

The Experience of Extended Bowel Resection in Individuals With a High Metachronous Colorectal Cancer Risk: A Qualitative Study

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This research was funded by the Victorian Cancer Agency and supported by the Australasian Colorectal Cancer Family Registry through a grant from the National Cancer Institute and National Institutes of Health (UM1 CA167551), and through cooperative agreements with members and Principal Investigator of the Australasian Colorectal Cancer Family Registry (U01/U24 CA097735). Win is an Australian National Health and Medical Research Council Early Career Fellow.

Steel, Trainer, Heriot, Lynch, Parry, and Keogh contributed to the conceptualization and design. Steel, Trainer, Win, and Keogh completed the data collection. All authors provided the analysis and contributed to the manuscript preparation.

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Submitted July 2015. Accepted for publication September 18, 2015.

Key words: colorectal cancer; surgery; patient experience; qualitative methodology

ONF, 43(4), 444–452.

doi: 10.1188/16.ONF.444-452

Purpose/Objectives: To ascertain individual experiences of extended bowel resection as treatment for colorectal cancer (CRC) in those with a high metachronous CRC risk, including the self-reported adequacy of information received at different time points of treatment and recovery.

Research Approach: Qualitative.

Setting: Participants were recruited through the Australasian Colorectal Cancer Family Registry and two hospitals in Melbourne, Australia.

Participants: 18 individuals with a high metachronous CRC risk who had an extended bowel resection from 6–12 months ago.

Methodologic Approach: Semistructured interviews. Data were analyzed thematically.

Findings: In most cases, the treating surgeon decided on the best option regarding surgical treatment. Participants felt well informed about the surgical procedure. Information related to surgical outcomes, recovery, and lifestyle adjustment from surgery was not always adequate. Many participants described ongoing worry about developing another cancer.

Conclusions: Patients undergoing an extended resection to reduce metachronous CRC risk require detailed information delivered at more than one time point and relating to several different aspects of the surgical procedure and its outcomes.

Interpretation: An increased emphasis should be given to the provision of patient information on surgical outcomes, recovery, and lifestyle adjustment. Colorectal nurses could provide support for some of the reported unmet needs.

Colorectal cancer (CRC) is the third most common cancer worldwide, affecting almost 1.4 million individuals in 2012 (Ferlay et al., 2015). In Australia, about 15,000 CRC cases are diagnosed each year, causing the death of about 4,000 individuals (Australian Institute of Health and Welfare, 2014). The prognosis of an affected individual is dependent on the stage of the tumor at the time of diagnosis and its associated treatments involving surgery and/or adjuvant radiotherapy and chemotherapy. However, a significant proportion of individuals who have a segmental resection for CRC are at an increased risk of developing a subsequent new primary CRC (Heneghan, Martin, & Winter, 2015; Parry et al., 2011). This is defined as metachronous CRC, which has an associated impact on overall survival (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005). Risk factors for metachronous CRC include young age at primary diagnosis, right-sided index tumor, tumor microsatellite instability, and familial cancer syndromes such as Lynch syndrome (Gervaz, Bucher, Neyroud-Caspar, Soravia, & Morel, 2005; Rex et al., 2006; Ringland, Arkenau, O'Connell, & Ward, 2010; Shitoh et al., 2002). For individuals with Lynch syndrome, the cumulative

lifetime risk of developing CRC is 50%–80% (Kohlmann & Gruber, 2004).

Metachronous CRC risk can be reduced at the time of index CRC surgery by the extent of the surgical resection, either removing a segment of the colon (segmental resection) or removing most to all of the colon (extended resection). An extended resection (subtotal colectomy with ileosigmoid anastomosis, total colectomy with ileorectal anastomosis, or proctocolectomy with ileostomy) is the most effective method to reduce the risk of subsequent CRC and is favored to segmental resection in individuals who are at increased risk for developing metachronous CRC (Giardiello et al., 2014; Natarajan, Watson, Silva-Lopez, & Lynch, 2010; Parry et al., 2011; Van Dalen et al., 2003; Win et al., 2013; You et al., 2008). Although extended resection is the preferred surgical option in patients with Lynch syndrome, a limited amount of controlled data compare surgical approaches for this group of individuals (Patel & Ahnen, 2012). Parry et al. (2011) studied the risk of metachronous CRC for 382 mismatch repair (MMR) gene mutation carriers who underwent surgery for an index (first primary) colon cancer. Of the individuals who underwent extended resection ($n = 50$), none was diagnosed with metachronous CRC at a mean of eight years, compared with 74 of 332 (22%) at a mean of nine years who underwent a segmental resection. In a group of MMR gene mutation carriers diagnosed with rectal cancer who underwent a proctectomy (removal of the rectum), Win et al. (2013) reported the cumulative risk of metachronous colon cancer as 19% at 10 years after surgery, suggesting that a total proctocolectomy should be considered in patients with Lynch syndrome who have an index rectal cancer.

