**Title: The informational needs and preferences of patients considering surgery for ulcerative colitis: results of a qualitative study.**

Short Title: Informational Preferences Surgery Ulcerative Colitis

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**Abstract**

Introduction: Patients considering surgery for ulcerative colitis face a difficult decision as surgery may or may not improve quality of life. NICE guidelines for UC emphasise the importance of providing quality pre-operative information to patients but note no quality studies for the desired content of this information. Our aim was to explore patient information preferences prior to undergoing surgery for ulcerative colitis.

Method: Semi-structured interviews with patients who underwent an operation and patients who considered but declined an operation were conducted. Interviews explored informational preferences, with emphasis on pre-operative information given, pre-operative information desired but not received and retrospective informational desires. Interviews were transcribed and coded using an inductive thematic analysis using NVivo software. Data saturation was assessed after twelve interviews, with interviews continuing until saturation was achieved. Ethical approval was gained prior to interviews commencing (16/NW/0639).

Results: A total of 16 interviews were conducted before data saturation was achieved (male n=7, female n=9). Eight patients declined surgery and eight opted for subtotal colectomy with; permanent end ileostomy (n=5), ileoanal pouch (n=3). A total of 4 themes and 14 subthemes were identified. Three dominant subthemes of informational shortcomings emerged: ‘long-term effects of surgery’, ‘practicalities of daily living’ and ‘long-term support’. Peer support was desired by patients but was infrequently supported by healthcare professionals.

Conclusion: Current pre-operative information does not address patient informational needs. Surgical consultations should be adapted to suit patient preferences. Clinical practice may need to be altered to ensure patients are better supported following surgery.

**Keywords:** Informational preferences, elective surgery, shared decision making

Introduction

Approximately 30% of patients with ulcerative colitis (UC) will require surgery during their disease course 1. Surgery may be undertaken as an emergency for severe active disease, toxic megacolon or bowel perforation. More commonly however, patients will undergo elective surgery where medical treatment is no longer felt to be suitable. A small number of patients will undergo elective surgery due to colonic dysplasia 2, 3.

The decision to undergo elective surgery is difficult, especially if there are remaining medical options. There are several decisions for the patients in this setting: whether to opt for surgery or not, and whether a permanent end ileostomy or ileal pouch-anal anastomosis is preferred. There are risks associated with each option. Medically managed patients risk repeated flares and the associated effect on quality of life, drug side effects and future dysplasia. Patients who undergo surgery may suffer from post-operative complications such as intra-abdominal collections, deep vein thrombosis and small bowel obstruction 4. Depending on the operation of choice, those with a permanent end ileostomy may have stoma complications such as parastomal hernia or significant psychological impacts, particularly in the younger age groups 5, 6, whilst those with ileoanal pouch risk pouchitis, increased stool frequency and pouch failure 7.

Shared Decision Making (SDM) is the process by which clinicians share information about treatment options with patients, empowering patients to make a decision suited to their individual preferences 8. National Institute for Health and Care Excellence (NICE) guidance for UC emphasises the importance of providing high quality pre-operative information to support an informed decision 9. However, guidance is based on three studies of low quality 10-12. It was therefore recommended that further studies be performed to assess patient informational preferences 9.

Previous studies have shown that patient and clinician preferences are misaligned 13. Differential preferences between clinicians could provide another barrier to SDM in UC due to implicit persuasion– a process whereby clinicians subconsciously place greater emphasis on the treatment options they feel are suited to the patient. Implicit persuasion has been found to exist in other specialities 14. With this, and the lack of guidance for the content of pre-operative information, information delivered may be subject to variability and may not be addressing patient informational desires. To ensure patients make an informed decision, informational needs must be established and addressed during pre-operative consultations. The aim of our study was to use established qualitative methods to describe patient informational needs and preferences when deciding between surgery and ongoing medical management for ulcerative colitis.

##

## Methods

*Ethical Approval*

This project was ethically approved by the North West – Greater Manchester South Research Ethics Committee on the 22nd August 2016 (REC reference: 16/NW/0639). Health Research Authority (HRA) approval was obtained on the 12th October 2016. Interview recruitment did not commence until both REC and HRA approval was obtained.

