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Pruritus strongly reduces quality of life in PBC patients – real life data from a large national survey

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**Background and Aims:** Pruritus is a common and agonizing symptom in patients with primary biliary cholangitis (PBC). Epidemiological data is however scarce and validated questionnaires investigating quality of life (QoL) have not been performed in larger cohorts of PBC patients. We aimed to investigate this symptom, its effect on QoL, self-management as well as medical treatment in a large national survey in Germany.

**Methods:** We developed and validated a detailed questionnaire with a total of 89 questions. QoL in regard to pruritus was measured by the validated ItchyQoL questionnaire. Itch intensity was rated on a numeric rating scale (NRS). Data is given as mean  $\pm$  SD.

**Results:** In total 577 PBC patients were included in this national survey. Sex ratio was 9:1 in favor of women (92% women, 8% men). The mean age was 53,2 ( $\pm$  14,6) years with PBC being diagnosed in average 6,9 (0–37) years ago. More 60% of patients were well informed knowing the change name of the disease, the alkaline level, and stage of fibrosis. Reported symptoms included fatigue (82%), pruritus (56%), joint pain (62%) and abdominal pain (49%) while only 8% of patients stated to be asymptomatic. More than 70% of patients reported on a reduced QoL. Two third of patients with pruritus reported to suffer since many years of this symptom. The mean itch intensity during the last four weeks was rated 4.2 (49.3% moderate and 9.1% severe intensity), while the worst itch reached a level of 5.5 (51.4% moderate and 25.8% severe intensity) on a NRS. The QoL of affected patients quantified by the ItchyQoL closely correlated with mean (Spearman correlation coefficient:  $r = 0,46$ ;  $p < 0.001$ ) and worst itch intensity ( $r = 0,42$ ;  $p < 0.001$ ). Self-management of patients to improve pruritus consisted among others of topical treatment (55%), cold water (33%), rubbing (27%), use of scratch tools (24%), and cold/ice pads (13%). Medical treatment was performed only in 19% of patients with the majority receiving antihistamines (63%). Other treatments consisted of cholestyramine (29%), opioid antagonists (5%), rifampicin (3%) and fibrates (3%). Only 23 patients reported on a successful anti-pruritic treatment

**Conclusion:** The prevalence of pruritus in the real life setting is high. Pruritus significantly reduces the QoL of affected patients with the majority of patients being not or only inadequately treated. Patients are forced to perform self-management. Pruritus represents a major unmet clinical need in PBC.

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