Conveying medication benefits to ulcerative colitis patients and effects on patient attitudes regarding thresholds for adherence

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Ulcerative colitis; Adherence; Medication benefits; Communication

Abstract

Background and aim: Adherence to medication that maintains remission by patients with ulcerative colitis (UC) is poor but little is known regarding patients’ perception of medication benefit that may enhance adherence rates. The aims were to study patients’ understanding and preference on methods of conveying statistical information and to study indicated thresholds for adherence to medication for UC.

Methods: Four methods of displaying information on benefits of maintenance therapy were explained to patients with UC in remission: relative risk reduction [RR], absolute risk reduction [AR], number needed to treat [NNT] and optical representation via Cates plot [CP]. Patients’ understanding and preference for each method were evaluated. Participants were asked to state minimum thresholds relating to relapse prevention and colorectal cancer risk reduction that they would require in order for them to adhere to medication for UC.

Results: Of 50 participants, 48% preferred data presentation by RR over CP (28%), AR (20%) and NNT (4%). 94% found RR easy to understand, better than AR (88%), CP (74%), or NNT (48%). For bowel cancer prevention, 94% indicated adherence for benefit levels of 61% RR but only 57% for the corresponding CP (P < 0.001). For relapse prevention, 78% of patients indicated adherence for benefit levels of 40% RR but only 43% for the corresponding CP (P < 0.001).

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Conclusion: Patients with UC prefer data presented by RR, and apply significantly higher thresholds for adherence when presented with CP compared to RR. Reduction of cancer risk may be a stronger motivator than maintenance of remission.

1. Introduction

Ulcerative colitis (UC) is a lifelong relapsing, remitting inflammatory bowel disease (IBD). Maintenance medication can effectively reduce relapse rates, while chemopreventative properties against the development of colorectal cancer have also been proposed for some medications, especially 5-aminosalicylic acid (5-ASA). The effectiveness of maintenance therapy is often impaired by non-adherence, which is reported in up to 40% of patients. It has been demonstrated that 5-ASA non-adherence results in increased relapse rates, which, in turn, impair quality of life and increase health care utilisation costs.

There is currently no simple and effective intervention to improve adherence in patients suffering from UC, or for that matter from any other chronic disease. Attitudes towards maintenance medication significantly influence adherence in IBD. For example, lack of belief for necessity of maintenance medication and concerns about potential side effects are both associated with reduced adherence levels. Furthermore, some patients fail to see the need for medication to prevent disease flares and see their medication solely as a tool to treat an existing flare. Others do not perceive the need for maintenance medication when they feel well. Any intervention aiming to improve adherence needs to convince the patient of the importance of maintenance medication. However, the medical literature expresses the benefit of medications using a variety of statistical results, which can be confusing to health professionals, let alone patients.

The benefit of a maintenance medication is a reduction in the risk of a flare occurring. There are four commonly used methods of describing such a risk reduction: relative risk reduction (RR), absolute risk reduction (AR), number needed to treat (NNT) and optical illustrations. The latter may include bar graphs or an illustration using ‘smiley faces’ (Cates plot [CP], see Fig. 1). Relative risk reduction is most commonly used by health care professionals, particularly in health information leaflets. However, in comparison to absolute risk reduction, NNT and Cates plot, RR gives no information on the absolute risk. The magnitude of the absolute risk (for example of experiencing a flare) may, however, be needed to fully assess the effectiveness of an intervention (preventing flares).

Only a few studies have examined patients’ preference of displaying statistical information. A US study of 470 patients revealed that patients were more inclined to take a hypothetical medication when benefits were displayed by RR rather than by AR. A study from New Zealand examined the views of 100 patients regarding methods of displaying cardiovascular risk reduction: a bar graph was preferred (57%) over RR (19%), absolute risk, natural frequencies, odds ratio and number needed to treat.

The understanding of, and preference for, optical illustration by Cates plot has so far not been studied. Furthermore, there are currently no data on how patients with IBD perceive

![Figure 1](example.png)
different methods of conveying benefit. Choosing the appropriate method will help patients understand the benefit; the first step in the patient’s formation of beliefs about necessity of maintenance medication. In a second step a patient will weigh up whether the scale of the benefit offered justifies adherence in his/her view. There are currently no data on the level of benefit expected by patients, which would encourage their adherence to maintenance medication.

