

**KEYWORDS** 

Colorectal cancer

Experience

Recovery

Older people Qualitative study

Social support

Kristina Sundt Eriksen, MSc, RN Sissel I. E. Husebø, PhD, RN Hartwig Kørner, MD, PhD Kirsten Lode, PhD, RN

OPEN

# Long-term Recovery After Colorectal Cancer Surgery Among the Old

A Qualitative Study

**Background:** Colorectal cancer is the third most frequently diagnosed cancer worldwide, disproportionally affecting older people. With modern treatment, older people are surviving cancer treatment and recovery. However, only a limited number of studies on the older person's experience of recovery exist. Knowledge of the experience of recovery among people 80 years or older is essential to optimize recovery and follow-up care. **Objective:** The aim of this study was to explore the experiences of persons 80 years or older during recovery up to 2 years after curative colorectal cancer surgery. Methods: This exploratory inductive qualitative study was conducted through 18 individual in-depth interviews between July 2020 and June 2021. Content analysis was used to analyze the data. **Results:** The main theme identified was Recovery among the old is a complex process. It indicated that older people operated on for colorectal cancer may have intricate health challenges that affect recovery in addition to their cancer and treatment. The main theme is built upon the subthemes Individual factors affect colorectal cancer recovery and External support systems facilitate and impede colorectal recovery. Conclusion: Important resources for recovery among old patients included their own coping ability and support from social networks and healthcare services. The identified barriers to recovery included other health problems and issues with healthcare services delivery. Implications for Practice: It is essential for healthcare personnel in contact with older patients to be aware of factors that influence their recovery to identify and preserve the older person's resources and implement health-promoting initiatives to optimize recovery when needed.

This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

Accepted for publication February 5, 2023. DOI: 10.1097/NCC.00000000001241

Author Affiliations: Department of Research (Ms Eriksen and Dr Lode) and Department of Gastrointestinal Surgery (Ms Eriksen, and Drs Husebø and Kørner), Stavanger University Hospital; Faculty of Health Sciences, University of Stavanger (Ms Eriksen, and Drs Husebø and Lode); and Department of Clinical Medicine, University of Bergen (Dr Kørner), Norway.

The authors have no funding or conflicts of interest to disclose.

Correspondence: Kristina Sundt Eriksen, MSc, RN, Department of Research, Stavanger Ûniversity Hospital, Gerd-Ragna Bloch Thorsens Gate 8, 4011 Stavanger, Norway (kristina.sundt.eriksen@sus.no).

olorectal cancer (CRC) is the third most frequently diagnosed cancer worldwide in both sexes.<sup>1</sup> Approximately 40% of all CRC patients in Norway are older than 80 years.<sup>2</sup> With increasing life expectancy, the number of people newly given a diagnosis of CRC is estimated to have risen proportionately. Improved treatments have led to more people living with cancer as a chronic condition rather than succumbing to the disease. National guidelines in Norway recommend that the follow-up care after curative CRC surgery of patients 80 years or older be determined individually outside systematic follow-up programs.<sup>3</sup>

Older people have a higher distribution of complex medical comorbidities, polypharmacy, and reduced reserve capacity in addition to the risk of experiencing social, functional, and cognitive decline.<sup>4,5</sup> Left untreated, CRC can cause severe symptoms and death, and surgery is the only curative treatment option. Elective surgery for CRC is considered safe among all patients.<sup>6</sup> However, CRC surgery is associated with short- and long-term complications and symptoms that may be particularly bothersome for older patients.<sup>7–9</sup> Physical functioning has been reported to be significantly reduced in older people 2 years after CRC surgery.<sup>8,10</sup> Reduced physical function and persistent symptom burden continuously affect recovery, everyday life, and coping capacity.<sup>10,11</sup> Thus, older people are more prone to having delayed recovery compared with their younger counterparts.<sup>12</sup> However, health-related quality of life has been found to have improved already 3 months postoperatively and be sustained forward compared with preoperative levels.<sup>13</sup> Studies that explored aspects of recovery after surgery for CRC among the old found variations in the quality of follow-up care, a lack of individualized rehabilitation, and experience of unmet needs of social support.<sup>14–16</sup> The risk of unmet needs of social support was associated with a high symptom burden.<sup>16</sup>

Despite experiencing challenges shortly after discharge, older people seem to cope and persevere.<sup>15</sup> This may be in accordance with the theory of salutogenesis, that is, the ability to perceive life as manageable and meaningful, in addition to the experience of situations as comprehensible, termed a person's sense of coherence (SOC).<sup>17</sup> Sense of coherence can be seen as a health-promoting resource that measures a person's capacity to cope.<sup>18</sup> Research has shown that SOC correlates with age and physical function in CRC recovery among the old<sup>19</sup> and protects against negative health outcomes in an older general population.<sup>20</sup>

However, there is a lack of knowledge on how older persons experience recovery beyond the first few postoperative weeks. Accordingly, we consider that knowledge of the long-term recovery of old patients using a qualitative approach is needed to better understand the challenges faced by this patient group and facilitate optimal follow-up. Thus, this study aimed to explore how persons 80 years or older experienced recovery up to 2 years after curative surgery for CRC.

