Diagnosis and management of bile acid diarrhoea: a survey of UK expert opinion and practice

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Supplemental data – questionnaire

Q1: Do you diagnose and treat patients with bile acid diarrhoea (BAD) / bile acid malabsorption (BAM)?

Yes/ No

Q2: Do you have a clinical position in the NHS?

Yes/ No

Q3: What is your current role?

Consultant, specialist registrar, research fellow, specialist nurse, other

Q4: Estimate the number of patients you have diagnosed with BAD / BAM

0, 1-10, 10 -50, 50-100, more than 100

Q5: When discussing chronic diarrhoea related to excess bile acids in the colon, which term do you prefer?

Bile acid diarrhoea, bile acid malabsorption, either depending on the clinical circumstance

Q6: In classifying the different types of BAD / BAM, which terms do you prefer? Please rank:

Primary of secondary, types 1, 2 and 3, overproduction or malabsorption

Q7: What symptoms, or clusters of symptoms, would routinely lead to you considering a diagnostic test for BAD/ BAM?

Intermittent loose stools, always having loose stools, variable loose and hard stools, intermittent hard stools, always passing hard stools, frequency of bowel movements >6x/day, frequency of bowel movements >3 and <6x/day, frequency of bowel movements 1-3x/day, frequency of bowel movements <1x/day, abdominal pain relieved by defaecation, abdominal pain after defaecation, faecal urgency at least weekly, faecal incontinence at least weekly, anal faecal soiling, loose stools and weight loss, loose stools and weight gain, green stools, yellow stools, black stools, red stools, other (please specify)

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Q8: Which of the following conditions do you recognise as associated with an increased incidence of BAD /BAM:

Ileal resection, right hemicolectomy, sigmoid colectomy, crohn's disease of the ileum, ulcerative colitis, microscopic colitis (lymphocytic or collagenous colitis), cholecystectomy, partial gastrectomy, bariatric surgery, small intestinal bacterial overgrowth, pelvic or abdominal radiotherapy, functional bowel disorder with diarrhoea (functional diarrhoea), functional bowel disorder with constipation (functional constipation), functional abdominal bloating/distension, irritable bowel syndrome with predominant diarrhoea (IBS-D), irritable bowel syndrome with predominant constipation (IBS-C), irritable bowel syndrome with mixed bowel habits (mixed D/C; IBS-M), other (please specify)

Q9: What diagnostic methods for this condition do you recognise?

Faecal bile acid measurements (total), faecal specific bile acid measurements, SeHCAT 7 day retention test, serum 7a-OH-4-cholesten-3-one measurements, serum FGF19 measurements, serum total bile acid measurements, therapeutic trial of a bile acid sequestrant, other (please specify)

Q10: Which diagnostic method do you use most frequently? Please rank:

Faecal bile acid measurements (total), faecal specific bile acid measurements, SeHCAT 7 day retention test, serum 7a-OH-4-cholesten-3-one measurements, serum FGF19 measurements, serum total bile acid measurements, therapeutic trial of a bile acid sequestrant, other (please specify)

Q11: Where do you think these tests should be available?

GP, hospital, hSpecialist centres (for each test)

Q12: The next questions are about your use of diagnostic tests in specific clinical situations.

How often would you request the test shown, in a patient without other significant findings on history or examination, with episodic diarrhoea for > 6 months, without predominant abdominal pain or bothersome bloating:

> **with >25% of the stools in the last 3 months being Bristol Stool Form Scale T6 / 7?**
>
> **with >25% of the stools T6 / 7, starting after cholecystectomy?**
>
> **with >25% of the stools T6 / 7, a history of Crohn's with resection of 50-100cm of TI, and negative CRP and calprotectin**
>
> **with >25% of the stools T6 / 7, a history of Crohn's with resection of 50-100cm of TI, and raised CRP and calprotectin?**

How often would you request this test in a patient, without other significant findings on history or examination, with features of IBS (abdominal pain > 1 day / week, related to defaecation and associated with change in frequency or form of stool for >6 months):

