

Everyday challenges following hospital discharge. A multi-method study identifying and describing areas of concern for patients during the first month after colorectal cancer surgery

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Abstract

Aim: Identify and describe areas of concern focusing on day-to-day variations during the first month after surgery for patients recovering from colorectal cancer surgery.

Design: A multi-method design was applied using diaries and interviews.

Method: Data was collected using semi-structured diaries kept 1 month after surgery by seven patients recovering from colorectal cancer surgery. Also, face-to-face interviews were conducted 1 month after surgery. Data from the diaries constituted a framework for the following directed content analysis of interviews.

Findings: Low levels of pain were experienced but caused reduced mobility and tiredness. Practical matters in daily living were restricted, while social life could be hampered by a frequent need to defecate. Appetite and consequently the ability to eat and drink was the most prominent concern, due to changes in taste and ability to tolerate food. Worries were mainly related to changes in bowel movements.

No Patient or Public Contribution.

KEYWORDS

colorectal cancer, concern, diary, interview, multi-method, postoperative recovery, self-care ability

1 | INTRODUCTION

As innovations in technology and care routines have made surgical care more efficient, and especially since the introduction of the Enhanced Recovery After Surgery (ERAS®) guidelines (Gustafsson et al., 2019; Varadhan et al., 2010), early discharge is a common routine in the care of patients undergoing colorectal cancer surgery. This means that patients are discharged from the hospital when there are no longer any medical reasons for inpatient care. Consequently, they need to manage an extensive part of recovery by themselves. However, patients appear to experience an uncertainty about their discharge and the following self-care which may

lead to a burden and a feeling of being abandoned (Lunde Husebø et al., 2020; Samuelsson et al., 2018). Studies focusing on the initial period after colorectal cancer surgery and discharge from the hospital show that recovery progresses rapidly during the first month after surgery, a period characterized by several disturbing symptoms related to surgery posing challenges for both patients and next of kin (Jakobsson et al., 2014; Norlyk & Harder, 2011; Norlyk & Martinsen, 2013). With this in mind, it is important for healthcare professionals to be familiar with various features of recovery and its progression, especially during the first intense month after surgery. Despite this, there is little research focusing on day-to-day recovery during the first month after surgery.

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Such knowledge can guide discharge information and follow-up routines to support patients' ability to take care of themselves following discharge.

In short, postoperative recovery has been defined as a process of returning to normality and wholeness. Hence, "recovered" means having the ability to control physical, psychological, social, and habitual functions as, or comparable to, before the surgery (Allvin et al., 2007). Several longitudinal studies including patients after colorectal cancer surgery have been conducted to capture patients' experiences of this process. For example, Beech et al. (2012) and Taylor et al. (2010) described recovery during the first year after surgery. Both highlighted how patients after discharge began a journey towards restoration and repair of the self and embodied control. The earliest part of the postoperative journey has been described in a few studies. Krogsgaard et al. (2014) conducted interviews with patients 2 weeks after colonic surgery. Besides concerns about whether tumour removal was successful, the patients described physical and unfamiliar symptoms that added to the worries. Everyday activities were limited due to symptoms, such as fatigue, bowel dysfunction and loss of appetite. This was confirmed in another study by Norlyk and Harder (2011), also interviewing patients 2 weeks postoperatively. Participants in this study expressed frustration at their restricted capacity for resuming everyday routines. Early recovery was described in more detail in a questionnaire-based study by Wennström et al. (2010) measuring the quality of life and pain once a week during the first month after surgery. Nausea, fatigue, dyspnoea, pain, and difficulties with defecation were problematic issues for the participants, especially 1 week after surgery. In the remaining weeks, the severity of symptoms decreased however, difficulties contacting the hospital about surgery-related symptoms were expressed. This was highlighted also by participants in the study by Krogsgaard et al. (2014) who either applied a "wait and see" strategy or tried to manage the symptoms based on experience.

In a prospective questionnaire study by Grimmett et al. (2017), 40% of colorectal cancer patients expressed suboptimal confidence in managing illness-related symptoms during the first 2 years after surgery. This was also evident in a study by Lo et al. (2021) in which patients experienced that the information given by the medical team was insufficient. Therefore, patients tried to develop their own strategies to ameliorate symptoms. This involved looking for information such as how to choose and track the diet to alleviate changes in bowel function. Several other studies report how patients have received insufficient information; patients do not know what to expect during recovery which leads to anxiety, insecurity, a feeling of being abandoned, and leaving them with a need to search for relevant information online (Lithner et al., 2015; Lo et al., 2021; Samuelsson et al., 2018). Ose et al. (2017) found that patients experienced getting support and guidance from healthcare professionals only when requesting it and that it was difficult to find a suitable person with enough time for a meaningful discussion. Lunde Husebø et al. (2020) concluded that future healthcare interventions should focus on supporting the treatment burden and the needs of patients and their families.

