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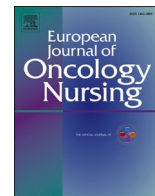
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## Experiences and perspectives of patients undergoing colorectal cancer surgery: A qualitative study

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### ABSTRACT

**Purpose:** This study aimed to explore the experiences of patients with colorectal cancer undergoing surgical treatment, capturing their perspectives from diagnosis through to post-discharge recovery.

**Methods:** A qualitative methodology was adopted, utilising semi-structured virtual interviews with ten patients recruited from a specialist colorectal clinic. Interviews were transcribed verbatim, and data analysed by the process of inductive thematic analysis, using interpretive description.

**Results:** Themes emerged across the domains of clinical and external, patient-level, and interpersonal and social factors affecting patient experience at diagnosis, surgery, and recovery stages. Clinical and external factors included the impact of the hospital environment, resource limitations, and the attributes of the clinical team, including ward nurses, clinical nurse specialists, and consultant surgeons, in providing compassionate support. Patient-level factors encompassed perceptions and emotional impacts of the diagnosis, and physical challenges post-surgery. Interpersonal and social factors included family support and the psychosocial impact of role changes during recovery.

**Conclusions:** Findings highlight the need for comprehensive, compassionate communication and tailored support across the patient journey. Recommendations include enhanced patient education on lifestyle impacts, resources to support family and peer networks, and more attention to psychosocial and emotional challenges in patient-centred care.

## 1. Introduction

Colorectal cancer is the third most common cancer, with the second highest mortality rate (Sung et al., 2021). Surgery, which may involve the creation of a temporary or permanent stoma, is the main treatment modality, while chemotherapy or radiotherapy, or both, are used in selected cases before (neoadjuvant) and or after (adjuvant) surgery (Rønning et al., 2016; Eriksen et al., 2021). Treatment for colorectal cancer can be life-changing for patients depending on needs specific to the individual (Drury et al., 2017). Common symptoms include fatigue, nausea, psychological distress, and issues related to sexual and urinary function, which can all impact on quality of life (Bregendahl et al., 2015; Jakobsson et al., 2017; Jonsson et al., 2011; Wennström et al., 2010; Worster and Holmes, 2009). A common side effect of surgical treatment

is bowel dysfunction, experienced by more than 80% of patients who undergo sphincter preserving surgery (without permanent colostomy) (Keane et al., 2017). The formation of an ileostomy or colostomy can significantly impact patients' quality of life (Brown and Randle, 2005). Our study focused on patients with cancers of the colon and rectum, with "colorectal cancer" used to describe these cancers specifically, excluding anal cancer.

Quantitative aspects of the trajectory being diagnosed and treated for colorectal cancer have been investigated and Patient Reported Outcome Measures (PROMs) have been developed, including for use in UK contexts (Sutton et al., 2019). However, existing literature highlights the need for a more in-depth understanding of patients' experiences and perspectives from diagnosis through the weeks following discharge, as this can help identify unmet needs while recognising the unique nature

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of each patient's journey (Samuelsson et al., 2018; Worster and Holmes, 2008). The transition from hospital to home has been highlighted as a crucial period for patient education and support, particularly as patients work to regain control over their lives (Anderson et al., 2013; Lithner et al., 2015).

Worster and Holmes (2008) explored patients' post-discharge experiences, yet participants focused on preoperative challenges, highlighting the importance of support during diagnosis. Patients facing colorectal surgery, especially the potential for a stoma, experience significant emotional stress, with 35–71% of patients reporting symptoms of anxiety or depression Chaudhri et al. (2005). Additionally, untreated preoperative distress in patients with colorectal cancer is linked to a lower quality of life two years post-surgery (Foster et al., 2016).

Recent qualitative studies on patient experiences have largely been conducted in Scandinavia (Eriksen et al., 2021; Jakobsson et al., 2017; Jonsson et al., 2011; Lithner et al., 2015; Samuelsson et al., 2018) and Asia (He et al., 2021; Lo et al., 2021), with only two UK-based studies by Anderson et al. (2013) and Sutton et al. (2019), which both used focus group interviews. While informative focus groups may limit discussions of sensitive issues, individual interviews could provide more in-depth understanding of patient experiences (Bullock, 2016). Scandinavian studies focusing on older adults indicate that, while they generally manage well post-discharge, improvements in follow-up care (Eriksen et al., 2021) and information provision are needed (Samuelsson et al., 2018).