The goals of colorectal surgery in individuals with a high metachronous CRC risk are primary cancer treatment and metachronous cancer prevention, while maximizing quality of life (QOL) and life expectancy. For a 25-year-old with Lynch syndrome, immediate extended resection results in the greatest life expectancy (Syngal, Weeks, Schrag, Garber, & Kuntz, 1998). However, the surgical decision must take into consideration many psychological and experiential factors, including perceived and actual potential future risk of cancer with its associated anxiety and desire to avoid additional cancer treatment, surveillance alternatives, and impact on QOL. Following an extended bowel resection, patients may experience altered bowel function even after long-term adaptation, which may adversely affect QOL in terms of social activities, travel, and ability to work. This is particularly pertinent because individuals with a high metachronous CRC risk are often disproportionately young at diagnosis of the

index cancer. Pollett et al. (2014) studied QOL after surgery in individuals with familial CRC and did not find a significant adverse effect on QOL following segmental or extended resection in any of a large number of domains of life, including physical functioning and body image. Other research supports this finding, suggesting that extended resection is a reasonable surgical option for patients with a high metachronous CRC risk (bin Mohd Zam et al., 2005; Church et al., 1996; Delaney et al., 2003; Haanstra et al., 2012; You et al., 2008).

Patient QOL following extended therapeutic resection and the use of the multimodal care pathway for patients undergoing CRC surgery (Nygren et al., 2012; Smith et al., 2014) have been widely studied. However, little is known concerning the patient experience of extended bowel resection from a qualitative perspective and whether patients' lived experience of surgery and its effects equate with their expectations prior to surgery. Therefore, the aim of the current study was to ascertain personal experiences of extended bowel resection in individuals with a high metachronous CRC risk, with a particular emphasis on the surgical decision and self-reported adequacy of the information received in relation to specific time points of treatment and recovery.

Methods

Participants

The current study's procedures were approved by the Human Research Ethics Committees of participating institutions (University of Melbourne, Peter MacCallum Cancer Centre in Melbourne, and Royal Melbourne Hospital). Participants were identified and recruited through the Australasian Colorectal Cancer Family Registry (ACCFR), Peter MacCallum Cancer Centre, and Royal Melbourne Hospital. Eligible participants were those who were aged 18 years and older, spoke English, were contactable within Australia, and had an extended bowel resection (subtotal colectomy with ileosigmoid anastomosis, total colectomy with ileorectal anastomosis, or proctocolectomy with ileostomy) following a diagnosis of CRC between six months and 12 years prior to the interview. Given the rarity of this surgery, broad inclusion criteria around the time since surgery was necessary to recruit the number of participants required to reach saturation of the main themes. Participants were not selected on the basis of their genetic status, and those with significant ill health were not recruited into the study.

Eligible participants initially were contacted by phone, either by an ACCFR representative if they were a member of the registry or by one of their treating specialists if they were sourced through one

of the participating hospitals. Patients who agreed to receive additional information about the study were sent a participant information sheet and then contacted by the first author to arrange an interview. Participants were given the option of a face-to-face or telephone interview with one of the study investigators. Recruitment ceased once saturation of the main themes was reached.