Nursing interventions have been described as responding to the patients' incapacity to care for themselves because of a deteriorated health status or ill-health (Orem et al., 1995). Further, it has been stated that nursing interventions have the potential to reduce patients' incapacity by imparting knowledge to them that can increase their self-care agency and self-efficacy (Matarese et al., 2018). It is therefore important that nurses and other healthcare professionals share their knowledge with patients upon their discharge from the hospital. Although, such information may be inadequate because of healthcare professionals' lacking knowledge of the recovery process, especially its earliest phase, and their knowledge of patients' most common concerns.

In previous research focusing on the early recovery phase, data have been collected retrospectively, a few weeks after surgery. However, this may be associated with recall bias if participants have forgotten what it was like during the first weeks. Also, the collection of data at one point in time reduces the opportunity to describe day-to-day variations in recovery. Collecting data on an everyday basis would add more authentic experiences but only few studies have applied this strategy and for the purpose of tracking specific postoperative symptoms. Therefore, this study aims to identify and describe areas of concern focusing on day-to-day variations in recovery during the first month after surgery for patients recovering from colorectal cancer surgery.

2 | METHOD

2.1 | Design

The consolidated criteria for reporting qualitative research (COREQ) was used in the reporting of this study (Tong et al., 2007) that has a multi-method approach including data from both diaries and interviews. Due to the potential physical and emotional strain of recovery, patients' memories could be affected during retrospective interviews. Hence, the approach enabled eventual gaps in the narratives to be filled with experiences noted in the diaries (Snowden, 2015). The authors who conducted this study were female, Registered Nurses with a PhD and experienced in qualitative and quantitative research methodology. At the time of the study, they worked as teachers and researchers at a university.

2.2 | Setting

Patients included in the study were cared for at a specialist colorectal surgery unit where perioperative care was structured following ERAS® guidelines (Gustafsson et al., 2019). Accordingly, patients were encouraged to eat, drink and become mobile as soon as possible after surgery. The use of tubes, drains and catheters was limited, as was pain relief using opioids, to promote a rapid return to habitual functions. Patients were hospitalized only as long as there was a medical reason.

2.3 | Participants

Patients who had undergone elective surgery to remove colorectal tumours were considered for inclusion. A further criterion was their ability to document their recovery in a diary and participate in an interview.

2.4 | Recruitment

A purposeful sampling strategy was used, and participants were recruited during their hospital stay after surgery. Since the authors did not have any affiliation with the ward where patients were cared for, thus being unacquainted with the patients, nurses on the ward assisted for 18 months in identifying patients that might be interested in participating. Suggested patients were then personally approached by the first author, providing them with verbal and written information about the study. Patients who chose to participate were given a diary and instructions about how to fill it in.

2.5 | Data collection

Data were collected by the first author using the diaries and additional face-to-face interviews conducted 1 month after surgery. Diaries as a tool for data collection have been frequently used in research and especially when changes are expected over time or when participants might have difficulties remembering. According to Bartlett (2012), the use of diaries can compensate for short-term memory problems in, for example, people with cognitive impairments. In health research, structured diaries are the most used (Thomas, 2015). The diary in this study was semi-structured and contained some questions with fixed answers enabling the participants to reflect on and grade the level of, for example, perceived pain, mobility and activity level (see Appendix S1). Other questions were open-ended, allowing the participants to elaborate on their answers. The questions in the diary were formulated based on previous research indicating areas of concern for patients recovering from colorectal cancer surgery. The diary had one page for each day and participants were encouraged to fill it in daily until the day of the interview when the diary was collected.

About 3 weeks after surgery, patients who had agreed to participate ($n = 13$) were contacted by the first author to decide a time and place for the interview. However, only seven participants had filled in their diaries thus constituting the sample for this current study. Reasons for not filling in the diary included forgetting or finding it tedious if there was no change in their condition.

The majority of interviews ($n = 6$) were carried out at the home of the participants. One was conducted in a private room in the hospital ward as the participant was still hospitalized due to postoperative complications. All interviews were conducted in solitude with no other persons present. An interview guide was used and contained the opening question, "Could you describe how you experienced

your recovery after surgery from the time that you came round from your anaesthetic until now?" Field notes were made during the interviews and additional questions were asked if clarification or more information was needed. The interviews were recorded and transcribed verbatim, and lasted from 24 to 59 min, with a mean of 46 min.

