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Information needs for recovery after colorectal surgery: Patient focus group study

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Contributions: SJC, CJCM, JPT, and DGJ, conceptualised the study and had input into its design. SB convened and administered the focus group. SJC, MDSL, and CJCM collected data, which were analysed by SJC and CJCM. All authors drafted the manuscript and approved the final version for submission. CJCM is the study guarantor.

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What does this paper add to the literature?

This qualitative focus group study provides important insights into the information needs of patients undergoing colorectal surgery. A series of barriers to understanding and retaining information during recovery are described, as well as insights into how the provision of information may be improved. The findings provide a needs assessment for the development of future information resources.

Abstract

Aim: The provision of information to patients is an important part of recovery after colorectal surgery. This study aimed to define patient information needs, barriers to effective understanding, and insights into how information-provision may be improved.

Method: A patient focus group was convened. This comprised a broad, convenience sample of eleven participants from across the United Kingdom with experience of major colorectal surgery. A semi-structured topic guide was used to facilitate discussion about previous experiences of information-provision and how this may be improved. Data were analysed thematically and are presented as major themes.

Results: Overall, participants felt that their information needs are poorly prioritised by healthcare professionals. Barriers to understanding and retaining information include highly emotional situations (such as receiving bad news) and inappropriate information design (such as the use of inaccessible language). Participants expressed how information resources should: 1) address patients' individual information needs; 2) empower patients to take an active role in their recovery; 3) support patients with meaningful education and sign-posted resources; and 4) recognise patients' heightened need for information during recovery at home.

Conclusions: This study provides key insights into the information needs of patients undergoing colorectal surgery. These should inform the development of future information resources, whose format, timing, and design are currently supported by low quality evidence.

Introduction

The provision of information to patients undergoing colorectal surgery is strongly recommended by enhanced recovery guidelines. This aims to reduce anxiety, increase preparedness, and improve the overall experience of treatment (1). The evidence to inform how information is provided to patients, however, is low (2). Previous research has explored a range of resources specific to colorectal surgery, including educational videos, face-to-face consultations, and mobile device applications. Some of these have led to positive clinical benefit (such as reduced length of stay and fewer complications), but the reported outcomes in these studies are heterogenous and the clinical benefits are variable (3).

Patients value detailed information about their treatment (4). In delivering this, healthcare providers must ensure that information resources are designed appropriately to meet patients' needs. A core information set for colorectal cancer surgery was recently developed to standardise the content of this process. This was produced collaboratively between patients and healthcare professionals to ensure that all relevant content needs were considered (5). Other aspects of information-provision, such as the format of delivery, timing, and design, are also important. When information is designed poorly, it is harder to process and requires greater cognitive attention and mental effort to retain (6). Provided that the challenges of information delivery are understood, evidence-based information design and cognitive principles can be used to maximise understanding and retention.

The aim of this study was to explore patients' experiences of receiving information, and in doing so, to explore areas for possible improvement. It sought to produce a needs assessment to inform key priorities for the development of future information resources.

Methods

Ethics & Governance

Research ethics approval was confirmed by the University of Leeds School of Medicine Research Ethics Committee on 2nd November 2018 (MREC-18-017). The manuscript is reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (7).

Research Team & Reflexivity

One male researcher with a clinical-academic background in surgery and health sciences (SJC) and one female researcher with extensive experience of qualitative research (CJCM) facilitated the study. No researcher-participant relationships were declared. The positioning of the researchers, including their motivations, were established prior to the start of the study. One researcher (SJC) declared an interest in improving recovery after surgery, which was considered as a relevant bias during the collection and analysis of data.

Study Design

An exploratory qualitative study was undertaken using a patient focus group on 7th November 2018. This method was selected due to its appropriateness for collecting a broad range of views and exploring underlying meanings (8). A short quantitative survey was administered to objectively define participants' information needs according to items set out by the Enhanced Recovery After Surgery (ERAS) recommendations for elective colonic surgery (1). Participants were asked to identify their 'top-5' and 'bottom-5' information needs.

Participant Selection

A convenience sampling approach was used. Invitations to take part were sent to potential participants via a national charitable body, whose public members have declared an interest in helping with bowel-related health research. Patients were eligible to participate if they had previously undergone abdominal surgery for the treatment of bowel disease. No time limits with consideration to diagnosis or surgery were set. Since the topic was focussed, a single focus group with diverse characteristics was considered to offer a range of constructive experiences.