Data Collection and Analysis

A qualitative approach was adopted to capture patients’ experiences in their own words through semistructured interviews, which, to the researchers’ knowledge, had not previously been done with this group of individuals. Prior to the interview, participants were provided with a written and verbal explanation of the purpose of the interview, what participation in the interview would involve, and their rights as a participant. Informed consent was obtained verbally if over the phone or written if in person, and the par-

ticipants’ demographic information was recorded by the interviewing investigator. The interviews were semistructured and were designed to obtain information about the participants’ experiences of being diagnosed with CRC, the decisions that were made regarding surgical treatment, and the short- and long-term sequelae of their surgery. Participants were encouraged to describe their feelings and emotions during the times of diagnosis, treatment, and recovery, and whether their information needs were met at each of these time points. The interviews lasted 50 minutes on average and were audio recorded and transcribed verbatim. The transcripts were de-identified but were not edited to alter any of the participants’ statements.

Thematic analysis was employed because it suits questions related to understanding people’s experiences or perceptions and looks for patterns in the data. The data were analyzed thematically through reading the transcripts multiple times. The coding framework emerged from the data analysis, and all data were coded into the themes identified with the support of QSR NVivo qualitative data management software. Additional analysis of each theme was conducted to make sure the full variability in the data could be captured by the analytical framework developed. Double coding was used to ensure that any bias in the interpretation of the data was brought to attention and further clarity was reached.

Results

Twenty-six people agreed to be contacted about the study, of which 18 completed an interview over the phone or in person. Recruitment ceased once saturation of the main themes was reached at 18 interviews. The demographic characteristics of the participants are summarized in Table 1. Ten participants had subtotal colectomy with ileosigmoid anastomosis, six had total colectomy with ileorectal anastomosis, and two had proctocolectomy with permanent ileostomy. Individual characteristics are illustrated in Table 2. Most of the study participants were males (n = 12) aged from 26–49 years at time of extended resection, of which 10 had confirmed Lynch syndrome. The mean age of all participants was 43 years, the mean age of females was 38 years, and the mean age of males was 46 years. For those who had not undergone genetic testing (n = 8), each was known to be at high risk for metachronous CRC because of their young age at diagnosis (younger than 50 years) and/or family history of CRC or other Lynch syndrome–associated cancers.

Types of Surgery

Three types of surgical experience were present among the cohort: (a) nine participants received

TABLE 1. Sample Characteristics (N = 18)	
Characteristic	n
Gender	
Male	12
Female	6
Age at interview (years)	
30–49	8
50–69	10
Age at extensive resection (years)	
26–49	12
50–59	6
Time since extensive resection (years)	
0.5–2	5
3–8	5
9–12	8
Marital status	
Single	4
Married/de facto	12
Divorced or separated	2
Health insurance	
Private	10
None	8
Type of surgery	
Emergency surgery followed by extensive resection	3
Extensive resection for index CRC diagnosis	9
Extensive resection for recurrent CRC following segmental resection for index CRC	6
Stoma	
Temporary	1
Permanent	2
No stoma	15
Genetic status	
Lynch syndrome	10
Not tested	8
CRC—colorectal cancer	

an extended resection for their index CRC diagnosis; (b) six participants had a segmental resection for their index CRC diagnosis and later had an extended resection for a recurrence or metachronous cancer; and (c) three participants had emergency surgery to explore the cause of symptoms, which resulted in the diagnosis of their index CRC. Two of these participants received a segmental resection as an emergency procedure and, at a later date, underwent an extended resection. The third participant received an extended resection during emergency surgery. Overall, three participants received an ileostomy, two of which were permanent.

Discussion and Decision Making About Extended Resection

Surgeon-presented decision: The most common scenario when deciding about the type of surgical procedure to be performed was for the surgeon to make the decision, followed by a discussion with the patient about why an extended resection was the best option (n = 11; 8 extended resection for index CRC diagnosis, 3 previous CRC diagnosis and segmental resection with extended resection following CRC recurrence). Participants in this scenario, who varied in age at diagnosis from 26–56 years, were content with the surgical decision being made for them by their treating specialist and then having the decision explained to them (see Figure 1).