The participants began filling in their diaries on different postoperative days, ranging from postoperative days 2–9. In addition, the interviews took place on a day that suited the participants meaning the participants also finished keeping their diaries on different days (range postoperative day 20–30). Consequently, the amount of diary-data varies across the period, although participants filled in their diaries over a mean of 21 days.

2.6 | Ethical considerations

Research Ethics Committee approval was obtained before the study started from "REDACTED". Patients were given information about the study both orally and in writing. Since patients were approached with an invitation to participate during the first days after surgery, they were considered as vulnerable and therefore, they were carefully informed about the voluntariness and possibility to withdraw at any time. Written consent was collected before the patients started to fill in their diaries.

2.7 | Data analysis

Data analysis was made in two steps. In the first step, diaries were reviewed and information within was compiled in separate figures and tables aggregating participants' daily notes for the specific questions. This was a way to visually identify areas of concern during the first month of recovery. The four areas of concern that emerged from the diaries served as a "framework" during the second step of the analysis. In the second step, a directed content analysis, as described by Hsieh and Shannon (2005) was performed on the interview transcripts. Accordingly, transcribed text that corresponded to any of the four areas of concern was extracted and transferred into separate data sheets, one sheet per concern. This sorting was made by the authors individually. The authors then compared and discussed their respective sorting to reach an agreement. Lastly, extracted data representing the different areas of concern were reviewed and reflected on to formulate a final description of how the narratives from the participants supported and explained the findings from the diaries.

3 | FINDINGS

Seven patients participated in the study, completing both the diary and interview. Participants had a mean age of 72 years and were mainly female ($n = 5$). Four participants had cancer of the colon and

three had cancer of the rectum. The length of hospitalization varied from 6 days up to 70 days for one participant who suffered from protracted complications after surgery. Details of participant characteristics are presented in Table 1.

Areas of concern that were identified in the diaries were *pain, activities in daily living and social life, appetite and ability to eat and drink, and worries*. In the following, data from the diaries will be presented and then further described using the findings from the interviews.

3.1 | Pain

There was a variation between both participants and days, as regards postoperative pain (Figure 1). Nevertheless, the pain seemed to be in the lower continuum for most participants during the first week after surgery then continuing to decrease and eventually become absent by the end of the diary period. Some participants reported a higher level of pain intensity.

Additional comments in the diaries revealed that pain led to reduced mobility, tiredness and the need to rest, and negatively affecting moods. Despite the pain, all participants reported that they had been able to be up and moving every day, although to varying extents.

During the interviews, participants further explained that thanks to the analgesics they received, they were only in mild pain, which was more of a sensation of tightening or irritation around the surgical wound. This sensation was more noticeable at night and when getting out of bed.

TABLE 1 Patient characteristics (n = 7)

Gender (n)	
Male	2
Female	5
Age (years)	
Mean (SD)	71.7 (6.5)
Min-max	62–80
Cancer site (n)	
Colon	4
Rectum	3
Surgical procedure (n)	
Right sided hemicolectomy	1
Sigmoid resection	3
Low anterior rectal resection	1
Abdominoperineal resection	2
Length of hospital stay (days)	
Mean (SD)	19.6 (28.2)
Median	7
Min-max	6–70

Abbreviations: n, number; SD, Standard deviation.

Mainly in the middle of the night. There was a tightness that stayed put. But the pain wasn't powerful, that was kept at bay. You get a lot of tablets, you know?

(5)

For some participants, perineal stitches or abdominal drains caused higher pain intensity. At times, this was something that was difficult to cope with emotionally and also led to needing additional analgesics.

I've been in so much flipping pain, these drains, and they have sewn up my rear, inside and out, and I'm struggling to sit. I suppose you could say I'm in pain in like four or five places, so all of this combined can make things really difficult sometimes, still, so I get a few extra tablets every now and then.

(2)

3.2 | Activities in daily living and social life

The majority of participants indicated in the diaries that they had been able to take care of themselves and have a social life. However, participants explained that shortly after surgery, practical things such as getting dressed by themselves or putting shoes and socks on were difficult. In addition, activities such as housework or going for longer walks were difficult later on during the first month after surgery.

In the interviews, several participants stated that they had not expected recovery to take so long. Upon returning home, the participants' reduced ability to take care of themselves made them feel dependent on family members.

It was nice to come home... But then you feel a bit useless when you cannot do anything. He [husband] has to cook but it's working out well... Lucky there's the two of us really.

(6)

The participants' social lives could be hampered by a frequent urge to go to the toilet, or by pain and tiredness. Participating in social contexts was described both as something to be avoided and as appreciated. The unpredictable urge to visit the toilet discouraged participants from leaving their homes to go grocery shopping or visit colleagues at work. Having visitors at home could be exhausting and tiredness made some participants say no to visitors. However, visits could also be an appreciated way to help the time pass.

