Clinical: Diagnosis and Outcome

Abstract citation ID: jjae190.0586
P0412
Predicting outcomes of disease in patients with Primary Sclerosing Cholangitis and Inflammatory Bowel Disease: a retrospective multicentric study

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Background: The impact of coexistent IBD and PSC on disease progression and prognosis is unclear. This study evaluates outcomes in patients with both conditions, using the novel PSC Risk Estimate Tool (PREsTO) for PSC prognosis.

Methods: A retrospective multicentric study identified IBD-PSC patients through a national survey. PREsTO was calculated to predict PSC-related liver decompensation, and IBD progression was tracked via composite outcome measures.

Results: Among 77 identified patients from six nationwide participating centres, 59 were included, predominantly with ulcerative colitis (77%) and pancolitis (89%). Median ages at diagnosis were 22.3 for IBD and 29.8 for PSC, with follow-ups of 12.0 and 6.9 years, respectively.

PREsTO predicted a median 5-year risk of liver decompensation of 5.3% according to baseline characteristics. However, within this period only 1 patient experienced variceal bleeding; no other liver decompensation events were reported. Notably, over full follow-up, there were 20 additional events: jaundice (7), variceal bleeding (1), cholangitis (5), pruritus (7). One patient (1.7%) ultimately required liver transplant.

For IBD, during follow-up, 10 patients (17%) were hospitalised for IBD-related reasons (1 bowel subocclusion, 9 flare-ups). Twelve patients (21%) required at least one course of corticosteroids, and 34% started advanced medical therapy, of whom 57% needed either dose optimisation or modification. Three patients underwent surgery due to refractory disease activity (1 colectomy, 2 proctocolectomies). Importantly, 39% of patients showed subclinical disease activity at the last follow-up, indicated by faecal calprotectin above 250µg/g.

Conclusion: PREsTO may overestimate liver decompensation risk in our IBD-PSC population, which may be due to a young population. However, the impact of PSC extends beyond portal hypertension complications. Nonetheless, the high prevalence of IBD subclinical inflammation in this group raises concerns about potential disease progression and increased cancer risk.