2. Aims

The primary aims were to determine patients’ understanding and to elicit the preferred method of displaying statistical benefit information of 5-ASA medications. The secondary aim was to establish what thresholds patients with UC apply in order to adhere to 5-ASA maintenance medication.

3. Methods

3.1. Recruitment

Patients with UC from the rooms of five office-based gastroenterologists were invited to participate by invitation letter. Eligibility screening was conducted by telephone a week later. Inclusion criteria were a confirmed diagnosis of UC and current remission. Patients were eligible for participation if they either received 5-ASA or no medication for UC. Exclusion criteria were prior colectomy and treatment with immunomodulators or biological agents to ensure a homogenous cohort of patients with mild to moderate UC.

3.2. Demographic and background data

Baseline demographic data on sex, age, marital status, ethnicity, length of disease, highest level of education and household income were collected. If applicable, adherence to 5-ASA medication was measured using the Medicine Adherence Report Scale (MARS) score, which has been fully validated for the use in IBD. It uses four self report questions to derive score from 4 to 20.11 Patients with scores $\geq 16$ were considered 'good adherers'. Intentional non-adherence was assessed by a three question version of MARS removing the question on forgetfulness.

3.3. Understanding and preference of conveying methods

The first part of the study examined the perceived understanding and preference of four methods of displaying statistical information. Three included conventional numerical approaches: relative risk reduction [RR], absolute risk reduction [AR], and number needed to treat [NNT]. The fourth was an optical representation via Cates plot [CP]. These methods were demonstrated to the participants in printed form and verbally explained using stroke prevention by the hypothetical drug A as an example. For illustration purposes patients were given statements “Taking drug A for a year reduces the chance of developing a stroke by 60%” for RR; “Taking drug A for a year reduces the chance of developing a stroke from 10% to 4%” for AR and “Eighteen patients need to take drug A for a year to prevent one stroke” for NNT. Finally, a Cates plot was shown and explained to patients (Fig. 1). Patients then ranked ease of understanding (agreement with “I find this easy to understand”) and completeness of information provided (agreement with “This provides me with all the information I want”) on 5 point Likert scales. Preference of display method was indicated by ranking.

3.4. Thresholds for adherence

The second part of the study elicited patients’ minimum expectations that would convince them to adhere to 5-ASA medication. To remove any potential bias from prior or current 5-ASA exposure, the medication discussed was named as a hypothetical drug, X. Participants were asked to imagine that they were prescribed drug X as long term medication and had not experienced any adverse effects. Information was collected separately for two key benefits of prevention of flares and prevention of colorectal cancer. The participants were given a range of 5 levels of benefits for RR, AR, NNT and CP. Levels expressed the same statistical data but were presented in the four different methods. (There were only 4 ranges of levels for CP for cancer prevention because the two highest levels of benefit created the same diagram.) Participants were then asked what level of benefit is at least required in order to convince them to take drug X as a long term medication (for an example see Fig. 2).

3.5. Analysis and ethical approval

Analysis was performed with SPSS and used chi square tests to determine the relationship between demographics and the methods patients prefer. The study was approved by Concord Repatriation General Hospital Human Research Ethics Committee (HREC/11/CRGH/95).

4. Results

4.1. Demographics

Of 50 participants (mean age 50 years, range 23–77), 82% of patients had UC for more than 5 years. 86% of patients took 5-ASA medication for their UC with a mean MARS score of 16.4 (range 8–20). Demographic data are summarised in Table 1.

4.2. Assessment of the four display methods and preference of display methods

The vast majority of patients found RR, AR and CP easy to understand (94%, 88% and 74% respectively), but NNT proved difficult to understand for 44% (Table 2). RR was the most preferred method by 48% of the participants, followed by CP (28%). In contrast NNT and CP were however ranked least preferred by 48% and 42% respectively (Table 2).
4.3. Correlation of demographics and preference

Patients’ preference for RR and CP was not influenced by any of the demographical factors age, gender, marital status, ethnicity, employment, education, income and duration of the disease. Preference for RR or CP was not significantly associated with total MARS scores. Participants preferring RR had however significantly lower levels of intentional non-adherence as assessed by the 3 question MARS (P = 0.049).