*Sample*

A purposive sample of patients who had interaction with either gastroenterology or inflammatory bowel disease nurses or surgical services at Sheffield Teaching Hospitals were identified. Patients were recruited in the following treatment categories:

1. *Considered but not undergone surgery.*

*Patients in this group must have had surgery discussed with them either by the gastroenterology or surgery teams. This was established by screening patient notes to ascertain if a formal discussion had taken place.*

1. *Surgery undertaken: with the formation of a permanent end ileostomy.*
2. *Surgery undertaken: with the formation of IPAA.*

Patients who underwent emergency procedures only were not included. Patients were included if they had initial emergency surgery but had later elective procedures (proctectomy/pouch formation). We aimed for a large age range to ensure emergent themes were not age specific, and representative of the wide age range seen in clinic.

*Methodological Framework*

A qualitative methodology was adopted using semi-structured interviews. Qualitative methods were chosen to allow detailed exploration of patient experiences and preferences. The interviews are reported in line with the consolidated criteria for reporting qualitative research (COREQ) 32-item checklist 15.

*Method of Approach*

Patients were recruited from Inflammatory Bowel Disease or colorectal surgical service out-patient clinics (D.B or M.L) or the study was discussed during telephone consultations (M.L or the IBD nurse team). Patient information sheets (PIS) were given out in clinic or posted after telephone contact.

Patients were contacted between 24 hours and one week after receiving a PIS and interviews arranged for those willing to take part. Signed consent was obtained at the time of the interview.

*Relationship with Participants*

All patients met a member of the research team during recruitment. No patients were known to D.B before being approached. Patients were made aware that D.B was a medical student and that the reason for the research was to provide guidance to clinicians for the content of pre-operative information using their experiences of receiving information. It was assumed that, with D.B not being involved in the patients’ care, there would be no bias limiting patient responses in the interviews.

### Research Team and Reflexivity

*Personal Characteristics*

Interviews were completed by a single interviewer (DB), a male medical student at the University of Sheffield, following training in interview techniques with GJ, a Professor of Health Psychology with prior experience in SDM and semi-structured interview techniques. Interviews were dual coded by D.B and M.L, a surgical trainee at Sheffield Teaching Hospitals.

*Data Collection*

Interviews were conducted in a semi-structured manner containing both open and closed questions in a non-clinical area at either the Northern General or Royal Hallamshire Hospital sites of Sheffield Teaching Hospitals NHS Foundation Trust, UK. This ensured the participant was at ease, minimised the chance of background noise, and avoided interview interruption. Only D.B and the participant were present during the interviews.

Questions were established following discussion with a group of experts consisting of a surgeon (M.L), a gastroenterologist (A.L) and a health psychologist (G.J). The semi-structured nature of the interview allowed the interviewer to diverge from the interview schedule to explore other areas of interest. The focus of the interviews was to detail surgical information the patient received, additional information that patients would have wished to receive at the time - but did not receive, and retrospective information needs based on experience of living with their decision. A discussion was also included about other information resources (such as online information). At the start of each interview, the patient’s experience of UC, including diagnosis and symptoms, was explored, in order to ease the patients into the interview and establish rapport. Information retrieved in this section was not expected to be reported as it does not relate to informational preferences.

Interviews were expected to last between 30 and 60 minutes. Interviews were recorded using a digital audio recording device to allow for transcription at a later date. After the first and second interviews, there was a debrief to ensure interviews were being conducted appropriately. We did not plan for any repeat interviews. After the interviews were completed, they were transcribed by DB. Transcripts were not returned to participants for comments or correction.

### Data Analysis

Following transcription of the interviews, they were coded by D.B and M.L using NVivo 11 Computer-Assisted Qualitative Data Analysis Software (QSR International, Australia). Data analysis was via an inductive thematic approach utilising a systematic approach as outlined by Braun and Clarke 16. Using this approach initial codes were collated into themes, which were defined as important parts of the transcript that related to the research question. Emergent themes were subsequently refined by either merging two similar themes, or breaking down themes into themes and sub-themes. Emergent themes were discussed and collaboratively analysed by D.B, M.L and G.J to ensure a consensus was reached. Once consensus was established, themes and sub-themes were defined and named by the consensus. The names of themes were established by the consensus, ensuring the name of the theme accurately represented all the sub-themes within each theme. Participants were not asked to provide feedback of the emergent themes.