Given the global prevalence of colorectal cancer and the critical period from diagnosis to post-discharge, there remains a notable gap in qualitative research exploring patient experiences through this journey, particularly in the UK context. This study aimed to address this gap by examining the experiences and perspectives of patients who underwent colorectal cancer surgery, with or without stoma formation, and who may have received neoadjuvant or adjuvant treatments such as chemotherapy or radiotherapy.

This study aimed to explore the experiences of patients with colorectal cancer undergoing surgical treatment, capturing their perspectives from diagnosis through to post-discharge recovery.

## 2. Methods

### 2.1. Qualitative approach and research paradigm

This was a qualitative study adopting an interpretive description methodology, utilising semi-structured one-to-one interviews to capture the experiential narratives of patients who underwent surgery for colorectal cancer. The Standards for Reporting Qualitative Research (SRQR) guidelines were followed to ensure rigour and transparency (O'Brien et al., 2014). Interpretive description offers a flexible approach that is particularly suited to exploring the intricate psychosocial and biological interactions within illness experiences, favouring inductive rather than deductive analysis (Thorne, 2016; Thorne et al., 1997). Individuals with lived experience of illness provide unique, expert insights, making this methodology well-suited for understanding complex patient journeys.

### 2.2. Researcher characteristics and reflexivity

The research team comprised two qualitative researchers (SL and LEE) and two clinicians (CH and AR) with expertise in this patient population. A reflexive approach acknowledged that qualitative themes are co-constructed through the researchers' assumptions, skills, and the data (Braun and Clarke, 2019). The first author's role as a Colorectal Clinical Nurse Specialist may have influenced responses but also fostered rapport, enabling honest discussions and mitigating the risk of emotional distress.

### 2.3. Context

Participants were recruited from a specialist colorectal clinic at a National Health Service (NHS) hospital in London, United Kingdom (UK), which performs approximately 140 colorectal resections annually.

### 2.4. Sampling strategy

A convenience sampling approach was used to recruit patients with diverse experiences across age, gender, background, and treatment types.

#### Inclusion criteria:

- Adult patients over 18 years of age, able to communicate in English,
- Patients who underwent surgical resection for confirmed colorectal cancer,
- Patients with sufficient physical and cognitive capacity to consent and participate in one-to-one interviews

#### Exclusion criteria:

- Patients medically unfit to be interviewed, for example, if severe symptoms prevented comfort during participation.

Participants were eligible if they had undergone surgery three weeks to three months prior to discharge, allowing adequate recovery time while experiences remained recent.

### 2.5. Ethical issues pertaining to human subjects

The study was approved by the Research Ethics Committee of the NHS Health Research Authority (reference: IRAS ID: 312887) and registered with the Research Department at the School of Health and Medical Sciences at City St George's, University of London (reference: ETH2223-0145) as the Sponsor for this study.

The study adhered to key research ethics principles:

- 1) Informed consent. Eligible patients received a Patient Information Sheet and consent form within two weeks to three months post-discharge. Consent was collected securely via a University Qualtrics® account, and participants could withdraw at any time.
- 2) Integrity. Each participant was assigned a study ID and data handling adhered strictly to the Data Protection Act 2018, the General Data Protection Regulations 2016, and the Data Protection Bill, ensuring participant confidentiality and data integrity.
- 3) Risk of harm. The interviewer, an experienced Clinical Nurse Specialist, monitored for distress during interviews and provided follow-up support, with referral to a psychologist if needed.

### 2.6. Data collection

Recruitment and interviews were conducted in parallel between June and November 2022. To minimise risk of infection associated with COVID-19, interviews, lasting 30–40 min each, were conducted virtually using a secure Zoom or Microsoft Teams University account, at a time convenient for participants. An interview guide (Supplementary Material) based on the study objectives was pilot tested with the first participant. The guide covered six main topics: (a) feelings at diagnosis, (b) quality of information, (c) stay in hospital, (d) the treatment received, (e) feelings when receiving the postoperative histology results and (f) challenges faced since the operation.

### 2.7. Data analysis

Thematic analysis, utilising QSR NVivo 12 software for qualitative analysis, allowed a rigorous process of data familiarisation, coding, and

theme identification Braun and Clarke (2006). Analysis was conducted in parallel with data collection and audio recordings were transcribed verbatim by the first author. Data were analysed inductively to generate overarching themes and sub-themes that describe similar underlying experiences among participants. To minimise interpretive bias, 20% of transcripts were randomly selected and coded by SL, and cross-checked with those generated by CH. Reliability was assessed by theme concordance and any conflict was resolved in discussion with LEE. Findings were reviewed and approved by all authors.