## Methods

This study has an exploratory inductive qualitative design to illuminate patients' experiences of recovery in the first 2 years after surgery.<sup>21</sup>

## Participants and Procedure

Participants were recruited from a university hospital in Western Norway with a catchment area of 18 municipalities with approximately 400 000 inhabitants. The hospital performs more than 300 elective or acute CRC operations annually and is the only hospital that offers surgical services for CRC in the catchment area. Approximately 40% of the operations are on people 80 years and older.

Convenience sampling was applied because the participants themselves had to take action and contact the researcher to volunteer to participate.<sup>22</sup> The inclusion criteria were (1) having undergone elective curative resections for stage I to III CRC between 1 and 2 years prior and (2) being 80 years or older at the time of surgery. Exclusion criteria were (1) the presence of cognitive impairments and (2) the inability to understand and speak Norwegian.

An electronic patient record database was screened in May 2020 to identify persons matching the inclusion and exclusion criteria. Invitations to participate were sent to all identified persons who met the inclusion criteria by mail with detailed information on the study, along with return envelopes for the informed consent form. After receiving the consent forms, the first author phoned the participants to set a time for the interview.

Of the 15 eligible participants, 10 agreed to participate. The first 7 interviews were conducted in July and August 2020. One informant proved unsuited for participation in the study due to reduced general and mental health and was therefore excluded. Because of a rise in the reported number of COVID cases in the area, data collection was paused until May 2021, when the pandemic regulations permitted the resumption of interviews. Because of the extended time since surgery, 3 participants awaiting interviews were excluded. Consequently, an additional recruitment round was performed in May 2021. Of 31 eligible participants, 14 agreed to participate in the study. However, only 12 interviews were conducted as little new information was brought forth in the last interviews and we concluded that saturation had been achieved. The interviews were conducted in June 2021. To sum up, the first 6 interviews were conducted in 2020, followed by 12 interviews in 2021, resulting in a total of 18 individual face-to-face in-depth interviews.

### **Data Collection**

All interviews were conducted by the first author (K.S.E.) in the participants' homes and lasted approximately 1.5 hours each. Before the interviews, an interview topic guide was developed based on the study's research objective and existing literature<sup>15,19</sup> (Table 1). The interviews started with the overarching opening question: "Can you describe your experience after surgery, how you felt, and what you experienced in the first days at home, the first weeks, months and year, up until now?" The participants' response to the opening question often covered several items in the interview topic guide. It was therefore used flexibly to accommodate items and issues raised by the participants.<sup>23</sup> Follow-up questions were asked to clarify uncertainties and to obtain more detailed descriptions. The participants were encouraged to speak freely about their experiences of recovery.

Opening question: Can you describe your experience after surgery, how you felt, and what you experienced the first days at home, the first weeks, months and year, up until now?

Topic Areas	ltems	Questions
Significance of the disease	Experience of symptoms	Which symptoms have you experienced?
in everyday life	Experience with complications	Have you experienced complications? If yes, can you describe further?
	Influence in everyday life	How did the experience (symptoms or complications) affect everyday life?
	Stoma or anastomosis	Did you have a stoma because of your surgery?
		How did you experience having a stoma?
		What challenges have you had with your stoma?
		How did the wound heal?
Coping	Need for support	What support did you need?
		Was there any support you wished you had?
	Involvement of social support	Do you have any family, friends, or others who helped during recovery?
		What was the nature of these tasks?
Follow-up care	Possibility of influencing follow-up	Did you have any influence in the organization of your follow-up?
	Organization of follow-up	Have you been in contact with healthcare services after discharge? What
		kind of follow-up care have you received?
	The general practitioner's role	How has your general practitioner been involved after discharge? Did you talk to your general practitioner about your cancer surgery or recovery?
	Other follow-up arrangements	Have you had contact with other healthcare personnel after discharge?
	Inclusion of next of kin	Were your next of kin, family, or friends involved in communication with healthcare services?
		Did they receive any information before discharge or after doctor visits?
	Information	Did you receive information regarding recovery, activity, possible
		complications, or ways to handle symptoms? Did you miss any

Abbreviation: CRC, colorectal cancer.