*Sample Size*

We aimed to interview a minimum of 12 patients, as described in the literature 17. We also aimed for a minimum of five pre-operative and five post-operative patients. Once the minimum number of interviews had taken place the level of data saturation was assessed. Data saturation was assessed collaboratively by three researchers (DMB, MJL, GLJ). Coded interview transcripts were discussed by the group, with data saturation concluded when there were no new emergent themes and sub-themes. Interviews would continue until data saturation was achieved.

*Participant Confidentiality*

All study participants were assigned a study ID at interview to ensure patient confidentiality was preserved. Study ID’s were used during reporting of the data and identification of different transcripts. Patients were unable to be identified by their study ID alone.

## Results

A total of 16 interviews (male n=7, female n=9) were undertaken between November 2016 and June 2017. Eight patients considered but declined surgery and eight opted for surgery with permanent end ileostomy (n=5) or ileoanal pouch (n=3). Study ID 16 had not undergone an operation at the time of interview but was on the waiting list. This participant stated a preference for a permanent end ileostomy, rather than an ileoanal pouch, therefore was included within this group for analysis. We note this participant would not be able to provide data on retrospective informational desires based on experience of living with their decision. However, they were able to provide rich data for the information that helped in the decision between surgical treatment options – hence the consensus was to include the participant within this group.

The median age of patients at the time of the interview was 42 years (range 22-74). For those who had undergone surgery (n=7), the median time since the first operation was 4 years 1 month (range 10 months-18 years 6 months). Three patients declined to participate after initially agreeing to take part, but did not provide explicit reasons for non-participation. Patient demographics are summarised in table 1.

Data saturation was achieved after the 14th interview, with two further interviews confirming saturation. The median interview length was 41 minutes (range 28-61). A total of 4 themes and 14 subthemes related to informational preferences were identified. Emergent themes, subthemes and data saturation are shown in table 2. A fifth theme, *disease experience*, was also identified but was not related to informational preferences. Only themes related to informational preferences are reported (see data collection in methods). The 4 themes were:

* Theme 1 – *Experience of receiving surgical information*
* Theme 2 – *Decision making* e.g. surgery *vs* medical management and IPAA *vs* stoma
* Theme 3 – *Information preferences* – this was based on retrospective informational desires from reflections of consultations and the lived experience of treatment choices.
* Theme 4 – *Online information* – including use, what was accessed and why it was used.

Theme 1: *Experience of receiving surgical information*

*Timing of first surgery discussion*

The first-time surgery was mentioned to patients by a healthcare professional was generally limited to when failure to respond to medical therapy was evident, particularly to steroids and anti-TNF-α agents. Younger patients described abrupt conversations about surgery relating to their risk of colon cancer or the need for surgery in later life, as described in the extracts below:

 [surgeon] ‘look you can take these medicines for the rest of your life anyway and ultimately get cancer and we’ll [surgeons] cut out your bowel….’ (Study ID 07)

[surgeon] ‘you really have to do it [surgery] at this point… Sooner or later you will end up with some sort of cancer to the bowel and it won’t be good’ (10)

A small number of patients had to actively probe healthcare professionals about treatment options after failing to respond to different medical treatments, as illustrated by these two patients:

‘…we [the patient] went onto adalimumab... So at that point I was asking the questions of ‘what if this doesn’t work?’’ (02)

‘There’s not a great deal more I can try after this [vedolizumab]. And I had this theory that if they could cut out the infected part of the colon and re-join it, would I be better off doing that? So I asked them [IBD nurses] about surgery…’ (11)

*Content of information received*

Only one of the patients interviewed (Study ID 11) did not have a discussion with a surgeon. This participant discussed surgery with the IBD nurses, but did not express an interest in further exploration of surgery. All patients described how they received information about at least one of the procedures available to them, and the risks involved.