Setting

The focus group was facilitated in a non-clinical setting. The investigators (SJC and CJCM), along with five non-participating representatives from charitable bodies and other academic representatives (i.e. information design experts) were present throughout. All non-participating individuals sat away from the main group and did not influence the group dynamic.

Data Collection

A semi-structured approach to questions was used throughout the focus group. This was informed by a topic guide which was developed co-operatively with a patient representative in order to ensure the discussion was balanced and relevant (*Supplementary File 1*). The focus group was audio-recorded, with field notes made throughout and agreed by the investigators at the close of the session. The focus group lasted for 2 hours. Participants were invited to contact the investigators with further comments after the session but no further comments were received.

Data Analysis

The transcript was checked to ensure patient confidentiality was maintained and material removed which could possibly identify individuals (i.e. name of their doctor, family members). Coding was inductive, identifying issues of importance to patients. Data were later explored using the conceptual framework developed by Entwistle and colleagues (9). This became the initial coding frame. Codes were sorted into categories based on how they relate to one another, and themes formed using a process of indexing, charting, and mapping (10). The researchers (SJC, CJCM) agreed the coding index, which was then applied to the remaining transcript by one researcher (SJC). No dedicated qualitative software was used. A full outline of codes and themes are presented in *Supplementary Table 1*.

Results

Focus Group Demographics

Eleven patients provided consent and took part in the focus group. A broad range of demographics were represented, including 7 female participants (63.6%) and a selection of age groups (41-50: n=1; 51-60: n=6; 61-70: n=4). Participants received treatment at hospitals located in seven different regions of the United Kingdom and most were 3-5 years (n=5/11; 54.5%) out of surgery. The majority of participants underwent surgery for bowel cancer (n=10/11; 90.9%) (Table 1).

Information Needs

All participants considered education and counselling (i.e. information about how to access these) to be a priority information need. Other needs were: pre-operative health optimisation (n=7/11), pain control (n=7/11), approach to surgery such as “key-hole” techniques (n=5/11), eating and drinking (n=5/11), and mobilisation (n=5/11). A full outline of priorities is shown in Table 2.

Providers and Formats of Information

A total of 13 information providers were extracted from the transcript. This included members of the direct perioperative team (*surgeons*; *anaesthetists*, *nurses*), allied professionals (*dietitians*, *physiotherapists*), as well as others including care-coordinators, family and friends, and district nurses (Table 3). A total of 10 information formats were discussed, including traditional formats (*written material*, *face-to-face*) and casual formats (*Google, YouTube, other websites, etc).* A full outline is provided in Table 3

Theme 1 – Information-provision is not prioritised by healthcare providers

The group expressed how healthcare providers sometimes appear reluctant or unable to provide patients with necessary information. This causes them to lose confidence in their healthcare team, as they view shortcomings in information-provision to represent a lack of concern or knowledge:

- *'When I was leaving the hospital, I said "do I have to be careful what I eat?" and no one answered me' (Female)*
- *'An auxillary nurse went to the computer, googled it and just printed me something off' (Female)*
- *'They didn't think about what, as a patient, I needed – they just said "here's all this stuff" and just gave it to me' (Female)*

Some of the group explained how the provision of information can sometimes feel trivialised or even erroneous. Patients feel the need to reach out for information to enable them to engage in recovery, but what is offered may fall short of their expectations. The information which is provided to them can be inconsistent and this was a considerable source of confusion and anxiety.

- *'I had to ask the surgeon because the information is so [non-verbal: unsatisfactory] …and he just said eat, drink and be merry because you could walk out that door and get run over by a bus' (Female)*
- *'I had this food that they wrote down, what you should expect each day, and I was trying to do that…It wasn't until a nurse said "oh, you don't need to force yourself" (Male)*

Theme 2 – High emotional state precludes effective understanding

The group talked at length about the difficulties of understanding information during emotionally challenging situations. Feelings of shock, fear, and uncertainty after receiving bad news precluded good understanding of any subsequent information about recovery.

- *'You're just in such a state aren't you so it doesn't go in' (Female)*
- *'As soon as you say,* 'yes, you've got cancer' then bang, the *shutters go down, and you don't hear any more… I didn't hear anything for three days' (Female)*

There was wide agreement that state of mind is a key determinant of good understanding. Information must be clear, consistent, and reinforced across a broad range of formats. Importantly, healthcare professionals must be sensitive to patients' underlying anxieties otherwise information may appear disingenuous or even add to their burden. The support of family members can help to mitigate these challenges.

