Development of a nutritional assessment and dietary management algorithm for patients with Inflammatory Bowel Disease
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IBD Patient Involvement in Research Day
Friday 18th May 2018

#IBDPRD
Summary

This study is developing a patient-centred algorithm to better recognise the patients with IBD who need dietary advice. It includes a self-assessment tool for patients to score their nutritional health. The algorithm will help identify the patients who would benefit from more support around their diet, and those at risk of malnutrition. This will help more people have quicker access to the right dietary treatment, improving their psychological, social and physical health.

Demographics

<table>
<thead>
<tr>
<th>Summary</th>
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<tbody>
<tr>
<td>Respondents:</td>
<td>34</td>
</tr>
<tr>
<td>Male:</td>
<td>13</td>
</tr>
<tr>
<td>Female:</td>
<td>21</td>
</tr>
<tr>
<td>Crohn’s</td>
<td>34</td>
</tr>
<tr>
<td>UC</td>
<td>0</td>
</tr>
<tr>
<td>Median Age</td>
<td>36.5</td>
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<tr>
<td>Mean Age</td>
<td>38.9</td>
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PPI themes and discussion

1. What are your thoughts about taking a liquid diet excluding all normal food and drink for 6 weeks before surgery?

66% of respondents would agree to it
- Would only agree if the benefit of a liquid diet were proven. Liquid diet is emotionally and socially difficult, added burden of sterilising water and making the drinks
- Liquid diet research prior to surgery seems a good idea but what if patient goes into remission prior to surgery?
- Depends on person, type of OP and how they cope emotionally and if they done liquid diet before
- Advocate liquid diet - benefitted previously
- Hard when taking steroids
- Difficult for younger patients
- Psychological impact of not being able to eat when it is a very stressful time of life
- Social impact – social life linked to eating and drinking
2. What do you think about [randomising into] the 2 groups (liquid diet vs usual care)? What if allocated to a group you didn’t want?

Majority (2/3) will prefer not to randomised.

- ?ethical issue about not offering treatment that may be significantly beneficial
- Unhappy about being put in the usual care group if you have previously been told that a liquid diet produced a better outcome
- If randomised to usual care but can’t eat ?Would be an exclusion criteria
- Plans to exclude people who are allocated to usual care but can’t tolerate normal diet
- Would want to make decision themselves, especially if they have had positive experience with liquid diet in the past
- Patient preference model over RCT
- Wouldn’t be happy in usual care as would only ever want liquid diet & improve surgical outcome

3. What if the hospital was randomised?

- Yes as choice taken away from patient, could have better correlation of results from 1 team who treat patients in same way. Other hospitals may make other decisions
- Would recommend allocating hospital to trial to avoid patient dilemma and to carry out in more uniform manner

Other topics raised by group:

In general:

- Why not offer specialist dietician support to all Crohn’s patients as all could benefit?
- Why not self screen? 2/3 positive for thinking an IBD specific screening tool is a good idea
- Why are there not objective measures of malnourishment e.g. bloods?

Diet and Flares:

- Definition of flare varies between people and need to be more specific in definition of flare? “grade flare”
- Classed differently between different people but only interested in what the individual is feeling
- Are you flaring significantly enough for it to alter what you are eating?
- When would you decide to change what you are eating?
• Use of a scale
  - Grade mild to severe
  - Then ask have you changed your diet because of the above?
• Ask if weight has been stable and BMI but just because you don’t lose weight
doesn’t mean you might still have a depleted muscle mass
• Use of asking about BMI
  - Can be malnourished but overweight
  - Needs to be used as part of the tool
• Question about avoiding any specific foods or food groups
  - Individuals might only be avoiding one
  - How can you tell if they are having a balanced diet if you don’t ask
  people to list all the foods and specific groups they are eating