A review of Primary Biliary Cholangitis practice in Wales: Time for specialist care


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Background and aims

• Primary biliary cholangitis (PBC) is an important yet under-diagnosed condition which causes significant impact on patients both symptomatically and through progression to end stage liver disease.
• Therapeutic advances in PBC make assessment of UDCA treatment response critically important[1-3].
• We studied the clinical practice around PBC in Wales which has a population over 3 million people with rural/urban diversity.
• Clinical services reflect that diversity with small district hospitals and larger, liver units.

Methods

• We developed a clinical audit tool with UK-PBC and EASL guidelines.
• Data was retrospectively collected by specialist trainees in each health board, including differences in adherence to standards between clinicians.

Results

• A total of 406 patients, mean age 59.7 years ±13.5, (73% female) were identified.
• 88.5% had positive AMA >1/40 at the time of diagnosis
• 26.2% had liver biopsy and likely to be requested by a hepatologist (51.4% Vs 25%) p=0.039 χ²
• 47.8% had cirrhosis of which 54.3% had screening for HCC and requested mostly by hepatologists (84%).
• Surveillance for varices occurred in 38% patients and 9% had varices.
• Out of 26 patients considered for a liver transplant, 12(2.9%) underwent orthoptic liver transplantation.

Comparison between the differing clinicians managing PBC

- DEXA scan in the last 5 years
- High risk patients (bilirubin > 50μmol/L or ↓albumin)
- Assessment of response to UDCA in 1 year
- Patients on UDCA at the optimal dose of 13-15mg/kg

Percentage (%) of PBC patients

- Hepatologist
- Luminal gastroenterologist
- General gastroenterologist

Symptom enquiry during follow up

- Fatigue
- Pruritus
- Recent weight documented

Conclusion

• This study provides a unique insight into current services for PBC patients across Wales.
• There were significant discrepancies in adherence to standards between hepatology and gastroenterology managed patients.
• Patients managed by hepatology were more likely to receive optimal UDCA dosing and have response documented at 1 year.
• This study has uncovered areas requiring improvement like documentation of fatigue and pruritis.
• These findings will be used to review the PBC care pathway in Wales to improve adherence to standards and access to new therapies.

References


Contact

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