### 3. Results

Twenty-five patients met the inclusion criteria during the study period; two were excluded as did not have access to an online meeting software. Ten participants, seven female and three male, provided informed consent and were include in the study. Of these, eight participants were married, two single, nine identified as White British and one as Other White. All patients were older than 40 years of age (mean age 62.9 years, range 43–78).

Three participants were referred to the colorectal surgical clinic through the NHS bowel cancer screening programme, five were referred by a general practitioner, one was admitted via the emergency department, and one had undergone prior treatment at the clinic. Eight of the participants had an anterior resection (three with temporary ileostomies), one had a proctectomy with an existing colostomy, and one had a right hemicolectomy; six also had neoadjuvant chemotherapy.

Eleven themes described patients’ experiences and perceptions of their diagnostic and treatment journey of colorectal cancer. These themes were mapped against three overarching domains: 1) Clinical and external factors; 2) Patient-level factors; 3) Interpersonal and social factors. Fig. 1 visualises the conceptual model developed from the thematic analysis.

#### 3.1. Clinical and external factors

##### 3.1.1. The hospital environment

All participants were admitted to a surgical ward, and many described the environment, especially the noise, as a barrier to their well-being, often resulting in disturbed sleep. The noise came from multiple sources, including other patients, staff, and equipment:

“it’s almost like a complete assault on your senses, noises, the smells, the lights, the beepers, being with strangers ... I found that very difficult” [P5]

However, one participant felt that the ward environment positively impacted their well-being, as other patients provided entertainment and

support: “... very entertaining. If you’d been in a private ward you probably would have died of boredom ...” [P8].

##### 3.1.2. Personal attributes of the clinical team

All participants expressed appreciation for many of the staff, highlighting kindness, a positive attitude, and a caring approach as essential qualities. The Clinical Nurse Specialist was frequently mentioned as a key source of emotional support and information, while the kindness of the ward nurses was also valued.

“Being able to contact the clinical nurse specialist at any time, directly, to ask some of the most trivial questions, has always been a really important lifeline to me ... always reassuring and caring” [P7]

The importance of feeling safe and comfortable with their consultant surgeon was also highlighted:

“I felt comfortable, and I felt positive, and I felt safe with [name]” [P5].

##### 3.1.3. Lack of human resources

Most participants reported negative experiences due to insufficient hospital and community resources, particularly a shortage of staff. This affected timely diagnosis, as many struggled to secure a GP appointment:

“I continue to have symptoms and tried to get through to the GP ... you just ring and ring and ring” [P1].

One participant reported that staff shortages contributed to discharge errors, resulting in their leaving the hospital without the correct medication:

“I was discharged with an absolutely blank discharge form ... and I actually said, am I not meant to be taking injections or something, and they looked at the note and said ‘No’ ... the discharge was a complete disaster!” [P10]

Participants empathised with the ward nurses, recognising the high patient-to-nurse ratio and the pressure on staff. The heavy workload often impacted the level of care provided:

“I could actually see that they were generally struggling to sort me out, and made me feel really sorry for the nurses because I could see the level of stress all day there” [P2]

##### 3.1.4. Communication and patient education

This theme emerged at every stage: diagnosis, treatment, and recovery. Participants discussed the verbal and written information

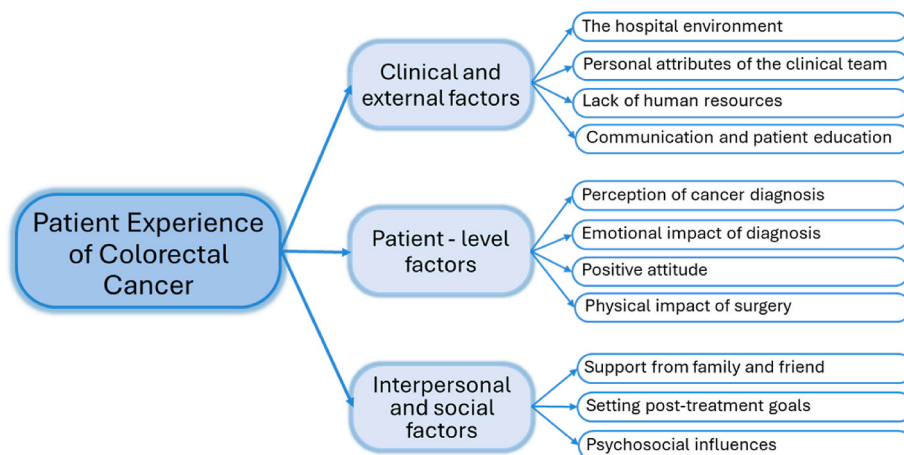


Fig. 1. Conceptual model of factors influencing patients’ experience of colorectal cancer.