Shared decision-making process: Four participants experienced a shared decision-making process with their surgeon (one extended resection for index CRC diagnosis and three previous CRC diagnosis and segmental resection with extended

TABLE 2. Characteristics of Individuals Undergoing Surgery for Index CRC

Participant	Age at Interview (Years)	Age at Extensive Resection (Years)	Type of Surgery
Surgeon-Presented Decision			
Participant 1 (male) ^a	60	50	Extensive resection for index CRC
Participant 2 (female) ^a	52	42	Extensive resection for index CRC
Participant 3 (male) ^a	44	34	Extensive resection for index CRC
Participant 4 (female) ^a	33	26	Extensive resection for index CRC
Participant 5 (male) ^{b, c}	30	29	Extensive resection for index CRC
Participant 6 (female) ^b	63	50	Extensive resection for index CRC
Participant 7 (male) ^b	57	46	Extensive resection for index CRC
Participant 8 (male) ^b	68	56	Extensive resection for index CRC
Participant 9 (female) ^a	48	38	Previous segmental resection for index CRC, extensive resection following CRC recurrence
Participant 10 (male) ^a	51	45	Previous segmental resection for index CRC, extensive resection following CRC recurrence
Participant 11 (male) ^b	65	57	Previous segmental resection for index CRC, extensive resection following CRC recurrence
Shared Decision-Making Process			
Participant 12 (male) ^{a, d}	43	42	Extensive resection for index CRC
Participant 13 (male) ^a	60	52	Previous segmental resection for index CRC, extensive resection following CRC recurrence
Participant 14 (male) ^a	49	41	Previous segmental resection for index CRC, extensive resection following CRC recurrence
Participant 15 (female) ^b	41	41	Previous segmental resection for index CRC, extensive resection following CRC recurrence
Emergency Surgery			
Participant 16 (male) ^{a, d}	54	45	Emergency segmental resection followed by extensive resection
Participant 17 (female) ^b	30	30	Emergency segmental resection followed by extensive resection
Participant 18 (male) ^b	66	55	Emergency extensive resection

^a Had confirmed Lynch syndrome

^b Not tested for Lynch syndrome

^c Had a temporary ileostomy

^d Had a permanent ileostomy
CRC—colorectal cancer

SURGEON-PRESENTED DECISION (N = 11)

"I'm not a doctor, and I'm not gonna try and evaluate, you know, what he should be doing and what he shouldn't be doing. He knows his thing, obviously, and, you know, I just had complete faith in him." (Participant 8, age 56 at extensive resection)

SHARED DECISION-MAKING PROCESS (N = 4)

"So they were taking me through the options. . . . That was the first real conversation I'd had with anyone about, you know, the full range of options. . . . They effectively said it was my decision . . . so I thought, well, the upside [of having an extensive resection] is I'm gonna pretty much rid of all the risk of future cancer. . . . The right decision was made in the end." (Participant 12, age 42 at extensive resection)

EMERGENCY SURGERY (N = 3)

"We didn't actually know. They just thought, at that stage, it was a cyst. . . . I'd just been told that I'd had all of, basically all my large bowel removed, and they'd been able to stretch the small bowel over and join it up so I wouldn't have a colonoscopy bag. Yeah, that was basically it." (Participant 18, age 55 at extensive resection)

INADEQUATE INFORMATION PROVISION (N = 1)

"I would have liked to have known, arriving at the hospital, that they would be performing an enema with a nurse sort of thing and a saline solution. . . . You've already done all that sort of [preparation] stuff, and, all of a sudden, you're thinking you're about to go under surgery, but, no, you've got to go through this [enema] first." (Participant 14, age 41 at extensive resection)

ADEQUATE INFORMATION PROVISION (N = 7)

"I think I knew enough about the operation and the risk involved and what was involved in terms of anesthetic and the duration of the operation and all that. That was great." (Participant 15, age 41 at extensive resection)

FIGURE 1. Participant Comments About Discussion, Decision Making, and Information Provided on Extensive Resection

resection following CRC recurrence). This decision-making process included the surgeon presenting options—and sometimes advocating strongly for a certain treatment—but with the patient making the final treatment decision.

Emergency surgery: For the three participants who received emergency surgery, no discussion was held in advance concerning the possibility of an underlying CRC diagnosis.

Information Provided About the Surgical Procedure

Only one participant felt that information provision could have been better around the preparation that was required prior to extended resection surgery, which came as unexpected to him, even with previous surgical experience of a segmental resection.

Seven participants reported being adequately informed about the extended resection surgical procedure and its associated risks. Their main source of information was the operating surgeon and surgical team. They reported being given the opportunity to ask questions and raise any concerns with the surgical team, although many of them felt content not knowing every detail of the surgical procedure. The remaining 10 participants did not comment on the adequacy of information provided about the surgical procedure.