The depth to which surgery was discussed ranged between patients. This variety was predominantly due to patient reluctance to discuss surgery, in particular stoma formation. A few patients mentioned how they were open to surgery but dismissed it as an option when the possibility of a stoma was raised, as outlined by one patient:

‘Because I was that adamant I didn’t want it [a stoma] I think I cut the surgeon off mid-sentence and said ‘look you’re wasting your time because this is something I [the patient] don’t want.’ (04)

It was also common for patients to mention the difficulty of assimilating the volume of information during consultations. In particular, there was mention of the length of clinic appointments, with 10-20 minutes inadequate for a number of patients. Statistics related to risk of side effects were viewed variably by patients – with some patients reporting numerical quantification of risk as unhelpful, whereas some felt statistics helped them appraise the likelihood of side effects, as demonstrated by one patient below:

 ‘If someone says there’s a 1% chance of something happening I’d probably laugh it off. But if someone says there’s a 40-50% chance of something happening I’d probably be like ‘oh dear’… if I was to choose to have it [the operation], it depends on those statistics.’ (13)

Utilising a diagram in practice to help explain operations to patients was common and all patients agreed that visual presentation of the operation helped in their understanding of the procedures. It was also fairly common for patients to see stoma nurses to be provided with ‘practice packs’. In two cases the stoma nurses offered patients a telephone number of another patient who previously underwent the same operation and was willing to discuss their experiences of living with a stoma. Both these patients found this to be very helpful in understanding day-day life with a stoma as it gave them a ‘real life’ perspective.

*Written information*

Patients reported receiving a large number of leaflets from both the gastroenterology and surgical teams, particularly from the IBD and stoma nurses. Although leaflets were easy to understand, they were often described as containing unhelpful information. Written information focussed on operative details, and information about post-operative practicalities were described as ‘vague’ and ‘generic’, particularly diet advice. There was concern about the content of leaflets from the younger generation – with leaflets not providing information on the long-term sequelae of surgery. Leaflets about stomas also centred around the older generation, with no leaflets aimed at younger patients, as demonstrated by this extract:

‘…it [the leaflet] was aimed at old people, it had old people on the photos all the way through… Which at 16 it’s not really what you want to… I associated it with older people. Seeing a leaflet about old people… It’s not very helpful’ (15)

Theme 2: *Decision Making*

Understanding what information helped patients in their decision between treatment options is key to delivering patient-centred pre-operative information.

*Surgery vs Continued medical management*

Surgery is seen as the last resort by most patients, including those who underwent surgery. For those on continued medical treatment, the aversion to surgery was clear. The reluctance to consider surgery was primarily due to requirement of a stoma, even if only temporary. This was common in both younger and older patients – with all age groups stating a stoma was unappealing. Younger patients often cited age as the primary reason for avoidance of a stoma and they would consider stoma formation if they were older. Concerns about a stoma in older patients were limited to managing and changing the stoma. However, younger patients expressed concern about exercise, going out with friends and attracting a partner, as demonstrated below:

 ‘I was 26, 25. Thought it was going to be the end of the world if I had the bag at that age. How would I go out? How would I meet anybody?’ (09)

Patients who underwent surgery did so due to severe restrictions on quality of life and an inability to continue in the same vein, as illustrated by one patient:

‘I just was so poorly I didn’t care about the risks... I just wanted this operation. Because I couldn’t cope with the life I got.’ (01)

The decision for surgery was also influenced by the idea that surgery effectively cures the condition and removes intestinal symptoms. Patients recognised the relapsing-remitting nature of UC and stated a preference for undergoing surgery on their own terms, rather than as an emergency. Although drug side effects were mentioned, they did not impact on patient decisions for or against surgery.

Interestingly the stoma nurses did not directly influence patient decision making. Instead stoma nurses were utilised to discuss stoma care post-operatively. Contact with a peer with a stoma, as described above, was very helpful to patients in understanding daily-life post-operatively. However, as with stoma nurses, peer support did not influence on decision making, instead being utilised for advice on how to manage post-operative practicalities using peers anecdotal experience.

*Ileoanal Pouch vs Ileostomy*

Patients who opted for an ileoanal pouch, or stated they would opt for a pouch if they had surgery, did so to restore ‘normal’ functioning. These patients recognised that there was a chance of complications that could result in poor quality of life, but the ability to revert back to stoma formation influenced the decision heavily – with patients stating they ‘might as well try’ pouch formation.

