Collect information relating to current and future treatments for AIH.

**Methods** The survey was co-designed by clinicians caring for patients with AIH and patient representatives. It was distributed electronically and the weblink disseminated to patients by AIH Support, LiverNorth and the British Liver Society, and available to patients in any country. Data was collected anonymously and descriptive analyses were undertaken.

**Results** There were 270 survey respondents, including 13 post-transplant patients. The median age was 55 [range 17–83] years and 94% were female. Age at diagnosis was 48 (1–77) years with duration since diagnosis 2.5 (0–67) years. 157 (58%) patients self-reported having another immune-mediated disease and 49 (18%) an overlap syndrome. Overall, 172 (64%) felt they had experienced side effects (SE) from their AIH treatment. Only 107 (42%) recall potential SE being discussed prior to starting treatment. Table 1 summarises the commonest treatments and the associated patient-reported SE. 109/175 (62%) said they would definitely or probably take part in a clinical trial to look for better drugs for AIH.

**Conclusions** This survey demonstrates that patients perceive treatment side effects to be a significant problem in AIH. Over half the cohort experienced SE with prednisolone, most commonly attributing cognitive symptoms or fatigue to this medication. The impact of SE is demonstrated by patients’ willingness to be involved in trials of novel therapeutics. This should encourage the community to develop further clinical trials and prioritise quality of life for AIH patients.

**REFERENCE**

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**Abstract P183**

**Figure 1**  Pooled mean SF-36 scores in patients with AIH vs. controls

Mean SF-36 subscale scores were available in 6 studies (633 patients). Pooled analysis indicated greater patient-control differences in the physical subscales GH and RF (figure 1). PCS scores were reduced more than MCS scores in four studies.

In a case-control study, 11% (n=103) patients with AIH had PHQ-9 scores indicating clinically relevant depression (PHQ-9>10), significantly more than controls (p<0.001). Severe anxiety (GAD-7>15) was more common in AIH vs. controls in this study (p=0.006) and STAI scores were higher (STAI1 p<0.001, STAI2 p=0.04) in another.

Four studies compared disease activity and QoL, one of which found an association. Seven studies looked at association of cirrhosis with QoL, three found impaired physical (not mental) health, with no association in four. In two studies reporting comorbidities, these correlated with worse SF-36 physical subscales (RP, BP, GH). There were associations (one study each) between corticosteroid use and lower EQ-5D-5L Utility Index, with depression (PHQ-9), and with worry scores (CLDQ).

**Conclusions** Patients with AIH have impaired QoL compared to the general population, in both physical and emotional components. Studies to date are heterogeneous and it is difficult to compare results. Further research is needed to fully explore the impact of AIH on QoL.

**REFERENCE**
1. Leighton J*, 2Charlotte Lloyd, 3Lin Lee Wong, 4Ann Brownlee, 5Penney Gray, 6Emma Culver, 7Neil Halliday, 8Michael Heneghan, 9David Jones, 10Jessica Dyson.
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10.1136/gutjnl-2020-bsgcampus.259

**Abstract P183 Table 1**

<table>
<thead>
<tr>
<th>Predicted</th>
<th>Azathioprine</th>
<th>Budesonide</th>
<th>Mycophenolate mofetil</th>
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<tr>
<td>Currently taking</td>
<td>110 (41)</td>
<td>150 (56)</td>
<td>40 (15)</td>
</tr>
<tr>
<td>Ever taken</td>
<td>199 (74)</td>
<td>203 (75)</td>
<td>71 (26)</td>
</tr>
<tr>
<td>Experienced SE</td>
<td>112 (56)</td>
<td>73 (36)</td>
<td>19 (7)</td>
</tr>
<tr>
<td>Commonest SE</td>
<td>37% cognitive</td>
<td>32% gastrointestinal</td>
<td>54% cosmetic</td>
</tr>
<tr>
<td>(proportion of total medication)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>reported for</td>
<td>35% cosmetic</td>
<td>21% cognitive</td>
<td>17%</td>
</tr>
<tr>
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**Abstract P184**

**The Need for a More Holistic Approach to Managing Patients with Autoimmune Hepatitis**

**Introduction** Data from the national cohort study for autoimmune hepatitis (UK-AIH) demonstrates reduced health-related quality of life (QoL) for patients with AIH, related to ongoing disease activity and, in particular, corticosteroid treatment. To explore those findings, this International AIH Survey on Patients’ Views and Experiences was designed to
Abstracts

International AIH Survey on Patients’ Views and Experiences collected information about the support mechanisms that are currently available.