Information Provided About Recovery and Adjustment

Thirteen of 18 participants reported inadequate information provision in at least one of three clinical areas: surgical outcomes, recovery from surgery during the hospital stay, and long-term lifestyle adjustments.

Surgical outcomes: Six participants would have liked more information on the potential outcomes of surgery (see Figure 2). Three would have liked more information prior to surgery on the possibility of a permanent ileostomy and how that would affect their lifestyle. The surgical plan discussed beforehand for one of these participants was to have a temporary ileostomy, which would then be reversed a few months later. However, complications during surgery meant that this was not possible, and he woke up with an unexpected permanent ileostomy. Given this patient's experience, he was keen for all patients in this instance to be better informed prior to surgery about the implications of having a permanent ileostomy, even if only a slight chance exists that they may need one. Two participants unexpectedly had more than just their colon removed during surgery, including the removal of an ovary in one instance and the removal of a large number of lymph glands in another. Although both of these outcomes were necessary to reduce the risk of future cancers, these participants felt they should have been prepared beforehand for such an outcome.

For one participant who had emergency surgery, resulting in an extended resection, information around the possibility of being diagnosed with CRC would have been beneficial prior to surgery, helping him adjust to the news later. Only one participant reported that the information provided on the potential outcomes of surgery was adequate for him.

Recovery: Five participants reported inadequate information provision about the initial recovery period. Issues included not knowing what to expect physically and mentally, not being prepared for how many tubes and connections would be present after surgery, and not being certain about how long the

recovery process should take. Two participants reported receiving adequate information about the recovery period. One of these participants also reported inadequacies with the information provided prior to surgery about the recovery period but felt that the communication from the surgical team once he was in recovery was adequate.

Lifestyle adjustment: The need for more adequate information on lifestyle adjustment following surgery was reported by five participants. These participants would have liked lifestyle advice about diet, how to manage bowel movements, and how to adjust to life in general following an extended resection. Four other participants commented that the information provided about lifestyle adjustment adequately met their needs. Stoma nurses were valued highly among the few who had an ileostomy, but they did not have enough time to spend with patients.

Worry About Health in the Future

Toward the end of each interview, participants were asked, “Do you worry about your health in the future?” (see Figure 3). The majority of participants described being worried about their health in the future ($n = 12$); five spoke about actively trying to not worry because they believed they were doing everything they could do to prevent another cancer (i.e., extended resection followed by regular screening), and seven were worried about local recurrence or developing a cancer in another site. The remaining six participants did not spend time worrying about their health in the future because they felt that they were doing everything they could to prevent another cancer. Overall, no correlation was found between confirmed Lynch syndrome and worry about health in the future, with participants with confirmed Lynch syndrome falling into each response group.

Discussion

Recognition is increasing that, for a subgroup of patients diagnosed with an index CRC, extended surgical resection can provide therapeutic and preventative benefit in terms of treating the index cancer and reducing the risk of a metachronous CRC. With this shift in clinical practice comes the responsibility to inform patients of the short- and long-term consequences of such a procedure. The current study focused on personal experiences of extended bowel resection in individuals with a high metachronous CRC risk, with a particular emphasis on self-reported adequacy of the information received in relation to specific time points of treatment and recovery.

Solomon et al. (2003) suggested that, without explicitly seeking patient preferences and incorporating

FIGURE 2. Participant Comments About Information Provided on Recovery and Adjustment

SURGICAL OUTCOMES

Inadequate Information Provision ($n = 6$)

“Prepare the patient for what you’re going to be up against when you have a permanent bag . . . if there is any realistic chance that they’re going to end up with a permanent bag. It was never really talked about . . . what that’s gonna mean from a lifestyle point of view, from a management point of view, from a psychological point of view.” (Participant 12, age 42 at extensive resection)

“If they didn’t know they were going in for a cancer operation, just to say, ‘Well, look. There is an off-chance that there could be a cancer there.’ My surgeon didn’t seem to think there would be. Yeah, I think just to warn people and say, ‘Yeah, there is a chance that maybe we could find a cancer.’” (Participant 18, age 55 at extensive resection)

Adequate Information Provision ($n = 1$)