Patients who opted for permanent end ileostomy noted increased stool frequency as a major deterrent to pouch formation as this symptom was a key factor in opting for surgery in the first instance, as illustrated by one patient:

‘I think in my eyes, if I get an internal pouch I’m going to go back again the way I was before I had my stoma…’ (05)

Patients opting for permanent stomas made this decision after the initial surgery, stating that stoma formation had little impact on quality of life thus they saw little point in risking further surgery. Although pre-operative patients stated anxiety about the prospect of stoma formation, patients who underwent surgery explained their fear of stoma formation decreased post-operatively, primarily due to improvement in their quality of life.

Theme 3: *Information preferences*

In this section the aim was to explore what information patients would have liked to have received but didn’t, what information they would have liked based on their experience of their decision, and from whom this desired information is best delivered.

*Retrospective informational desires*

In terms of information about surgical procedures, two patients discussed lack of information. Both of these patients developed features of Crohn’s disease after pouch formation. Neither was told of the possibility of future reclassification to Crohn’s disease but neither patient said it would have affected their decision for surgery. They were however slightly aggrieved they made their decision on the basis that the surgery would be curative, but were now facing a change in diagnosis, as outlined below:

‘It would have made it [surgery] a less straight forward decision. I think what I’ve described was a straight forward decision but it wouldn’t have been as straight forward because it wouldn’t have been that final whereas it felt final at the time. ‘ (07)

Patients also had differing views about the depth of information that should be provided about operations and their complications. Some patients reported not receiving detailed surgical information, and it was therefore retrieved from other sources such as the internet. Other patients discussed not wanting detailed surgical information for fear of this putting them off surgery, as illustrated by one patient:

‘Cos’ I made the mistake once…I asked the nurse about how they were going to do it [the operation]… she gave me the full ins and outs of what they’d do but it completely freaked me out.’ (15)

All patients expressed their greatest informational desire as the long-term effects of surgery, including recovery, diet and return to daily activities such as return to exercise and ability to complete daily tasks, such as looking after their children. Despite this, all patients who underwent surgery explained the information they received was inadequate in preparing them for the length and difficulty of recovery. Patients that opted for surgery stated that the surgical team estimate return to fitness to be 8 weeks’ post-surgery, but this was often markedly underestimated, as one patient uses previous surgical experience to explain:

‘The surgeons’ response was within 8 weeks you should be fit and well. But I had my appendix out in September…, and I know from that they [the surgical team] said then ‘within 8 weeks you’ll be absolutely fine’. But I wasn’t. I was still in so much pain and that’s just an appendix.’ (16)

Patients also described a lack of support from healthcare professionals in recovery and adaptation past the initial 8-week period. This is despite many patients facing difficulty months after the operation, as outlined by one patient:

‘…that’s where I personally, that’s when I started to struggle. It was like 4, 5, 6 months after… I found life in general at that time really overwhelming because I still couldn’t physically cope. I was still tired and weak.’ (08)

The general consensus of surgical patients was there needs to be better information about long-term recovery and sources of long-term support to ensure patients undergoing surgery know who to contact for support or advice should they require it.

Many patients were worried about return to exercise for fear of overexerting themselves, or causing a parastomal hernia. Yet no patients received any advice regarding exercise aside from ‘go at your own pace’. Patients found this ambiguous and difficult to interpret without a recommended timeline or some basic advice about return to exercise and sport.

Diet was frequently mentioned as something on which more information was needed, but was not provided sufficiently, or at all. Patients found the lack dietary advice frustrating and that the topic was frequently discussed in online fora. Some patients reported following diet advice from the internet which had a detrimental effect on symptoms, as detailed below:

‘I knew what to eat to thicken it up [stoma output] and…what to drink or eat to clear a blockage. And lots of that came from the internet. I did make mistakes on it, I did eat the wrong things early on and I did block it up.’ (07)

Practicalities of stoma care was a common trend in those with either permanent or temporary stomas. Patients explained there was a lack of ‘soft stuff’ from the stoma nurses that would have helped them adapt faster post-operatively, such as what underwear/clothes are recommended to conceal the stoma, and what products are best to prevent parastomal skin irritation.

