clinical and etiological classification of chronic pruritus. Adapted from Ständer et al.<sup>[6]</sup> For the management of patients with chronic pruritus, the IFSI developed a classification system, in which patients are divided according to their clinical presentation into those presenting predominantly with an inflammatory skin condition (IFS group I), those with pruritus in apparently normal skin (IFS group II) and, finally, those with pruritus accompanied by chronic scratch lesions (IFS group III). Regarding its etiology, chronic pruritus can be attributed to dermatological, systemic, neurological, somatoform, multifactorial, or unknown causes. These classification systems provide guidance to the attending physician on the diagnostic and therapeutic approach to the patient with chronic pruritus. IFSI indicates International Forum for the Study of Itch. Adaptations are themselves works protected by copyright. So in order to publish this adaptation, authorization must be obtained both from the owner of the copyright in the original work and from the owner of copyright in the translation or adaptation.

and those with chronic scratch lesions (eg, prurigo nodularis; IFSI III). Patients can also be further categorized based on the underlying etiological cause for their pruritus, ranging from dermatological, systemic, neurological, psychiatric, and multifactorial to unknown causes<sup>[8]</sup>. These classification systems serve to assist the attending physician in choosing the necessary diagnostic procedures and targeted therapies in each case (Figure 1).

Despite the heterogenous patient characteristics, most CP patients report experiencing a moderate or high itch intensity. Moreover, CP induces many secondary conditions, such as sleep disorders, depression, anxiety, feelings of shame due to visible skin lesions, and a substantial impairment in quality of life, in up to 70% of the affected individuals<sup>[2,4,9]</sup>. Interestingly, most patients share similar therapeutic goals, which are not limited solely to relief from itch<sup>[10]</sup>.

### CP patients: what are their needs?

Therapeutic goals can be compiled by means of a comprehensive questionnaire for an assessment of the treatment benefit. One such questionnaire is called the Patient Benefit Index (PBI), of which there are currently several different versions available for a large variety of dermatological and nondermatological disorders. It was validated in 2009 for patients with CP (PBI-P)<sup>[10–12]</sup>. Patients complete a Patient Needs Questionnaire (PNQ) pre-treatment and the Patient Benefit Questionnaire (PBQ) post-treatment so that a weighted, patient-reported benefit can be calculated. The PBI-P's 27 items refer to aspects of psychosocial life and physical factors.

The therapeutic goals of >2500 pruritus patients who completed the PBI-P were recently analyzed in a comprehensive study<sup>[13]</sup>. It was found that therapeutic goals related to the diagnosis and medical therapy, such as the reduction of pruritus or confidence in the therapy, were regarded as either important or

very important by nearly all subjects. The average needs of pruritus patients are apparently higher than those of other general dermatological patients, such as those with atopic dermatitis<sup>[14]</sup>. When analyzing the therapeutic needs of CP patients, it also seems to be necessary to differentiate them, for example, by their sex or according to their IFSI classification category. It has been shown, that the reduction of itch-related symptoms (depressive feeling, nervousness, or burning sensations) is more important to women, whereas men attempt to improve social contacts, partnership, and sex life. Patients with either pruritus and scratch lesions (eg, prurigo nodularis) or inflamed, pruritic skin evaluated various therapeutic goals, including being “pain-free,” as being significantly more important than patients with noninflamed, pruritic skin<sup>[13]</sup>.

### Management in the dermatological office

Many patients with CP visit a dermatologist due to itch-inducing dermatoses or the presence of scratch lesions. The dermatologist thus has a pivotal role in the management of CP patients. By collaborating with local physicians of other specialties, dermatological practices can initiate the first steps toward performing diagnostics and thereby reduce the volume of patients in specialized itch centers. Pruritus is in fact the most common symptom in dermatology. It is estimated that approximately one-third of patients presenting to a general dermatology office report having experienced itch within the last week, and a majority of these suffer from CP despite previous therapeutic measures<sup>[15]</sup>. Interestingly, 62% of the patients described this symptom as the reason for their seeking of a medical consultation, whereas 38% presented with other dermatological issues (eg, skin tumors) and did not associate this symptom with their visit to the doctor. The attending dermatologist should therefore actively screen for

pruritus to prevent the oversight of a pruritic condition that would result in it being left untreated<sup>[15]</sup>.