Since I'm on my own a lot in the afternoons... it has been nice to have someone come round and talk to me for a little while.

(7)

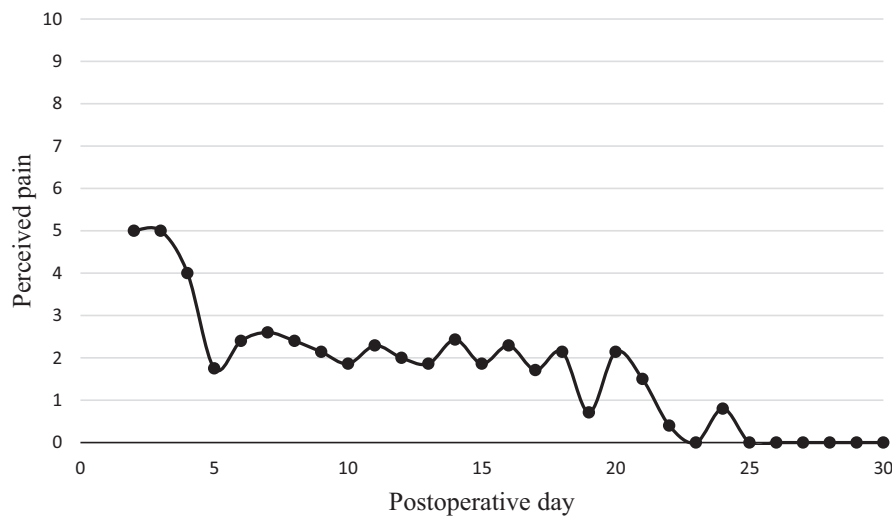


FIGURE 1 Mean pain intensity as indicated on a 10-point scale ranging from 0 = no pain to 10 = worst imaginable pain.