- *'You've got to keep giving the information in different ways…eventually people will take it' (Female)*
- *'You've got to remember that patients are people with feelings, and not a tick-box' (Female)*
- *'Fortunately, my wife was with me and she said "no, the doctor told you this", really?' (Male)*

Theme 3 – Appropriate information design facilitates understanding

There was agreement that good information design facilitates effective understanding, with both positive and negative experiences discussed. Resources are commonly 'text-heavy' and produced using technical or inaccessible language. The structure of information is important since this can be used to rationalise large volumes of content and help patients to retain it. In particular, patients desire an overview of recovery early in their 'journey' as this guides their understanding and promotes active engagement. Poor attention to design can lead to feelings of being unimportant and information needs being overlooked.

- *'The quality of information I got was absolutely superb' (Male)*
- *'I felt a lot of stuff was printed, but printed really wrong or badly… half the stuff was missing so I felt like I was an after-thought" (Female)*
- *'I come from a training background and the thing that we always say is keep it simple and use plain English' (Female)*
- *'Overview for me is the thing that is missing. It was always just the next two weeks. I would have liked to understand when I was diagnosed what the next year would look like' (Male)*

Theme 4 – Information-provision should be personal

The group emphasised that information-provision is 'not one size fits all'. Impersonal and formulaic provision of information overlooks individual needs and patients may feel distanced or disengaged from their treatment. It was acknowledged that tailoring specific information resources is not always feasible, but individualised goals set by 'trusted' healthcare providers are beneficial as they motivate patients to engage with recovery.

- *'The people on the forms were, sorry, not people like me. They were older people. I was young, I wanted to be fancy free…' (Female)*
- *'The images just did not relate to who I was and I really, really struggled with that' (Female)*
- *'And it was saying, okay you need to have done this much exercise... It sort of built up what you should eat and how much you should do. So that was really great' (Male)*

Theme 5 – Information-provision should aim to empower

The group expressed that information should empower patients to take control of their recovery. Not all patients are capable of independent care, but many are driven to pro-actively look forward and facilitate their return to baseline functioning. To this end, the desire for information can be profound as patients seek out enablers of recovery.

- *'My focus was very much next stage, not now' (Male)*
- *'It was a few days after my resection and I was saying to them 'you have to walk me around the ward now', or 'I have to get to the bath to do this thing'' (Female)*
- *'This is the bit that you can do to help yourself' (Male)*

Theme 6 – Information-provision should aim to support

Whilst patients desire empowerment during recovery, support is essential throughout. Absence of this is detrimental, in that it causes distress, anxiety, and excess burden. Patients feel unsure about what is normal during their recovery, which leads to self-seeking of information from sources that are unregulated and possibly inaccurate. Good information can help to facilitate support through appropriate sign-posting and suggestions for self-education.

- **'***I had to knock on the door myself and plead for help…' (Female)*
- *'You have no idea…so you do what you do. You look it up on Google, and you see and fear the worst' (Female)*
- *'What we're saying is that a lot of the information we're getting, we're getting ourselves… it's not been provided for us' (Female)*

Theme 7 – Information needs persist long after discharge

A strong view was expressed that information needs do not stop at the point of hospital discharge. The transition from hospital to home recovery is abrupt and often unexpected. Patients must come to terms with leaving a supported environment to coping alone at home. This can feel daunting, but may be mitigated by clear pathways to relevant support channels.

- *'Everyone just disappears and you suddenly feel really, really helpless' (Female)*
- *'…coming out of both [hospitals], I still lack information' (Female)*
- *'So, for me it's the fact that there is someone that I can contact and they will get back to me' (Female)*

Discussion

This study provides important insights into the information-needs of patients undergoing colorectal surgery. Information is important to patients at all stages of recovery, but emotionally-demanding situations and poor information design are barriers to understanding. To improve the provision of information, resources should be personal and aim to address patients' individual needs. They should also empower patients to take control of their recovery by instilling knowledge and confidence. Importantly, information needs do not stop at the point of discharge. These are often greatest after discharge as patients continue their journey towards recovery beyond the supported environment of the hospital ward.