provided about their diagnosis and treatment, highlighting the importance of clear and comprehensive communication. Most gave positive feedback on the quality and quantity of information they received:

“People were informative, were caring, gave me time to speak and ask questions, and not leave without being fully informed” [P4]

However, one participant felt their postoperative histology was poorly communicated, as they learned of their need for further treatment only after being re-admitted for complications:

“The whole they found cancer in the lymph nodes piece just sort of came out of the woodwork really ... I think that probably could have been handled a bit better ... it’s treating the person as a whole” [P10]

Others, while generally satisfied, suggested that practical advice, such as guidance on diet, side effects, and driving, would have been helpful for recovery:

“Before the operation, just having had a little crib sheet, Q&A or something, maybe the same for leaving hospital ... with reminders of what to eat and the driving point” [P9]

### 3.2. Patient-level factors

#### 3.2.1. Perception of cancer diagnosis

Participants shared their thoughts on what might have caused their cancer. While one participant admitted they hadn’t considered it, others linked their diagnosis to their lifestyle, particularly diet. One participant working shifts in the hospitality industry noted:

“I think mostly we’re down to my really messed up diet ... eating the wrong food and eating at the wrong time” [P2]

#### 3.2.2. Emotional impact of diagnosis

For both symptomatic and asymptomatic participants, the diagnosis came as a shock, significantly impacting their emotional well-being:

“Quite a shock to the system ... wasn’t the news I was expecting. Looking back at the symptoms, I should have been a little bit more prepared” [P9]

The fear of the unknown, particularly waiting for test results, was a major source of anxiety. For one participant, unfamiliarity with colorectal cancer worsened this stress:

“The most stressful time was waiting for appointments for the scans and then the period waiting for the diagnosis. You’re in an area that you know nothing about ...” [P7]

#### 3.2.3. Positive attitude

Participants discussed the importance of maintain a positive outlook on their diagnosis and treatment. One participant drew on faith, viewing the experience as ultimately hopeful:

“I think it gives you that hope that an awful lot of people may not be able to tap into. You can’t change a diagnosis, the key is how you manage it ...” [P4]

#### 3.2.4. Physical impact of surgery

All participants experienced physical changes after surgery, particularly in bowel function. For some, this included the impact of the newly formed stoma which required advanced planning for their daily activities and dietary adjustments:

“I had to get used to complete new diet because of the ileostomy. ... and you have to make sure that you think your day ahead, well planned, much more planned than before” [P2]

One participant noted the impact the stoma had on body image: “I’m

copied with it [the stoma] fine now, but you know, to see this alien on your body ... it’s strange” [P7]. Even those without a stoma experienced urgency and bowel frequency, affecting their day-to-day activities: “As long as I knew there’s a loo nearby, I’m a happy bunny” [P3]. Some participants reported additional physical effects, such as prolonged paraesthesia of the lower limbs and fatigue, often linked to post-operative effects.

### 3.3. Interpersonal and social factors

#### 3.3.1. Support from family and friends

Participants sought support from various sources, sometimes choosing to confide only in certain people to protect their family members. One participant shared how a friend with a similar experience provided a supportive outlet:

“My best friend was diagnosed with breast cancer a few years ago. So she went through a similar thing, and she as well felt that she got to the point where you don’t want to talk about it all the time ... by talking to each other, we’re protecting our families a bit” [P5]

Another participant highlighted his wife’s emotional challenges during his treatment:

“It was a bit of a shock to her, she found it quite stressful ... just sitting at home from seven o’clock in the morning not really knowing what was going on” [P10]

#### 3.3.2. Setting post-treatment goals

Setting goals and planning activities post-treatment helped participants maintain emotional well-being and encouraged moderation in daily activities. One participant used her daughter’s graduation as motivation:

“I wanted to go to my daughter’s graduation. I knew that if I pushed myself, and I went backwards, I wouldn’t be able to go, so I had to behave myself” [P5]

#### 3.3.3. Psychosocial influences

The surgery impacted participants’ psychosocial well-being, particularly for some who had to shift their role from a caregiver to a care recipient, like one participant with young children:

“I am kind of looking forward to getting past all of this ... have my energy levels back up to be a good mum again. It’s quite difficult to delegate the home stuff” [P9]

Most participants were retired or worked from home, but for those who had to travel or work away from home, taking time off work or relying on benefit was psychologically challenging:

“I worked for many, many years and I never went through the benefits system, so I had no clue how that works until this time. And I was absolutely shocked to realize that ...” [P2]

## 4. Discussion

This study highlights a range of clinical and external, patient level, and interpersonal and psychosocial factors influencing the experiences of a group of patients undergoing surgery for colorectal cancer. These factors reflect the complex interplay of environmental factors, personal attitudes, and support systems, and the physical and emotional challenges across diagnosis, surgery, and recovery phases. These results are in line with the pre-COVID-19-pandemic findings of Sutton et al. (2019), exploring experiences of patients in a different UK context.

The hospital environment was described as having a notable influence on patient well-being. Similar to other studies (Abelson et al., 2018; Jonsson et al., 2011; Samuelsson et al., 2018; Worster and Holmes,



2009), our participants reported that the noise and busyness of the ward were disruptive, especially affecting their sleep quality. However, one participant found fellow patients as a source of comfort and entertainment. These findings suggest that, where possible, noise should be minimised, and supporting earlier discharge could enhance recovery, as home settings often better meet patients' comfort and rest needs (Bernard and Foss, 2014).

Despite these challenges, the personal attributes of the clinical team, such as kindness, empathy, and attentiveness, were consistently appreciated by participants, who felt that the compassionate approach of their ward nurses, Clinical Nurse Specialists (CNSs), and consultant surgeons significantly contributed to their comfort and recovery. These findings align with prior research emphasising the value of patient-centred care and suggest that both emotional and informational support are integral to patient satisfaction (Jonsson et al., 2011; Simpson and Whyte, 2006). The CNS, in particular, was frequently cited as a vital resource for both emotional reassurance and practical guidance, supporting previous studies on the importance of the CNS role in cancer care (Broughton et al., 2004; Worster and Holmes, 2008). Additionally, feeling "safe" with their consultant surgeon was a theme noted by several participants, reinforcing findings by Appleton et al. (2018) that perceptions of safety in clinical relationships positively impact patients' psychological well-being.

Staff shortages added additional challenges, as delays in care impacted patients' sense of safety and continuity of care. Data for the present study were collected following the COVID-19 pandemic, which significantly strained healthcare resources in primary care, an impact echoed by participants in this study who faced long waits for diagnostic appointments, forcing them to demand medical investigations. The pandemic led to a 30% reduction in primary care consultations, reflected also in a reduction in referrals for colorectal cancer, which may have worsened access to timely diagnoses (Watt et al., 2020; Morris et al., 2021).

Participants gave positive feedback on the information received, though some reported that practical guidance for the early recovery period, such as managing diet and side effects, would have been beneficial. Research has shown that receiving consistent verbal and written information, as well as follow-up communication from the healthcare team, such as sensitive handling of post-operative histology results, can help patients feel more secure and supported (Aasa et al., 2013; Fujimori and Uchitomi, 2009).

Similar to other studies, diagnosis of colorectal cancer had a significant impact on the participants' emotional well-being (Abelson et al., 2018; Worster and Holmes, 2008). Anticipation of diagnostic results and fear of the unknown created significant distress, particularly as many participants had limited prior knowledge of colorectal cancer. Also, concerns whether their former lifestyles, such as dietary habits, inactivity, and stress, may have contributed to their diagnosis were expressed, echoing previous research on colorectal cancer prevention (Perera et al., 2012). Participants valued compassionate information provision at all stages, and many noted that having information provided in both verbal and written formats would have enhanced their understanding. These findings reinforce the importance of clear, tailored communication throughout the patient's journey to address individual information needs and reduce anxiety (Epstein and Street, 2007; Worster and Holmes, 2008).