4.4. Minimum threshold expected for bowel cancer prevention

Thresholds required for adherence differed between the four methods of display. For bowel cancer prevention, 94% indicated adherence for benefit levels of 61% RR or lower when presented with the data as RR (Table 3). In other words, 94% would adhere if the medication offered a relative risk reduction between 21% and 61%. However the proportion of patients indicating adherence, when presented with the corresponding CP, was significantly smaller (57%; P < 0.001). Considering the actual benefit offered by 5-ASA for bowel cancer prevention 94% of participants would have chosen to adhere to maintenance medication.

4.5. Minimum threshold expected for relapse prevention

The thresholds required for relapse prevention also differed between the methods. 78% of patients chose a threshold of 40% or lower when shown data as RR (Table 4), but only 43% chose the corresponding CP (P < 0.001). In other words, 78% would adhere if the medication offered a relative risk reduction between 10% and 40%. Taking into account the actual benefit level of relapse prevention offered by 5-ASA 78% of participants would have chosen to adhere.

5. Discussion

This is the first study investigating how to convey the benefits of maintenance medication to patients with IBD and also the first to examine the understanding and preference of optical illustrations using CP for any condition. We have demonstrated that in our cohort of IBD patients RR is the most preferred method and is perceived as the easiest to understand by patients. The study also demonstrated that most patients with UC indicated that they would adhere to 5-ASA when aware of the benefits derived from it.

Conveying the benefits of an intervention is an integral part of communicating with patients whether it concerns public health advice (for example cigarette smoking), participation in cancer screening programmes or the need for adherence to maintenance medication. In each case the aim is to convince a person of the benefits. For several years doctors have been advised to use AR, NNT and CP rather than RR, largely based on

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Patients’ assessment of display methods.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>RR</td>
</tr>
<tr>
<td>1st choice preference</td>
<td>48%</td>
</tr>
<tr>
<td>Least preferred</td>
<td>6%</td>
</tr>
<tr>
<td>Easy to understand</td>
<td>94%</td>
</tr>
<tr>
<td>Completeness of information</td>
<td>50%</td>
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</table>
While these three methods undoubtedly convey more information, even health care providers find them difficult to understand. The few studies addressing the patients' views have produced conflicting results. Relative risk reduction maybe seen by many experts as lacking vital information, but our data clearly show that the vast majority of patients prefer RR. This finding is supported by two other studies demonstrating the popularity of RR. While experts and health care professional may take issues with RR over its simplification of a more complex situation, the very same simplification may be attractive to patients. A simple, easy to understand figure is preferred over more complex and complete information. Overloading patients with information may be as detrimental as supplying insufficient information. Actual comprehension of statistical information was not formally examined by our study. A Cochrane review demonstrated recently that patients' comprehension of RR and AR was similar, while patients found RR more persuasive than AR or NNT. As such our findings of perceived understanding and patient preference are consistent with previous publications.

Patients' views on methods displaying information by optical illustration are complex. Our study showed CP to be the second most preferred option, while at the same time it was ranked least preferred by nearly half of patients. Optical representation may appeal to 60% of the general population estimated to be “visual learners.” We used CP hypothesizing that it might be easier for patients to understand the effect on a group by connecting smiley faces to individual patients. RR was however clearly the preferred option over CP. In contrast a bar graph was preferred over RR in another study, which may relate to the type of optical illustration used or general preferences for/against optical illustrations.

Patient preference is only one of several considerations, however, as the effects of subsequent patient behaviour need also be taken into account. We have demonstrated that patients apply significantly higher thresholds for adherence when confronted with CP rather than RR. It is conceivable that a large number as used in RR may appear more convincing, but CP could also deter patients by clearly showing the number of patients not benefitting. The appeal of RR to patients may not only lie in the simplicity of a single figure, but could also be influenced by the frequent use of RR in public health promotions and the general media.