The interviewer took field notes to navigate the interview, in addition to helping preserve and explore nonverbal communications through follow-up questions. The notes were not included in the analysis but sometimes served as additional information. The interviews were digitally recorded and transcribed verbatim.

#### **Data Analysis**

Data were analyzed according to the work on qualitative inductive content analysis by Graneheim and Lundman<sup>24,25</sup> to gain a deeper understanding of recovery from CRC surgery among the old. An analysis team consisting of the first, second, and last authors contributed to the analysis. All members of the analysis team are registered nurses and have experience with conducting qualitative studies and the accompanying analysis. The first author is a doctoral fellow at a university and has over 15 years of experience working with geriatric and CRC patients. The other members of the analysis team each hold a PhD in health science and have experience researching patients with cancer. The fourth author is a colorectal surgeon and professor with an extensive background in treating CRC patients.

The analysis was conducted in 3 steps. The first step began with familiarization with the transcripts to gain a comprehensive understanding of the extent of the data. The first author then performed a decontextualization of the interviews by identifying and dividing the interview transcripts into meaning units. The meaning units were condensed before they were abstracted and labeled with codes describing the content. A transcript of the meaning units with associated condensed meaning units and codes was distributed among the analysis team. Each member of the team systematically reviewed the entire transcript before discussing the decontextualization process and making appropriate adjustment to the codes. In the second step, the first author recontextualized the data material by forming subcategories based on patterns linking different codes. Patterns across subcategories were then linked in categories describing the visible patterns in the data.<sup>24</sup> In the third step, the mutual underlying meaning for several categories was interpreted into themes. A new transcript of the analysis

**	Table 2•	An Examp	le of the	Analysis	Process

Meaning Unit	Code	Category	Subtheme	Theme
"In the hospital, they said that when I got home, a (homecare) nurse would come. They would notify the homecare nurses that they should come, but that they probably would not be able to come until the next day. The next day, no one came, so I called my daughter, who in response called (the homecare nurses). It turned out they had not received notification that they should visit me." (P7)	Homecare nurse did not come as promised	Healthcare services may create problems in recovery	External support systems facilitate and impede colorectal cancer recovery	Recovery among the old is a complex process

with themes, categories, codes, and meaning units was distributed to the analysis team. The analysis team then discussed the recontextualization, which caused the emergence of a main theme, reducing the other themes to subthemes based on the interpretation of the underlying meaning of the themes.<sup>24</sup> See Table 2 for a detailed example of the analysis process. The qualitative data analysis software NVivo  $12^{26}$  was used to organize the data and support a systematic analysis.

## **Ethical Considerations**

Ethical approval was obtained from the Regional Ethics Committee of Western Norway (REK Vest 19983) as well as from the hospital. Eligible participants were provided with written and oral information about the study and their rights. Before the interviews, consent forms were signed and the information on the participants' rights was repeated. Pseudonyms were used to protect the identities of the participants.

### Trustworthiness

The study's trustworthiness was managed according to 3 characteristics: credibility, dependability, and transferability. This approach was first described by Lincoln and Guba<sup>27</sup> and has been recommended for qualitative content analysis.<sup>24</sup> Credibility was ensured continuously throughout the study through multiple actions. The authors have experience in working with surgically treated patients with CRC, geriatrics, and qualitative research methodology, which enabled them to gain insight and interpret the participants' experiences in a novel way that could otherwise be difficult. During the interviews, the interviewer continuously checked whether the understanding of the topic was correct. Although the study used a convenience sample, the variety in personal characteristics was considered adequate to ensure rich descriptions of the phenomena studied. During the analysis, discussions within the research team provided various interpretation of the analysis, critical discussion, and readjustment to the generated codes, categories, and themes. To ensure *dependability*, the same interview guide was applied to all the interviews with the same researcher to minimize the risk of inconsistency. To ensure transferability, detailed descriptions of the context, participants, recruitment, data collection, and analysis are presented. In addition, comprehensive descriptions of the findings were provided, together with appropriate quotations. The transferability of the results to other cultures may be limited because all the participants in the study were

of Norwegian descent. However, the detailed descriptions of the experience of recovery among the old can help readers to identify and transfer patterns of interest outside the current context.<sup>28</sup>

## Results

#### Sample

The participants' mean age at the time of surgery was 85 years, and the mean time since surgery was 18 months. Four participants lived in rural areas, 2 had received radiation before surgery, and 6 participants received a stoma as a part of the cancer operation (see Table 3 for further details).

During the interviews, participants described different aspects of recovery and their impact. *Recovery among the old is a complex process* constituted the main theme that represented the internal link between the 2 subthemes, each based on 2 categories (see Table 4).