Previous research has explored how patients view recovery after colorectal surgery within enhanced recovery programmes. Findings presented by *Gillis* and colleagues showed that patients want to be active participants in their care, but only when they have a good understanding of care pathways and their benefits (11). *Poland* and colleagues similarly showed that good understanding of bodily processes instils confidence in patients to self-manage their recovery (12). This is particularly important after discharge, when patients must personally navigate the transition between hospital and home to regain control of their daily life (13). The content of patient information has also been considered. *McNair* and colleagues recently developed a 'core information set' during a consensus exercise with patients and healthcare professionals. They identified 11 key items with a focus on surgical complications (such as anastomotic leak and surgical site infection), survival, stomas, and quality of life (5). This demonstrated the importance of involving patients at an early stage in the development process. Finally, it is important to consider the principles of human learning and information-processing. The ability to comprehend and retain knowledge is complex, in that situational factors, previous life experiences, core knowledge, and even genetic factors influencing memory, all lead to individual differences in understanding (14). Whilst it is challenging to address these factors in a single information resource, it is important to acknowledge that not all patients may process or understand information in the same way.

The main strength of this study is the detailed insight it provides into a relatively unexplored element of surgical care. The focus group format facilitated honest and unrestricted discussion about weaknesses of current information resources and how these may be improved. The main limitation is the restriction of data collection to a single focus group. Seeking out and exploring divergent voices was not possible here, but the broad sample of participants across a national setting (including most geographical regions of the United Kingdom) offered a diverse range of views on a narrowly defined topic. Since these align with previous studies, it is proposed that the data are sufficiently stable to draw meaningful lessons and help to inform constructive improvements (11, 12). Another possible limitation is the recent publication of updated guidelines for enhanced recovery after colorectal surgery. Whilst these include a small number of amendments compared to the previous iteration, the issues relating to information and education remain constant (15).

In summary, a needs assessment for the development of future information resources is provided. High quality evidence to inform the format, timing, and design of information is required and this must involve patients as close partners in development. It must also consider differing priorities between patients (traditional consumers of information) and health professionals (traditional providers of information) and how these can be harmonised. It is unlikely that current information resources will lead to patient harm, but optimising their delivery may be a target for clinical- and cost-effective gains in recovery. Future research should build upon the findings of this work and explore how the provision of information can be improved for patient benefit.

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Table 1 – Focus group participant demographics (n=11)

Demographic		N= (%)
Sex	Female	7 (63.6%)
	Male	4 (36.4%)
Age	41-50	1 (9.1%)
	51-60	6 (54.5%)
	61-70	4 (36.4%)
Years since surgery	<1 year	1 (9.1%)
	1-2 years	1 (9.1%)
	3-5 years	5 (54.5%)
	5-10 years	4 (36.4%)
Indication for surgery	Bowel cancer	10 (90.9%)
	Other	1 (9.1%)
Place of treatment	East Midlands	2 (18.2%)
	East of England	1 (9.1%)
	Greater London	1 (9.1%)
	North West	1 (9.1%)
	South East	1 (9.1%)
	West Midlands	2 (18.2%)
	Yorkshire & the Humber	2 (18.2%)
	Other – Non-UK	1 (9.1%)

Table 2 – Information needs of focus group participants according to ERAS items

ERAS Item	Top-5 rating (total n=11)	Bottom-5 rating (total n=11)
Education and counselling before surgery	11	0
Optimising health before surgery	7	1
Control of pain	7	0
The use of key hole surgery and other techniques	5	0
Return to eating and drinking	5	1
Mobilising early	5	1
Preventing ileus	4	0
Fasting and carbohydrates before surgery	3	1
Reducing the risk of blood clots	2	0
Anaesthetic method	2	3
Audit and compliance to ERAS	2	8
Nasogastric tubes	1	4
Drainage of abdominal fluid	1	4
Bowel preparation before surgery	0	2
Pre-medication for anxiety	0	9
Antibiotics before the start of surgery	0	2
Nausea and vomiting	0	2
Maintaining normal body temperature	0	8
Fluid management	0	1
Control of blood glucose/sugars	0	8

Focus group participants (n=11) rated each item as being within their “top-5” or “bottom-5” list of priorities for information-provision, as per the Method. ERAS: enhanced recovery after surgery.

Table 3 – Providers and formats of information discussed by participants

Information providers	Information formats
Surgeon/doctor	Written material
Anaesthetist	Pictures and images
Research nurse	Face-to-face
Auxillary nurse	Video
Staff nurse	CDROM/disc
Clinical nurse specialist	Forums
Physiotherapist	Google
Recovery nurse	External bodies/charities
Family/friends	YouTube
Care co-ordinator	Websites (other)
Stoma team	
District nurse	
Dietitian	
Multi-disciplinary team	