A reduced cancer risk was shown to be a strong motivator for adherence as patients indicated lower thresholds for adherence. There is some debate about the actual benefits derived from 5-ASA chemoprotection, but international guidance suggests its effectiveness. Adherence to 5-ASA produces definite benefits by reducing the flare risk and subsequent health care costs and may reduce the cancer risk. It may make therefore more sense to incorporate the cancer benefit in consultations even when some physicians remain somewhat unconvinced of this benefit. This study examined thresholds patients would consider when deciding on adherence. While this clearly indicates their intentions, actual adherence levels may also be influenced by a number of other factors such as inconvenience, forgetfulness and adherence may wane over time.

There is a pressing need for an effective intervention to improve adherence to maintenance medication for UC. The patients' view of maintenance medication has been shown to be the most powerful predictor of adherence. Our study results offer the basis for designing a drug counselling intervention aimed at changing patients' views of medication. We have demonstrated that RR is most likely to offer

Table 3  Minimum threshold applied (patient would take the medication if it offered a benefit of at least...) by patients for bowel cancer risk reduction using RR, AR, NNT and CP.

<table>
<thead>
<tr>
<th>Suggested benefit expressed as RR and equivalent AR, NNT and CP</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
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<tbody>
<tr>
<td>Number of patients</td>
<td>n=18</td>
<td>n=26</td>
<td>n=28</td>
<td>n=28</td>
<td>n=18</td>
</tr>
<tr>
<td>Relative risk</td>
<td>12</td>
<td>12</td>
<td>7</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Absolute risk</td>
<td>3</td>
<td>7</td>
<td>4</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Numbers needed to treat</td>
<td>4</td>
<td>8</td>
<td>12</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Cates plot</td>
<td>18</td>
<td>6</td>
<td>6</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

* Actual benefit offered by 5-ASA.

Table 4  Minimum threshold applied (patient would take the medication if it offered a benefit of at least...) by patients for bowel cancer risk reduction using RR, AR, NNT and CP.

<table>
<thead>
<tr>
<th>Suggested benefit expressed as RR and equivalent AR, NNT and CP</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
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<td>n=4</td>
<td>n=10</td>
<td>n=10</td>
<td>n=10</td>
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<tr>
<td>Relative risk</td>
<td>4</td>
<td>4</td>
<td>10</td>
<td>10</td>
<td>1</td>
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<tr>
<td>Absolute risk</td>
<td>13</td>
<td>5</td>
<td>15</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>Numbers needed to treat</td>
<td>18</td>
<td>11</td>
<td>11</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Cates plot</td>
<td>10</td>
<td>2</td>
<td>9</td>
<td>7</td>
<td>21</td>
</tr>
</tbody>
</table>

* Actual benefit offered by 5-ASA.
information in a suitable format. Cancer prevention may be a more convincing motivator for adherence than maintenance of remission alone. 5-ASA preparations are highly effective maintenance therapy and offer actual levels of benefits for cancer and flare prevention that meet or even exceed the expectations of the vast majority of patients. A counselling intervention based on conveying these benefits may therefore be the key to improving adherence. The authors are currently conducting pilot studies to examine the effects of such a counselling intervention.

Conflict of interest disclosure

CPS has received research grants from Ferring, Nycomed and Shire. PK has served as a speaker, a consultant and an advisory board member for AstraZeneca, Janssen, Orphan Australia. SL has served as a speaker, a consultant and an advisory board member for IBD/Nutrition companies including Baxter, Ferring, Warner Chilcott, Shire, MSD and has received research funding from Crohn’s Colitis UK, Raynaud’s and Scleroderma Association. JMCL has served as an advisory board member for Shire and Almirall. AR is a speaker/consultant for and on the advisory board for Procter and Gamble, Warner Chilcott, Ferring, Falk and Chiesi. RWL has served as a speaker for Abbott Australasia, Ferring Pharmaceuticals, an advisory board member for Abbott Australasia, Janssen Cilag Pty Ltd, Ferring Pharmaceuticals, and has received research funding from Nycomed unrestricted grant.

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