*Preferred source of information retrieval*

Despite a lack of information about the long-term effects of surgery on daily life, patients felt that surgeons were not best placed to give advice about daily issues encountered post-surgery. The stoma and IBD nurses were commonly cited as preferred sources of practical information, however patients who have been through the operation still report lack of practical information from these sources. The vast majority of patients (n=13) explained how they would prefer practical information from someone who had previously gone through the same surgery. It is noted that the three patients who did not desire peer support were the three oldest participants (62, 70 and 74). Some patients did seek advice from peers with surgical experience (n=4) or from organisations such as ileostomy association (n=1), but internet use for peer contact was much more common. Patients who underwent surgery but did not speak to a fellow patient explained their regret at not doing so, as demonstrated by these extracts:

‘If anything, they should offer to talk to somebody. I think it’d have been nice to talk to somebody who had one [a stoma].’ (05)

‘I could have done with speaking to other people that had it done [the operation]…there’s a lot of stuff you don’t pick up. Anecdotal stuff from experience that I don’t think you can put in a leaflet.’ (10)

‘I definitely, definitely should have spoken to someone who had the same surgery as I was having. I feel like that was a real let down that I didn’t speak to another patient, my age, who had this surgery.’ (14)

Despite the vast majority of patients desiring peer contact, only two patients were offered help in achieving contact with someone who previously had the operation. Importantly peer contact over the telephone or face-face was preferred to online forums. Many patients were also unaware of organisations, such as the Ileostomy Association, could help in achieving patient-patient contact.

Theme 4: *Online information*

During the interviews patients were asked about access of online information, particularly what was accessed, why it was accessed, and if it was useful.

Internet use was very common, with all but one patient (ID 01) reporting internet use for disease related information during their disease course. Patients commonly accessed websites such as NHS Choices, Crohn’s and Colitis UK and the Crohn’s and Colitis Foundation of America. These websites were accessed following recommendation from IBD nurses. It was also very common for patients to access information about diet, as mentioned above. There was concern about the information on these websites being aimed at making money, as outlined by one patient below:

‘They all seem to be advertising. I mean everything you go on they want to sell you something.’ (03)

The internet and social media were used widely in order to access patients who had previously undergone surgery. Patient contact via the internet was generally viewed as useful as patients had the ability to view and ask other users’ questions about daily practicalities faced post-surgery. Patient blogs, where a patient documents their day-to-day life after surgery, were also accessed frequently. Patient interaction on the internet did not influence patient decisions but did increase patient coping and adaptation post-operatively due to readily available advice about managing daily issues such as stoma leakages. Patients also reported having a greater understanding of the recovery process after reading patient blogs and forums. There was minor concern over the negativity and clinical accuracy of some blogs and forums, as explained by two patients:

‘I wouldn’t trust any Tom, Dick and Harry on the internet because you don’t know who they are. Unless they were some recognised person.’ (03)

‘Oh you know what I find it all [patient forums] really depressing… some others were a bit more positive, but I found… sometimes it was a competition. ’I’m iller than you’. (08)

Although the negative tone was a deterrent for some patients, others saw it as helpful negativity that helped them appreciate the potential negative outcomes from surgery. YouTube was used sporadically by patients to search for surgical information, with the main reason for not using YouTube being lack of awareness of such information on this platform. Those who used YouTube videos often watched videos blogs about going through the surgery and how to change a stoma. A small number of patients watched videos of the operation they underwent due to insufficient detail received during pre-operative consultations. Those who used YouTube agreed about its usefulness and the ability to witness things visually:

‘It did definitely [help the participant understand]. I thought Christ that was amazingly easy [changing the stoma] …I was surprised what was sticking out of his stomach there.’(09)

*Comparison of themes by age*

It is plausible to suggest that informational preferences vary with age. Figure 1 compares the emergent subthemes between ‘older’ and ‘younger’ patients. We defined younger patients as <50 years of age, and older patients as >50 years of age. Notably, we only have 3 older patients within our study, owing to the fact that many patients are of younger age when surgery is considered or undergone.