In contrast to Worster and Holmes (2009), who suggested that patient experiences of cancer diagnosis and treatment are broadly similar across all types of cancer, our findings indicate that colorectal surgery presents distinct challenges, particularly associated with stoma formation. Participants had to make dietary modifications and lifestyle adjustments to manage altered bowel function, a finding consistent with Burden et al. (2016). The need to plan activities around bowel habits, particularly for those who experienced urgency and frequency, impacted their routines and psychological well-being, with some adjusting their lives around proximity to toilets. The decision between

sphincter-saving surgery and permanent stoma formation is complex, and our findings suggest it is essential to communicate the likely outcomes and lifestyle changes that may accompany each option (Hou et al., 2017; Lu et al., 2017; Pachler and Wille-Jørgensen, 2004). This is important to consider when educating patients about the risks and benefits of a permanent stoma. We found that fatigue and paraesthesia also affected patients' well-being, highlighting the need to address these issues. Discomfort, physical weakness, eating difficulties, and bowel change should be discussed with patients before discharge, reassuring them that these symptoms are normal and typically resolve or settle within the first six months (Jakobsson et al., 2017).

Our study found that the patients' trajectory also impacted their psychosocial well-being. Participants coped with the emotional impact of diagnosis in various ways. For some participants, setting post-treatment goals helped maintain focus and motivation throughout recovery and it was underpinned that maintaining a positive outlook was an important coping mechanism, with some participants drawing on faith as a source of strength. The role of positive attitude and spirituality has been highlighted in other studies, which also found family members relied on the optimism of patients in maintaining a positive outlook, further underlining the importance of mental and emotional support within patient care (Asiedu et al., 2014).

Family and friends were important sources of support, though for some participants they also caused anxiety as patients often attempt to protect loved ones by sharing only selected information with them and confiding in certain individuals such as close friends (Abelson et al., 2018; Hildebrandt et al., 2019; Worster and Holmes, 2008). Role changes, such as moving from caregiver to care recipient, were challenging, particularly for participants with young families, highlighting the importance of preparing patients and their families for these shifts. Financial challenges were another key concern, particularly for younger participants and those who needed to take extended time off work. The impact of work and financial pressures on patient well-being is well-documented in recent studies and underlines the need for practical support and counselling to help patients manage these adjustments (Husebø et al., 2021; Tiranda et al., 2019).

#### 4.1. Strengths and limitations

This study contributes valuable insights to explore the experiences of patients with colorectal cancer from diagnosis through post-surgical recovery. Data collection post-COVID-19 pandemic provides further relevance, as it sheds light on the challenges faced by patients in a healthcare setting impacted by workforce constraints and limited access to the care services. However, there are also limitations associated with this study, with the main one being the convenience sampling approach from a single centre which may have limited diversity within the sample, particularly with regard to ethnic background, reflecting the demographic composition of the local district where the study was conducted. Additionally, the use of virtual interviews required participants to have digital access, which may have excluded some patients, potentially narrowing the scope of findings. The first author's role as the participants' Clinical Nurse Specialist may have influenced responses, potentially introducing social desirability bias (Paulhus, 1984). However, this familiarity likely also facilitated rapport and openness, which might have been more challenging with an unfamiliar researcher.

## 5. Conclusion

Findings of this study reinforce the importance of comprehensive and compassionate communication throughout the patient journey. Clinical nurse specialists and advanced nurse practitioners play a critical role in translating complex information into accessible terms, supporting patients' understanding and engagement. The study also highlights a growing awareness of lifestyle factors associated with colorectal cancer risk, which may have positive implications for public health. The study

further highlights the role of family and friends as both sources of support and potential stress for patients; thus, clinicians should consider offering patients access to counselling and peer support groups. Future research would benefit from purposive sampling that captures a more representative cross-section of the patient population and from in-person interviews to include those without digital access. Given the increasing incidence of colorectal cancer among individuals under 50 years of age, further investigation is essential to address the unique concerns of this demographic. Drawing from patients' experiences remains crucial in enhancing care delivery, emphasising the need for further research to better inform patient-centred colorectal cancer care.

### CRedit authorship contribution statement

**Claire Hannah:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Software, Writing – original draft, Writing – review & editing. **Lars E. Eriksson:** Formal analysis, Supervision, Validation, Writing – review & editing. **Andrew Ramwell:** Methodology, Validation, Writing – review & editing. **Sofia Llahana:** Conceptualization, Formal analysis, Methodology, Software, Supervision, Validation, Writing – review & editing.

### Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this article.

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### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ejon.2025.102794>.

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