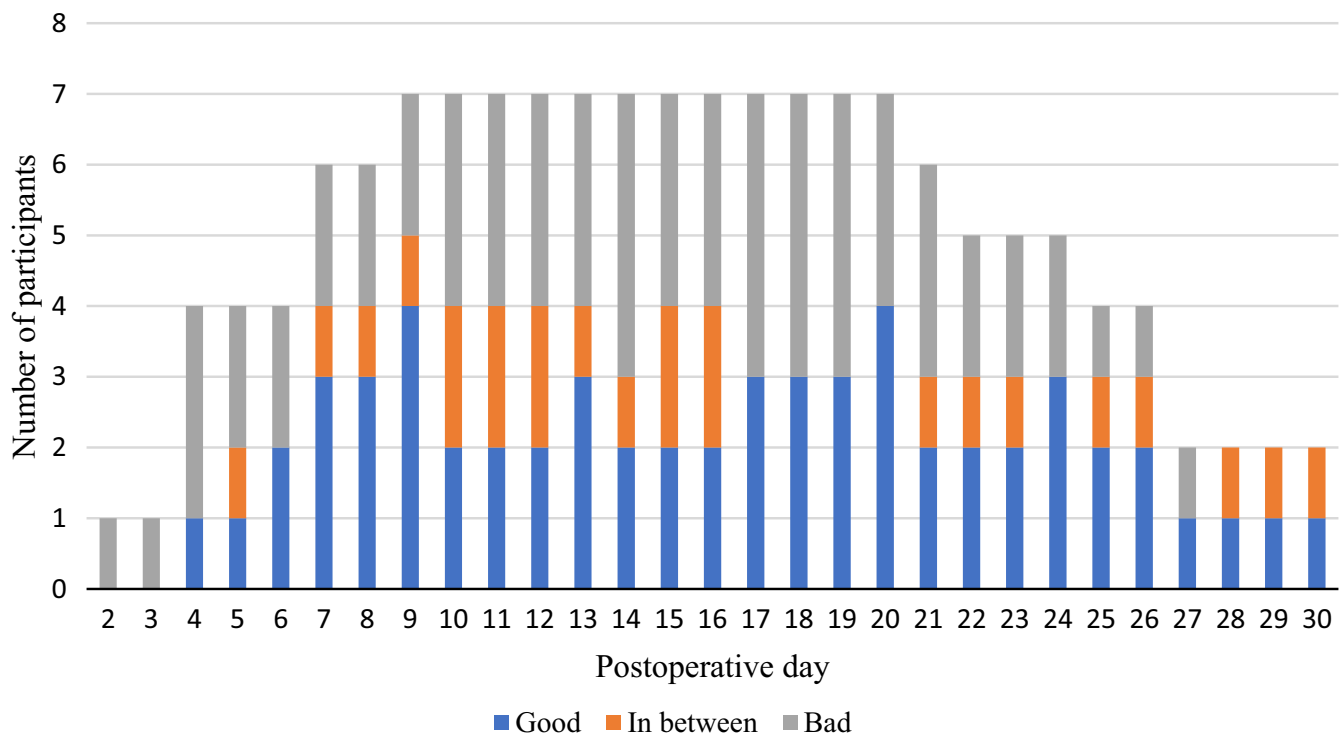


FIGURE 2 Overview of perceived appetite

The presence of an ostomy could initially induce feelings of uncertainty when meeting people outside the home, although one reflection was that it is better to be open about having an ostomy.

3.3 | Appetite and ability to eat and drink

Appetite changes and the ability to eat and drink caused some more concern. Figure 2 shows how only a few participants reported having a good appetite during the first month after surgery. Some participants marked a cross between “good” and “bad” in their diary, suggesting they had some deterioration in appetite. Figure 2 shows

this as “in between”. Hence, the majority of participants experienced poor appetite or somewhere “in between” and this condition seemed to be more or less consistent during the period. Appetite problems were reflected in the reported ability to eat and drink (Figure 3). Most participants experienced that they *could* eat and drink, however, this changed from day to day, showing signs of a slight deterioration in the second and third postoperative week.

Reasons reported for not eating or drinking were a lack of appetite and loss of taste. This was also reflected in the interviews. All participants described problems with eating during the first month. Not all felt nauseous, but the food did not taste the same, and they could only eat a little at a time. Participants merely ate because they

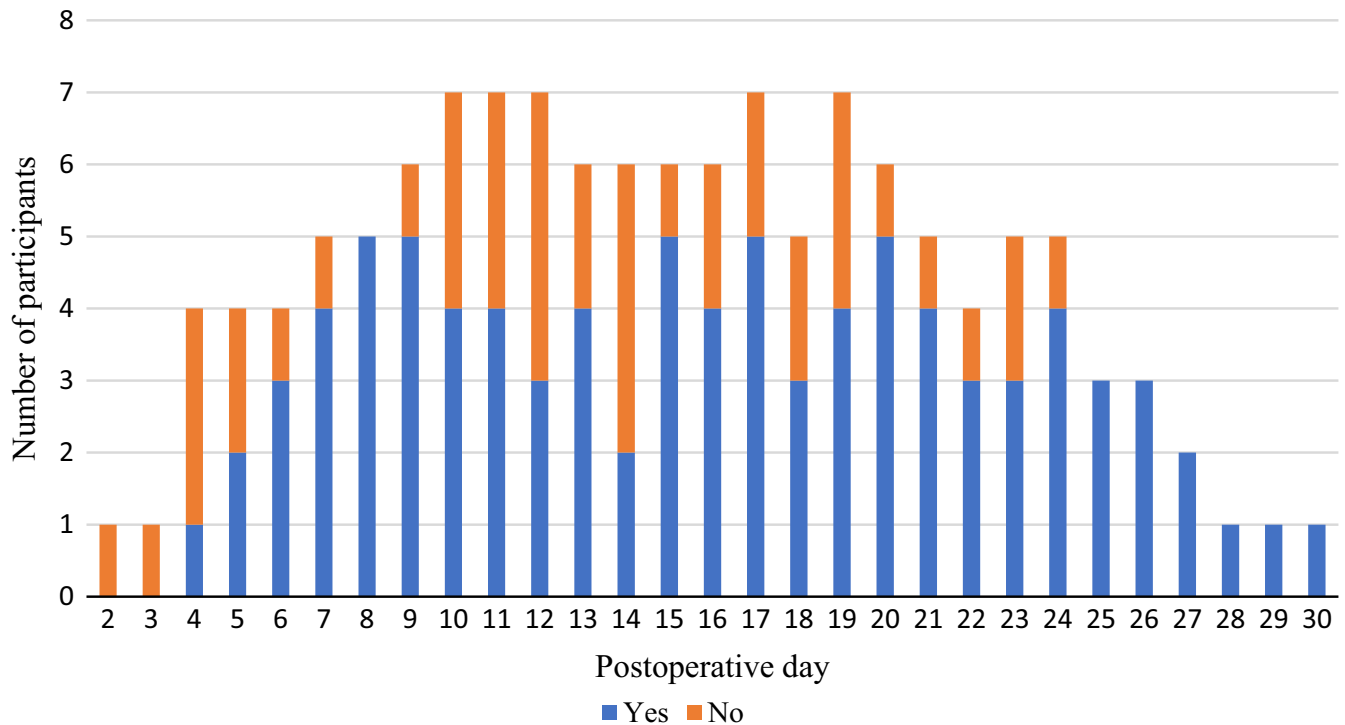


FIGURE 3 Overview of participants being able to eat and drink as they could before surgery

knew they had to. The participants had trouble eating regular food however, smoothies or ice-cream were easier to tolerate.