Despite a large age range, many of the subthemes were common between all ages. One subtheme was only common to the older patients, which was ‘clinician treatment preferences’. This subtheme consisted of patients explaining what they perceived to be clinicians promoting a specific treatment option, although this was only apparent in the older patients.

Younger patients had three subthemes specific to their age group. Some of the younger patients (n=3) accessed academic studies outside the clinical encounter to help them decide between treatment options. This was not common in older ages despite internet use in the older patients. Younger patients also expressed their desire for peer support and accessing the stoma nurses for support. This in contrast to the older patients who were disengaged with peer support, although one of the older patients described accessing an online forum.

*Comparison of themes by treatment group*

Differing treatment groups may also have differing preferences. Figure 2 illustrates the themes from the interviews by treatment group. Twelve of the fourteen subthemes were common to all treatment groups – adding strength to our results and data saturation. These results also indicate that informational preferences do not vary between patients opting for differing treatment options.

Two subthemes were only common to surgical patients only; clinician treatment preferences and academic studies. As described above, clinician treatment preferences are patient appearance of clinicians promoting a particular treatment option. In our results three surgical patients indicated clinicians were often in favour of continuing medical treatment rather than considering surgery, as outlined below:

‘The consultant I saw at the time was very much against surgery, very much a pills and potions man’ (10)

‘I mean they supported me when I made my decision [for surgery]. But they were all, I think they wanted me to try this infliximab’ (01)

Academic studies were more likely to be accessed by surgical patients to help decide between treatment options.

## Discussion

This study has used qualitative methodology to explore the informational needs and preferences of patients considering elective surgery for ulcerative colitis. It has highlighted that patients want information on recovery and long-term impacts of surgery to inform their decision. Post-operatively patients desire increased support and more practical information on adaptation to daily life. All patients indicated that the information of greatest importance was the long-term impact of surgery on daily life, including impact on usual daily activities, diet and exercise. Patients choosing not to proceed to surgery expressed fear of stoma formation and the effect it would have on lifestyle, which is widely documented in the literature 13, 18-20. Patients opting for surgery reported a general lack of practical information from healthcare professionals about initial recovery from surgery, diet, exercise and stoma care, thus internet use was common to access this information. Peer support was commonly desired but patients received insufficient information to help in accessing peer support. Although patients showed agreement with certain topics, patients views varied on the depth to which operations should be discussed and the best format of statistics to convey risk. The informational needs of patients do not vary based on treatment choice, but there may be age based variation to the preferred source of information.

This study highlights that provision of current information to patients does not address their greatest informational needs. Information provided to patients in this study put an unrealistic expectation on recovery time, and practical information about stoma care, diet and return to exercise lacked detail. Lack of dietary advice is common despite many patients regarding this as an informational need 21. This is surprising given that patients experience dietary restriction after surgery for UC, with high fibre foods the most common source of dietary intolerances post-proctocolectomy 22, 23.

Fear of causing a parastomal hernia and lack of exercise advice from healthcare professionals has also been illustrated in a recent national survey 24. This is despite a decreased incidence of parastomal hernias in the first year after surgery when: heavy lifting was avoided for 3 months, taught abdominal exercise were performed daily post-3 months and support belts were encouraged when undertaking heavy lifting 25. Lack of exercise post-operatively is also noted to effect post-operative adaptation, therefore avoidance of exercise is likely to delay global recovery 26.

Patients described a lack of support during their recovery process, with a sense of being left to adapt post-operatively. Where patients were followed up by healthcare professionals, consultations were limited to functionality of the stoma/pouch rather than a holistic assessment. Rates of depression after surgery for UC are reported to be 11-17% 22, 27. Patients may also experience long-term detrimental effects to body image and sexual life 22. Although depression and sexual life were not directly explored in our interviews, our results indicate a lack of exploration into psychosocial issues during post-operative consultations. Psychosocial problems, such as depression, could therefore be left unrecognised or inappropriately addressed, which could delay post-operative recovery and adaptation 26, 28.