“For me, it was enough. I think the scenario with the bag thing, at the start, when they said, ‘You could come out of it with a bag’ and stuff. I think that was good to let me know. . . . I wouldn’t want to be coming out of it and then they tell me . . . or wake up and you’ve got a bag. I wouldn’t have wanted that to happen.” (Participant 11, age 57 at extensive resection)

RECOVERY

Inadequate Information Provision ($n = 5$)

“I would like to have known about the sort of waking up period, like what is going to be sticking out of me. . . . [The surgeon] had mentioned that they would use uritheric stents . . . but just several things like being catheterized, having a rectal tube, having a wound tube, having a central line sutured to my neck, these are things I didn’t anticipate.” (Participant 5, age 29 at extensive resection)

Adequate Information Provision ($n = 1$)

“Whenever [the surgeon] came around, I got lots of feedback, and the fellow also did a pretty good job in communicating what was happening.” (Participant 5, age 29 at extensive resection)

LIFESTYLE ADJUSTMENT

Inadequate Information Provision ($n = 5$)

“That was really about it, that I’d have to go to the toilet more frequently. . . . It’s the lifestyle part seems a bit of a gap. . . . There really wasn’t any linkage between the doctor and recommendations for support groups or anything like that.” (Participant 3, age 34 at extensive resection)

Adequate Information Provision ($n = 7$)

“I had the dietitian come in and forewarn me about the dos and don’ts for dietary . . . movements that are going to happen on a very frequent basis, and you might not know they’re coming, which was all true. But I was given warning about that. Hints to sleep on certain things and all the rest of it. Wear certain things. I found my aftercare, nursing and the like, to be more than enough.” (Participant 14, age 41 at extensive resection)

“I’ve had a fair bit of contact with stoma nurses, but there are not enough stoma nurses there to deal with the demand. . . . It was hard for her to spend any quality time with individual patients to fully go over what was required. . . . They are a fundamental and absolutely required resource, and you do certainly need more of them.” (Participant 12, age 42 at extensive resection)

YES, ALTHOUGH I TRY NOT TO WORRY BECAUSE I'M DOING EVERYTHING I CAN. (N = 5)

"I suppose it's always a concern. I think you can't get too over-anxious about it. . . . There is that risk because I still have that mutated gene. . . . I understood that the reason I had a total colectomy was because the less bowel I had, the less likely I am to get bowel cancer. I'm still at risk of getting cancer." (Participant 13, age 52 at extensive resection)

YES, I WORRY ABOUT LOCAL RECURRENCE OR CANCER IN ANOTHER SITE. (N = 7)

"I'm conscious that I'm probably going to get an episode at one stage, maybe in the stomach. I do, I do [worry about getting another cancer]. I'm of a belief that I'm going to." (Participant 14, age 41 at extensive resection)

NO, I'M DOING EVERYTHING I CAN. (N = 6)

"I do my tests. No, I don't live every day worrying about cancer, no." (Participant 1, age 50 at extensive resection)

FIGURE 3. Participant Responses About Worries Related to Health Concerns and Cancer Recurrence in the Future

them into clinical decision making, patients with CRC may not receive the treatment that is best for them. Conversely, the majority of participants in the current study did not partake in a shared decision-making process but, overall, were content with the decision made to have an extended rather than a segmental resection (except for the one instance in which it was done as an emergency surgery) and felt well informed about the surgical procedure itself. However, despite satisfaction with the decision to have an extended resection, the majority of participants in the current study reported gaps in the information provided around surgical outcomes (e.g., the possibility of a temporary or permanent ileostomy), recovery (e.g., what tubes would be present), and lifestyle adjustment (e.g., diet and how to manage bowel movements).

In addition, despite recognizing that their metachronous CRC risk was drastically reduced as a result of the extended resection, many participants reported ongoing worry related to their health and risk of developing another cancer. This finding adds a novel qualitative perspective to the growing body of research on patient QOL following extended resection, with many studies reporting no significant adverse effects on QOL in this group and generally high patient satisfaction (bin Mohd Zam et al., 2005; Church et al., 1996; Delaney et al., 2003; Haanstra et al., 2012; You et al., 2008). This finding highlights the need for additional qualitative research to understand the depth of ongoing worry experienced by this patient group and how their worry compares to

other high-risk patients who have instead undergone a segmental resection.