Ha! They shovel it in me straight away and the food wasn't as good as the food the wife makes. I always got small portions, but I could barely manage to eat everything. I've lost five, six kilos.

(3)

3.4 | Worries

The participants recorded in their diaries that they were not particularly worried during the first month after surgery, however, a minor increase could be seen during the second and third postoperative week (Figure 4). The participants reported some worries about tiredness, especially at the start of the period, and about the urgent and frequent need to go to the toilet. They also worried about pathological diagnostics from surgery and uncertainty about the future.

In the interviews, worries about bowel activity were the most prominent. Participants explained that they were unprepared for this and were therefore frightened that something had gone wrong. Once they were able to talk to a specialist nurse or doctor and therefore learn that this was normal, participants felt relief.

No, I was not prepared for that at all. But I got it explained when I talked to my nurse. And, that reassured me.

(5)

4 | DISCUSSION

As stated in the background of this study, through the provision of knowledge, nursing interventions have the potential to enhance patients' self-care agency and self-efficacy (Matarese et al., 2018). This study aimed to collect such knowledge by identifying and describing areas of concern on each day of the first month after surgery. In the diaries, four areas emerged as bothersome. Those areas were further described during interviews that gave a clear picture of the recovery progress and any related concerns. In the following, findings will be discussed related to what is known from earlier studies and how the compiled knowledge can be incorporated into nurses' patient-education in connection to discharge from the hospital.

All participants in this study had experienced pain, describing it as being more of a tightening or irritating sensation around the surgical wound. This was especially the case when moving in bed or when sitting up. Analgesics helped keep pain levels low, which also can be seen in the findings by Mathiasen et al. (2021) interviewing patients 1–5 days after surgery with a focus on early mobilization. Participants in the study by Wennström et al. (2010) were followed for 1 month after surgery and reported pain to be dull and located above os pubis. Pain was greatest during the first week following surgery but could be managed using Paracetamol, which corresponds to our findings in this study, although with some exceptions. Participants in a study by Jonsson et al. (2011) also experienced low levels of pain, which they found surprising as they had expected the opposite. Nevertheless, participants who described their pain as bearable occasionally reported pain intensity of eight or nine on a 10-point visual analogue scale. This contradiction can also be seen