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with episodic diarrhoea in the last 3 months, with >25% of the stools T6 /7, and <25% stools T1 / 2

with variable bowel habit in the last 3 months, with >25% of the stools T1 / 2, and >25% stools T6 / 7

with variable bowel habit in the last 3 months, with >25% of the stools T1 / 2 ,and <25% stools T6 / 7

For SeHCAT, therapeutic trial, other

Figures as an indication of the estimated frequency in answers:

>99% = "Always"; >70% = "Usually"; 30-70% = "Sometimes"; <30% = "Rarely"; <1% = "Never "

Q14: How often would you offer treatment with a bile acid sequestrant to a patient with a SeHCAT result:

Between 0% and 5%, between 5% and 10%, between 10% and 15%, between 15% and 20%, , over 20%.

>99% = "Always"; >70% = "Usually"; 30-70% = "Sometimes"; <30% = "Rarely"; <1% = "Never "

Q15: Based on your experience, what response rate would you expect following optimisation of bile acid sequestrant therapy, in a patient with this SeHCAT result.

SeHCAT result between 0% and 5%, between 5% and 10%, between 10% and 15%, between 15% and 20%, over 20%.- Response rate >99% = "Always"; >70% = "Usually"; 30-70% = "Sometimes"; <30% = "Rarely"; <1% = "Never "

Q16: Which bile acid sequestrant do you use as first-line therapy?

Colestyramine, colesevelam, other

Q17: What dose of colestyramine do you start with in an average 70kg woman?

2g once daily, 4g once daily, 4g twice daily, 4g three times per day, other

Q18: What dose of colesevelam do you start with in an average 70kg woman?

625mg once daily, 1.25g once daily, 1.25g twice daily, 1.25g three times per day, other

Q19: Which of the following do you usually recommend? (Multiple answers)

Taking the bile acid sequestrant with food, taking the bile acid sequestrant last thing at night, taking other medication 1h before or 4h after the bile acid sequestrant

Q20: In a patient who has an incomplete response, which of the following have you recommended? (Multiple answers)

Increasing the dose of sequestrant, changing to an alternative sequestrant, low fat (40g/day) diet, avoidance of high FODMAP foods, increasing anti-diarrhoeal drugs such as Loperamide, other medication (please specify)

Q21: In your experience, in a patient with a SeHCAT of 3%, who has had an incomplete response, rank the likelihood of a response from the following:

Increasing the dose of sequestrant, changing to an alternative sequestrant, low fat (40g/day) diet, avoidance of high FODMAP foods, increasing anti-diarrhoeal drugs such as Loperamide, other medication (please specify)

Q22: In your experience, in a patient with a SeHCAT of 13%, who has had an incomplete response, rank the likelihood of a response from the following:

Increasing the dose of sequestrant, changing to an alternative sequestrant, low fat (40g/day) diet, avoidance of high FODMAP foods, increasing anti-diarrhoeal drugs such as Loperamide, other medication (please specify)

Q23: In the follow-up of a typical BAD / BAM patient treated with a bile acid sequestrant, please rate how you view the importance of these factors:

Review by specialist (at least annually), review by GP (at least annually), dietetic review, pharmacist review, contact with patient-support groups, annual check of vitamins A, D, E and clotting, monitoring of serum lipids, especially triglycerides:-

Importance (5 = high; 1 = low,)

Q24: Please rate the importance of the following in improving the overall experience of a patient with BAD.

Greater exposure in the popular press, greater role for patient and public involvement groups, increased recognition by national and international professional groups (BSG, UEG etc.), increased support from patient-support groups (BAD-UK etc.), better recognition of the condition by GPs, better recognition by Gastroenterologists, better recognition by dietitians, better recognition by pharmacists, greater access to current diagnostic methods, new diagnostic methods, improvement of current drugs, development of new drugs, better understanding of pathogenesis, other (please specify):

Importance (5 = high; 1 = low,).

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