However, taking a comprehensive medical history, including causal factors, concomitant diseases, current medication, and reactive diseases (eg, depression and anxiety), and performing a complete physical examination can be challenging due to the limited time frame of a patient visit. To address this issue, a standardized questionnaire has been developed by the National Working Group on Pruritus Research (*Arbeitsgemeinschaft Pruritusforschung*, AGP), which can be completed by the patient before the medical consultation (eg, in the waiting room)<sup>[16]</sup>.

Not only the pruritus itself, but also the accompanying conditions such as sleep impairment, and mental distress, impact the quality of life, according to 88% of patients. These factors should be taken into account when preparing a therapeutic plan. The patient needs should be queried and addressed, since sleep deprivation and a disruption of the everyday life are the major concerns of many of the affected. Moreover, as shown by inquiries via the PNQ, both treatment of the pruritic condition and associated skin alterations and an explanation of the diagnostic procedures used for identification of the underlying cause are of high priority to patients<sup>[6,13]</sup>.

Before referring a patient to a specialized center, dermatological offices should take a detailed medical history (eg, using structured surveys, as mentioned above), perform the necessary basic diagnostic procedures (eg, blood tests, common mycological diagnostics, histology, and direct immunofluorescence), and initiate basic therapeutic measures (eg, basic skin care, topical therapy, and antihistamines) even before the diagnostic procedures are concluded. If these measures prove to be ineffective, the physician may opt for a more target-specific therapy once the diagnostic findings are known.

### Management in the specialized itch center

Specialized itch centers offering inpatient and outpatient care play an important role in the management of CP patients, especially when they are refractory to common therapies. An interdisciplinary approach to the diagnosis and treatment that includes various medical specialties (eg, dermatology, internal medicine, neurology, psychosomatics, psychiatry, and pediatrics) is desirable due to the multifactorial nature of CP<sup>[4]</sup>. Such centers are rare and it is necessary for more and more itch clinics to be established, similar to pain clinics.

Of note, inpatient treatment may be required in certain instances. From a medical point of view inpatient care is indicated when the origin of the CP is highly complex and its clarification requires extensive diagnostic procedures, which may be difficult or take a long time to obtain in an ambulatory setting. In addition, if there is a suspicion of a malignancy-associated pruritus (eg, if b-symptoms are present and the CP is present for < 1 y) a battery of imaging procedures (eg, thoracic x-ray, ultrasound of the abdomen and lymph node stations, thoracoabdominal CT) can swiftly be performed in inpatients and thus avoid delays in the diagnosis of a potential life-threatening condition. Psychosocial factors may also constitute an indication for inpatient care. Patients with suicide ideation or those experiencing high suffering or severe sleep impairment due to the CP benefit from inpatient care. Specialists from other fields, in particular psychiatrists, psychosomatics, and psychologists, are of great importance for

these patients. In addition, the environment, in which the patient is inserted, may contribute to perpetuate the CP, for example, pruritus due to a scabies infestation in patients with living conditions with poor hygiene. Those too benefit from inpatient care.

Existing itch centers have developed a digital matrix for the routine care management of the patients, which allows a feasible and concise patient management and, in addition, is in use for the development of a diagnostic and therapeutic plan, allowing for the individual treatment of CP. This system is based partially on modular patient questionnaires. On the basis of a consensus reached by an international group dedicated to research on the assessment of pruritus<sup>[6,17]</sup>, patients are asked to complete questionnaires on the clinical features of the pruritus (ie, its characteristics and their medical history), pruritus intensity [eg, visual analog scale (VAS)], their quality of life [eg, ItchyQoL or the Dermatology Life Quality Index (DLQI)], anxiety, and depression [eg, Hospital Anxiety and Depression Scale (HADS)], and, as mentioned above, the PBI (Table 1). Some of these questionnaires are sent to the patients before their first visit, while the remaining questionnaires are completed onsite via a tablet computer. Although the questionnaire regarding the medical history and therapeutic goals should be completed during the initial consultation, the remaining questionnaires should be filled out also during follow-up visits since they serve as documentation on the progression of the symptom and its response to treatment. An assessment of the responses to the PNQ at the beginning of the therapy enables the assignment of therapeutic goals and serves as the basis for discussion and shared objectives. A survey of the achieved goals via the PBQ can facilitate the identification of particular problems in the treatment efficacy. Data entry via