Methods Clinicians and patient representatives designed the survey. An electronic weblink was disseminated by AIH Support, LiverNorth and the British Liver Trust, for anonymous data collection from patients in any country. Thematic qualitative and descriptive data analyses were undertaken.

Results A total of 270 responses were received (median age 55 [range 17–83 years], 94% female). Almost half (49%) reported being embarrassed to tell people that they have AIH. The majority attributed this to the stigma surrounding liver disease and the perception that their disease is self-inflicted or infectious (many suggested a name change from hepatitis), 53% worry about their disease either all or a lot of the time and 56% worry about the effect their AIH medication has on them either all or a lot of the time. A third of patients reported that worrying about the future is the most difficult aspect of living with AIH. Fatigue was the most frequent answer when asked about frustrations and difficulties associated with AIH.

In terms of patient support, 47% had accessed patient groups, with 79% being AIH-specific. This may be influenced by the route of survey dissemination and higher than in the whole patient community. The average helpfulness score was 7.9 (1 not helpful - 10 extremely helpful). Only 19% had access to a specialist liver nurse. Key themes were better access to specialist care, improved communication, proper acknowledgement of symptoms and more research to find better treatments with fewer side effects and, ultimately, a cure.

Conclusions Medical care often focusses on disease control but this data highlights important factors that impact on patients’ experiences of AIH. The stigma associated with liver disease and not feeling adequately informed about their treatments or prognosis leads to significant anxiety. A more holistic approach to care is needed and signposting towards support groups can be very valuable for patients.

P185
RADIIOLOGICAL RESPONSE TO TRANS-ARTERIAL CHEMOEMBOLISATION (TACE) DETERMINES OUTCOME IN PATIENTS WITH HEPATO-CELLULAR CARCINOMA (HCC)

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Introduction TACE is considered standard of care treatment for patients with Barcelona Clinic for Liver Cancer (BCLC) stage B HCC. Imaging post treatment determines further treatment offered, based on response. Radiological response is categorised as complete response (CR), partial response (PR), stable disease (SD) or progressive disease (PD). Outcome can be predicted pre-TACE or following the first treatment based on a number of parameters (HAP and ART ref). We wanted to demonstrate the survival differences based on radiological response to TACE alone when looking at patient outcome.

Methods All HCC patients treated with TACE at our regional centre since 2010 were included for analysis. Demographic details were obtained with proportion of cirrhotic patients, aetiology of liver disease, BCLC stage, Child Pugh Score and Hepatoma Arterial-embolisation Prognosis (HAP) score being calculated. Survival from diagnosis was calculated as well as the number of TACE procedures.

Results 268 patients were identified as having HCC treated with TACE in this period. 84.7% were male and 82.8% were cirrhotic. Patients all had BCLC stage A or B disease and most (94.1%) Child Pugh A disease. Common causes of liver disease were: Alcohol (34.2%), NASH (28.8%) and Hepatitis C (10%). HAP score was: HAP A (38.2%), B (40.1%), C (19.5%) and D (2.2%). Overall median survival for all patients receiving TACE was 862 days (IQR: 766–957). There was a significant difference in survival based on response after initial TACE (CR: 1284, PR: 840, SD: 820 and PD 306 days, log rank p<0.0001) and response after final TACE (CR: 1316, PR: 926; SD 1159 and PD 684 days, log rank p<0.0001). There was no difference in survival based on Child Pugh stage (p=0.700) or if patients had BCLC A or B disease (p=0.533).

Abstract P185 Figure 1

Conclusions Our data suggests that patients’ outcome following TACE for HCC relates to radiological response to treatment; those with CR having the longest survival and those with PD the shortest. Interestingly, those with PR and SD have similar outcomes based on response at first TACE and final TACE. Those with earlier stage disease (BCLC A) have similar outcomes to more advanced disease (BCLC B) suggesting that treatment determines outcome rather than initial stage of disease.

P186
LONG TERM ABDOMINAL DRAIN FOR REFRACTORY ASCITES: ROYAL DERBY HOSPITAL EXPERIENCE

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Introduction In those patients who are not a candidate for liver transplantation or TIPSS, the palliation of refractory ascites is challenging. Repeated large volume paracentesis (LVP) is effective but requires hospitalization. Long term abdominal drains (LTAD) have been considered as an alternative to minimize the need for admission and improve quality of life.