The appropriate information and support must be available for patient recovery and well-being. Previous research into the information-seeking behaviors of patients with CRC suggests that the most popular source of information for this group is usually their treating healthcare professionals, such as stoma nurses and the operating surgeon, rather than external sources, such as the Internet or support groups (Broughton, Bailey, & Linney, 2004; Nagler et al., 2010; O'Connor, Coates, & O'Neill, 2010; Papadakos et al., 2015; Sahay, Gray, & Fitch, 2000). However, some patients have reported feeling abandoned during the postoperative period, with little information from medical practitioners on how to manage their new bodily functions, leaving patients to discover through trial and error how to manage their symptoms (Beaver et al., 2010; Smith et al., 2014; Taylor, Richardson, & Cowley, 2010). Stoma nurses were highly praised by the few participants who had a temporary or permanent ileostomy, but they reportedly did not always have sufficient time to spend with patients. Information retention is also an issue, with patients sometimes struggling to recall information provided to them prior to surgery, even when it has been provided as part of a comprehensive informed consent pathway (Scheer et al., 2012). Therefore, the timing of information provision is of vital importance, as illustrated by a participant who reported both adequate and inadequate information provision about the initial recovery period. Although he felt overwhelmed and underinformed about the physical state he would be in immediately following surgery, he reported getting a lot of feedback from his treating surgeon and fellow later in recovery, highlighting the need for information about the recovery phase to be delivered pre- and postoperatively.

Limitations

The main strength of the current study is the qualitative method used to provide crucial insight into patient experiences of extended bowel resection in individuals with a high metachronous CRC risk. However, the current study did have some limitations. The size and heterogeneity of the sample limit the generalizability of findings, and the smaller number of women in the sample makes the researchers unable to comment on any gender differences. A comparison group (e.g., patients with a high metachronous CRC risk who have had a segmental resection) would illustrate whether the findings are specific to the targeted group. This is a retrospective study, so recollection bias is a possibility, although the researchers' opinion is that the most crucial aspects would be well retained in memory.

Implications for Nursing

Nurses caring for patients with CRC could provide support for some of the unmet needs reported in this article, overseeing appropriate referrals to additional support services following surgery, thereby enhancing the overall patient experience. Adequate and appropriate information provision prior to surgery can better prepare patients for life after surgery, potentially empowering them to keep fit and healthy once their treatment is over, with improved QOL outcomes as a result (Neuman et al., 2010). The researchers recommend that efforts be made to increase information provision and support to patients about the short- and long-term consequences of extended resection surgery, including potential surgical outcomes, the initial recovery period, lifestyle adjustment, and the potential for ongoing worry about developing another cancer. Such information needs to be comprehensible, unbiased, unhurried, upfront, and delivered at more than one time point (pre- and postoperatively) if it is to meet patient needs (Carney, Jones, Braddon, Pullyblank, & Dixon, 2006; Park et al., 2014; Scheer et al., 2012; Sjöstedt, Hellström, & Stromberg, 2011; Waller et al., 2015; Wright et al., 2006). Stoma nurses were highlighted as a “fundamental and absolutely required resource” who were mainly under-resourced and unable to spend a quality amount of time with patients. Additional research in this area should document the voice of nurses caring for patients with CRC so that the barriers to supporting this disproportionately young group of patients can be understood.

Conclusion

Individuals undergoing extended bowel resection because of a high metachronous CRC risk require

Knowledge Translation

- Despite not taking part in a shared decision-making process, participants felt content with the decision made to have an extended rather than a segmental resection, given they were well informed about the surgical procedure itself.
- Participants reported gaps in the information provided around surgical outcomes, recovery, and lifestyle adjustment.
- Although participants drastically reduced their risk of a metachronous colorectal cancer, some still experienced ongoing worry related to their health and risk of developing another cancer.

detailed information, delivered at more than one time point and relating to several different aspects of the surgical procedure and its outcomes. Although participants were content with the decision to have an extended resection, findings from the current study suggest that an increased emphasis should be given to the provision of patient information on surgical outcomes, recovery, and lifestyle adjustment. The researchers' findings also indicate that patients can experience ongoing worry about their health and their risk of developing another cancer, despite understanding that their metachronous CRC risk has been drastically reduced following extended resection.

The authors gratefully acknowledge all study participants of the Colon Cancer Family Registries and staff for their contributions to this project.

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