**Table 1**

#### Overview of tools used for measuring pruritus.

Assessment Outcome	Instrument
Medical history and pruritus characteristics	Medical history key questions (see Table 2)* Pruritus Questionnaire (example in Germany: Questionnaire of the National Working Group on Pruritus Research; <i>Arbeitsgemeinschaft Pruritusforschung</i> )*
Pruritus intensity	Visual analog scale* Numerical rating scale* Verbal rating scale
Quality of life	Global question: Is your quality of life impaired?* Dermatology Life Quality Index* (only dermatoses) ItchyQoL (all types of itch) 36-item short form
Psychiatric comorbidities	Hospital Anxiety and Depression Scale Beck Depression Inventory Hamilton Rating Scale for Depression
Sleep impairment	Stanford Sleepiness Scale Epworth Sleepiness Scale Athens Insomnia Scale
Scratch lesions	Scratch Symptom Score Prurigo Activity Scale
Scratching activity	Actigraphy Accelerometer
Course of pruritus	Dynamic Pruritus Score 5-D Scale Patient Benefit Index*

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\*Questionnaires and scales suited to be used in the dermatological offices.

tablet computers, which have proven to be user-friendly and cost-effective<sup>[19]</sup>, allows for the immediate transfer of the data to the patient file in the local electronic hospital information system, thus providing the attending physician with a simple and relevant overview that can be used to quickly assess the course of the treatment. In addition, the system may indicate the need for further treatment, depending on the pathologic scores of specific scales (eg, psychosomatic consultation if patients show high anxiety or depression scores).

A structured collection of the physician-assessed medical history and course of the CP is vital for ensuring a targeted diagnosis and efficient treatment (Table 2)<sup>[4]</sup>. To better facilitate the proceedings, it is desirable to perform the physician-assessed medical documentation in digital form by using a template available in the electronic hospital information system specifically developed for cases of CP. The digital templates should be adapted to the initial and follow-up visits, as they constitute different needs. The length, localization, quality of the symptoms, trigger factors, and skin findings, as well as the general medical history, prior therapies, and current medications, are recorded during the initial consultation. During the follow-up visits, the principal focuses of the inquiry are, among other aspects, the course of skin findings and the therapy, including side effects and the severity of the pruritus. Answers can be provided by utilizing a dropdown menu in the digital template containing predetermined responses or free-text fields. Scores from the scales and questionnaires completed by patients before their visit (eg, the VAS, HADS, and DLQI) appear on the digital interface and allow for a quick but insightful overview of the patient's current condition<sup>[6]</sup>.

Using digital media in routine care assists in the development of a comprehensive database or registry for CP, which can prove

to be valuable when targeting specific research questions. Provided the patient has given their consent, their clinical data are subsequently transferred to a central, pseudonymized database<sup>[21]</sup>. For quality assurance, the data of each case is first sent to a central storage unit for approval, where the consistency of the data and diagnosis are reviewed by a physician and, possibly, updated with regard to new test results (eg, laboratory findings and histology). Data are only transferred to the central database once it has been validated. This workflow ensures that all records are reviewed before their pseudonymization and that all data are current. The Center for Chronic Pruritus at the University Hospital of Münster is an excellent example for a specialized center utilizing digital media to comprehensively assess CP patients and build a central database, in which there are currently > 6700 individual entries.

### Obstacles and hurdles

There are still numerous obstacles to overcome in the health care system before patients with CP can be offered the best possible, or guideline-recommended, diagnosis and therapy. Said obstacles may vary from country to country, reflecting local political mandates, such as the remuneration system for the provided care.

Because of the aging population, an increase in the number of patients with CP can be expected in the near future. In addition, to save costs in the health care system, a trend in the centralization of services is taking place in many countries, diminishing outpatient care opportunities. Moreover, dermatologists may be urged to invest in more lucrative fields such as operative or esthetic dermatology, leading to a decrease in interest in conservative dermatological topics. For this reason, specialized itch