The preferred source of information about daily practicalities after surgery was demographically similar patients with previous experience of the same surgery, and not healthcare professionals. Peer support could prove an invaluable asset before and after surgery for both patients and professionals. The role of peer support in cardiac surgery has been assessed, finding peer support increased post-operative activity levels 29. Peer support has also been found to aid in coping pre- and post-operatively 30. Despite its potential usefulness, only two patients in this study were offered help in achieving verbal or face-face contact with fellow patients prior to surgery. It is easy to see the worry that patients could be deterred from surgery by a patient with negative experience. However, results of this study indicate patient decisions are not altered by peer support. Instead peer support is utilised by pre-operative patients to understand daily life post-operatively, and by post-operative patients for advice on managing daily issues using peers’ anecdotal experience. The role of peer support should be embraced and supported by healthcare professionals as it may aid in post-operative adaptation without having a detrimental effect on treatment decisions.

Written information in the form of leaflets was provided, however its content was suboptimal and not user friendly for the younger generation. Examination of patient information leaflets provided prior to oesophagectomy found leaflets to be inconsistent, incomplete and often misleading 31. Patients in this study were in agreement that written information, both in physical form and via the internet, would be beneficial if it was tailored to their needs, which have been elicited in this study.

The best way to communicate risk is highly debated. Delivering risk via numerical values has been suggested as the best format but it could discriminate against patients with low numerical skills 32. Other studies have suggested risk expressed with words such as ‘uncommon’ and ‘rare’ is preferred by patients, so long as there is numerical clarification of the definition of rare 33. The presentation of risks via visual techniques has also been suggested as superior, although it is noted differing risk formats may alter treatment choices 32, 34. The best format to deliver risk varied in this study which may come down to educational level – highlighting the need for healthcare professionals to tailor presentation of risk to the individual.

Studies in the literature are conflicting in the informational preferences of older patients – with some studies suggesting older patients have differential preferences, and others concluding age has no effect on informational preferences 35, 36. Our study, although a small sample size, indicates the informational needs of older patients are the same as younger patients. Older patients expressed the same fear of stoma formation and the desire for information around the long-term burden of surgery. Older patients differ in their preferences of informational retrieval, preferring to gain information from their clinicians as opposed to the younger patients, who preferred information retrieval from peers or stoma nurses. It is recommended there are further studies assessing the informational preferences of older patients in this setting.

Receiving pre-operative information forms a major part of making an informed decision for surgery 8, 37. This is the first study within the literature to directly assess patient informational needs and preferences when considering elective surgery for ulcerative colitis. Current literature focuses on patient treatment preferences and the information preferences of newly diagnosed patients 13, 19, 38. The use of qualitative methodology to establish patient information preferences has been used widely in the literature 39-41. Interviews were collaboratively assessed to ensure a consensus was achieved on emergent themes.

This study does have limitations. Although data saturation was achieved, the sample size is small and only includes those treated at a single centre. It may be that qualitative interviews involving the experiences of patients from other centres may produce different findings. However, results from previous studies conducted elsewhere do indicate that issues raised in this study are not trust specific 21, 24 . It is recognised that this is a retrospective study and that recall bias may be an issue. Despite this, many of the issues raised by patients were common between both pre- and post-operative patients. There is little guidance to sample sizes required to reach saturation. Guest *et al.* described how after 12 interviews new themes emerged infrequently 17. The National Centre for Research Methods published a review on sample size, with the correct sample size varying between studies 42. Our approach ensured data saturation was continually monitored and ensured an excess number of interviews did not take place if saturation had already been achieved. We achieved saturation from our interviews, which adds strength and validity to our findings.

In summary, these findings suggest several shortfalls in pre- and post-operative information and care. The best way to address these issues in clinical practice needs to be established, although it is clear a shift in the pre-operative information delivered to patients is required. Patients also need to better supported long-term after surgery, whether this be through peer support or healthcare professionals.

## Conclusion

Findings suggest that patients considering surgery for ulcerative colitis require extensive and clear information about possible long-term effects of surgery on daily life. This information is preferred from other patients who previously underwent the same surgery, although the IBD and stoma nurse teams were also acceptable sources. Clinical practice may need to be altered to ensure patients feel better supported in their recovery following surgery, including making patients aware of peer support organisations pre-operatively. Written information requires development to patients’ informational needs, ensuring material is directed to all age groups.

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