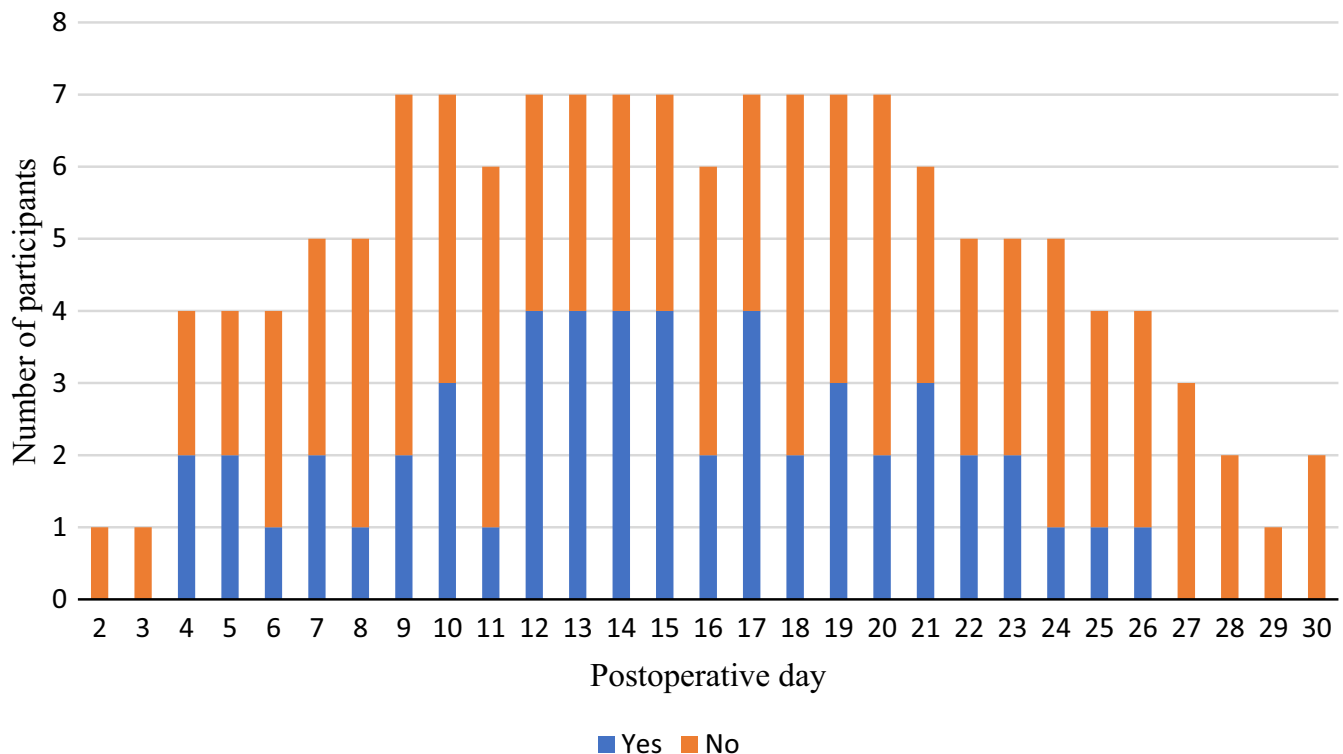


FIGURE 4 Overview of worried participants

in this study. However, one explanation given during an interview was the presence of painful abdominal drains or perineal stitches. Participants in a study by Norlyk and Harder (2011) described another aspect of postoperative pain as they struggled to be physically active 2 weeks after discharge and felt limited by pain. However, some of the participants had stopped taking the analgesics they had been prescribed, in order to be more in-tune with their bodies. Ose et al. (2017) discuss that such decisions require a proactive patient role, and thus emphasize the importance of enhancing self-care agency and self-efficacy. Therefore, pain and pain management should be included in patient-education.

Another area of concern for participants in the current study was activities in daily living and the ability to have a social life. Wilkinson and Whitehead (2009) suggest that the concept of self-care can be seen on a continuum ranging from shared care and reliance on medical assistance to a state of total independence. This can be associated with the postoperative recovery process in which patients are initially dependent on healthcare professionals but as recovery progresses, they become increasingly independent (Beech et al., 2012; Jakobsson et al., 2014; Norlyk & Harder, 2011; Taylor et al., 2010). However, in the current study participants described how care was shared with family members after discharge instead of healthcare professionals. Nevertheless, in their diaries, the participants noted that they had been able to take care of themselves and have a social life in the first month after surgery, however, they described a dependence on family members during interviews. Initially, participants experienced difficulties with basic activities such as getting dressed. Later on, participants identified a need for help with

household tasks. This was also described in the study by Krogsgaard et al. (2014) where relatives assisted with cooking and shopping but gradually, participants could perform more demanding activities such as cleaning or doing the laundry although weakness and fatigue limited them. This suggests that patients need to be made aware of the initial decreased self-care capacity postoperatively, so they can prepare both themselves and those close to them that they may need additional help.

The findings in this study have shown that pain and tiredness appeared to hamper social life, but the biggest obstacle is the need to be close to a toilet. The unpredictable and urgent need to defecate made participants hesitant about leaving their homes. Many previous studies (Di Fabio et al., 2008; Jakobsson et al., 2014; Jonsson et al., 2011; Krogsgaard et al., 2014; Tsunoda et al., 2007) have described altered gastrointestinal function after colorectal cancer surgery. In the study by Wennström et al. (2010), 29% of the participants reported difficulties with defecation 1 week after surgery, decreasing to 4% 4 weeks postoperatively. Participants in the study by Lo et al. (2021) strived to develop self-care strategies such as eating smaller meals, walking, eating a low-fibre diet and taking prescribed medication in a bid to alleviate bowel-related symptoms. Furthermore, the study reported that information related to these strategies had been collected from hospital nutrition departments, the internet and books. Since an altered gastrointestinal function is to be more or less expected in patients recovering from colorectal cancer surgery, it is important that this information is incorporated into patient education together with evidence-based recommendations about diet, exercise and medication. However, evidence should

also include patients' experiences of well-trying and successful strategies, although more research is needed in this area.

The third area of concern for the participants in the current study was nutritional difficulties. Loss of appetite due to changes in taste and only being able to eat small portions were statistically significant. Previous studies have highlighted how loss of appetite and nausea are problems related to nutrition (Krogsgaard et al., 2014; Wennström et al., 2010). Burden et al. (2016) have described unstable appetite, the smell of food and watching others eat as negatively affecting food intake even before surgery, thus causing weight loss. This weight loss continued after surgery impacting on the quality of life because of limited levels of energy. Loss of appetite and difficulties with eating and drinking could therefore be regarded as a major problem for patients recovering from colorectal cancer surgery, not least since wound-healing requires energy. Nutritional supplements could be one solution to increase energy intake, however they are not always tolerated due to aggravation of diarrhoea or taste preferences (Burden et al., 2016). Guided by knowledge from the current study, nurses could inform patients to be prepared for a deteriorated appetite and changes in taste and thus recommend eating easily digestible food, little at the time but more frequently than usual. However, it would be of value in future research to collect more knowledge about food that is perceived as easy to eat and digest by patients during the early postoperative period.