**Table 2**

#### Key questions in the assessment of chronic pruritus.

Question	Interpretation
(1) How long have you had the itching?	Neoplasms should be considered if itch is present for $\leq 12$ mo (eg, lymphoma or hepatic tumor)
(2) Did the itching appear at the same time or shortly after a new diagnosed illness/surgery/new medication?	Question regarding a temporal relationship to a possible underlying illness. Women of childbearing age should be asked about possible connection to pregnancy. Medication may lead to pruritus even months after its initiation
(3) Did the itching begin together with changes to the skin?	Yes: Dermatitis or lesions caused by scratching No: Pruritus due to systemic, neurological or psychiatric disorders
(4) Where is the itch located?	Localized (eg, neuropathic causes such as notalgia paresthetica) Generalized Alternating locations (eg, as described for prostate cancer) Consider scabies or arthropod bite reactions
(5) Are family members affected by itching?	
(6) Does contact with water (showering, bathing, etc.) trigger the itching?	Aquagenic pruritus, occurs in connection with polycythemia vera (length: > 30 min.) or unclear origins (length: < 30 min)
(7) Does scratching, rubbing or pressure trigger the itching?	Mechanically induced pruritus occurs in atopic dermatitis (so-called aloeknesis), urticaria factitia, mastocytosis, hydroxyethyl starch-induced pruritus and cholestatic pruritus
(8) Previous therapies?	Important for the planning of new therapies
(9) Is the quality of life impaired?	Yes/No. Question to assess the burden of pruritus
(10) Current intensity on a Numeric Rating Scale (NRS) from 0 (none) to 10 (most severe pruritus)?	Important for documenting the course. Ask questions 9 and 10 at every follow-up visit
(11) Do you have night sweats, lymph node swelling, unwanted weight loss?	Symptoms associated with malignant disorders

In addition to general medical history questions regarding previously diagnosed underlying illnesses, allergies, atopic disposition, present medications, etc.

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centers should be available on a larger scale and made to work in closer connection with peripheral offices. The appropriate training of attending internists and dermatologists constitutes the first important step needed to broaden quality care in the dermatological and general practitioners' offices.

In countries with a high number of CP patients receiving inpatient care, there is an increasing amount of difficulties emerging in this sector, including short hospitalization periods and the pressure to economize care. These issues lead to limitations in the diagnosis and therapy of CP. According to the health care system's remuneration scheme, a careful medical indication is essential to justify the costs of intensive dermatological diagnostic and therapeutic measures. Advanced diagnostic procedures for inpatient care include the screening of neoplasms, which is essential for those with CP persisting 12 months or less. In addition, an acute, symptomatic intervention may be indicated in cases of severe psychological strain and failure of outpatient therapeutic measures. Supplementary remuneration would thus be desirable for specialized centers in the future to enable a reasonable inpatient stay.

Another aspect to consider is that many available treatments for refractory pruritus remain off-label, and are therefore often deferred in favor of over-the-counter medication or approved topical preparations<sup>[22]</sup>. Off-label therapies may not be covered by patients' insurances or the health care system. This is especially relevant for specialist offices, which might have higher regulatory and economic constraints compared with specialized centers.

Management of CP in particular patient groups, such as pregnant and breastfeeding women or children, represents an additional challenge. Many systemic and topical therapies remain unapproved for these patient groups. Randomized clinical trials targeting these groups are therefore necessary in the future to achieve better care.

### Future perspectives

The introduction of technology to the management of CP is expected to greatly improve patient care. It is conceivable that data and documentation collected between patients visits can be made accessible to a broad audience of interdisciplinary attending clinicians on a central platform. The digital registration of all survey instruments that can be completed at both specialist offices and specialized itch centers is thus a goal to be strived for. This could have particularly convenient results for the future, for example, for elderly patients receiving telemedicine consultations.

CP is already a topic of discussion at important conferences and is the main focus at symposia for specialists, such as the World Congress on Itch (<http://www.itchforum.net>). The next important step toward a better future in patient care consists of sensitizing health care insurance providers. A better funding of outpatient care can decisively contribute to the optimization of general patient care, as well as the prevention of symptom chronicity and reactive mental distress with subsequent, time-consuming and possibly costly inpatient treatment methods. At present, this is not the case and a further decline in the financial situation is expected due to sustained cost pressures.

### Conclusions

High-quality care for patients with CP remains a challenge for practitioners and the health care system. An effective cooperation between specialized itch centers and dermatological offices is essential. IT solutions, which better facilitate the assessment of this complex condition, should be adopted in the clinical routine. In an era of regulatory and economic constraints, health care authorities should be sensitized to the present substandard care of patients with CP to make improvements.

### Conflicts of interest

The authors declare that they have no financial conflict of interest with regard to the content of this report.

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