The last area of concern involved worries about changed bowel function and uncertainty about the cancer prognosis and the pathological diagnostics. In the diaries, participants rated their worries as mild, but a slight increase could be seen during the second and third weeks following surgery. The reasons were not given, however, a different study showed similar results, i.e., a transient increase in anxiety 1 week postoperatively (Wennström et al., 2010). As several earlier studies have found (Beaver et al., 2010; Krogsgaard et al., 2014; Mohamed et al., 2021; Norlyk & Harder, 2011; Samuelsson et al., 2018), unawareness of what to expect when returning home could be a statistically significant cause of concern. Hence, anxiety and worries may increase when symptoms occur or if they do not get better and might result in anxiety and worries as demonstrated in the current study. This is yet another example that highlights the importance of patient-education before hospital discharge. Nevertheless, follow-up interventions are also important, as symptoms may change over time. These interventions could include nurse-led clinics or regular telephone contact initiated by nurses at the clinic since previous research has described that patients might hesitate to contact healthcare services as they are unsure if their symptoms warrant intervention (Krogsgaard et al., 2014).

4.1 | Strengths and limitations

This study was a multi-method study using diaries and interviews for data collection. The diaries were based on previous research emphasizing common problems among patients recovering from colorectal cancer surgery. Those problems were included as topics in the

diary but, this might have led to other areas being overlooked. To acknowledge other potential areas of concern, additional interviews were made. The diaries were not reviewed before the interview sessions and the interviews were conducted using open-ended questions. This strategy was chosen because we wanted to conduct the interviews with an open mind avoiding influence by information in the diaries. The use of diaries in combination with interviews was considered as a confirmation of findings thus enhancing trustworthiness (Lincoln & Guba, 1985).

A limitation of this study is the small number of participants caused by a high dropout. Also, the authors needed assistance from ward nurses in order to get in contact with potential participants. This was a factor that most probably limited the number of patients being approached in the first place. Furthermore, despite that recruitment lasted for 18 months and 13 patients agreed to participate, only seven completed their diaries leading to reduced transferability. This could depend on the semi-structured design limiting participants' opportunities to express in freely. On the other hand, it has been suggested that semi-structured diaries address the balance between participants' and researchers' agenda (Thomas, 2015). If the diary for the current study had been unstructured, the focus on postoperative recovery might have been lost. Also, we wanted to reduce workload and make it easy to keep the diary. There are other ways to collect diary data that could be more appealing to participants. For example, using smartphone applications which have been successfully tested in patients recovering from day surgery (Dahlberg et al., 2016). Future studies might benefit from using such an on-line data collection approach.

5 | CONCLUSION

The findings from this study identified four areas of concern among patients during the first month after colorectal cancer surgery that can guide practice and future research. Patient education at the time of hospital discharge should be built on evidence-based, professional knowledge about postoperative symptoms that are likely to occur and pose concerns for the patients during recovery. Previous research together with the compiled knowledge from this study can form such basis for patient education, addressing at least the problems described. Furthermore, as patients seem to develop their own self-care strategies to manage postoperative symptoms, more research is needed to collect knowledge about such strategies to fully be able to incorporate research informed self-care recommendations in patient education.

RELEVANCE TO CLINICAL PRACTICE

Colorectal cancer is one of the most common cancer diagnoses worldwide with increasing incidence. Surgery equals a chance for cure but will have an impact on the patient's self-care ability when returning home after surgery. As suggested in earlier research, nurses need to give patients with knowledge about the recovery

process before discharge, but this has shown to be a shortcoming leaving patients to seek information themselves. Findings from this study, suggest that patient education needs to involve at least information about postoperative pain, a potentially reduced ability to perform activities in daily living and to have a social life, a probably reduced appetite and ability to eat and drink, and also information about common worries. It is also important to adopt a patient-centred approach, designing follow-up routines based on each patient's capacity for self-care and considering individual support needs. ACKNOWLEDGEMENTS

None.

CONFLICT OF INTEREST

The authors declare no Conflicts of Interest.

DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions

ETHICAL STATEMENT

The Regional Ethics Board, Lund, Sweden (No. 2011/451).

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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