## Main Theme: Recovery Among the Old Is a Complex Process

The main theme describes several factors affecting recovery, such as the participants' general health condition, social relationships, and changes to everyday life caused by the cancer or treatment. External help from social networks and healthcare services promoted recovery by providing support when unmet needs occurred; however, an issue arose when expectations of support

* Table 3 • Characteristics of the Pc	articipants		
Characteristics n			
Age at surgery, y			
Median (range)	85 (81-92)		
Gender, n			
Female	10		
Male	8		
Marital status, n			
Married	11		
Single/widowed	7		
Location of cancer			
Colon	13		
Rectum	5		
Months since surgery			
Median (range)	18 (12-23)		

Table 4 • Overview of Theme, Subthemes, and Categories

Category	Subtheme	Theme	
The burden of recovery in old age The strength within the resilient older person	Individual factors affect colorectal cancer recovery	Recovery among the old is a complex process	
Healthcare services and social network provide support for unmet needs in recovery Healthcare services may create problems in recovery	External support systems facilitate and impede colorectal cancer recovery		

and reality were unaligned. This theme consists of 2 subthemes, namely, *Individual factors affect colorectal cancer recovery* and *External support systems facilitate and impede colorectal cancer recovery*. Each subtheme is built upon 2 categories.

## Subtheme 1: Individual Factors Affect Colorectal Cancer Recovery

This subtheme concerns individual factors of the older person that affect recovery. The older person's inner strength was exhibited through their management of adversity. Individual resources such as positive thinking and sheer determination helped them cope and persevere during recovery. At the same time, the burden of recovery in old age was divided between how the older person experienced challenges and symptoms from the cancer treatment, and how other diseases could shift focus away from recovery because of the manifestation of more alarming and intense symptoms.

## CATEGORY: THE STRENGTH WITHIN THE RESILIENT OLDER PERSON

The participants' reflections on challenges experienced during recovery and management demonstrated their inner strength. They described a motivation for active rehabilitation and a desire to acquire new abilities to be independent. Participants with stomas had to learn to perform self-care, also in less-than-ideal situations when experiencing leakage. Sometimes, they had to test different products to find the ones that suited their needs. Nonetheless, they wanted to end assistance from healthcare personnel as soon as possible once they could manage themselves; however, this could take a while.

In the beginning, they (home care nursing) came both in the morning and at night, but not for long.... Next, they just came in the morning.... Then I began changing the (stoma) bag by myself, which led them to only come Mondays and Thursdays to change the (stoma) plate.... After that, I said I could manage on my own. (P7)

They often needed help at the beginning of their recovery and had to be realistic regarding their own limitations. A few informants described situations in which they had exceeded their capacity in pursuit of independence, causing a setback in recovery. For a while, only essential chores were performed, and the rest had to wait. By implementing different types of aids, such as walkers or personal alarms connected to home care nursing, they tried to manage as much as possible by themselves. Several requested aids initially enabling them to stay self-reliant in addition to providing a feeling of safety. The use of aids was especially frequent in the first part of their recovery at home but sometimes continued further in their recovery journey.

You can function when you are old and had this (operation) and everything, but you have to want to. You cannot sit down, think, and feel sorry for yourself or something like that. You have to try to do what you can for as long as you can. I think that is very important. (P14)

Many of the participants had faced cancer before or had witnessed others going through cancer treatment, some with fatal outcomes. This experience altered their thoughts about the cancer trajectory, and they described being more resilient toward the psychological strain of receiving a cancer diagnosis, treatment, and recovery. They did not allow challenges or suffering in recovery to overshadow everyday life but rather focused on the positive. The cancer itself was not something they thought about; it was only when something went wrong that the thought of recurrence emerged, triggered by either new diseases or injuries. They often felt cured after the cancer surgery, and several informants expressed feeling lucky compared with others.

Another person had rectal cancer. He had to undergo surgery to receive a (stoma) bag. Afterwards, he was going home for a few months before having a new surgery where they would try to make a new rectum. When you think about such things, I am actually problem-free. (P11)

#### CATEGORY: THE BURDEN OF RECOVERY IN OLD AGE

The participants experienced a lack of capacity to manage recovery. Most of their attention was initially drawn to feelings of being impaired by symptoms such as pain, reduced appetite, reduced general condition, and reduced physical function and energy. They also experienced problems related to urination and the leakage of urine, stool or stoma leakage, odor, sleep, and mental capacity. Some experienced complications such as ileus, hernia, or infections and described this as causing a deterioration in recovery.

When it (the surgical wound) was infected...everyday life was affected of course.... I was not productive since I could not do anything, it hurt. I managed to care for myself because that was important to me. No, I needed help, and I had no energy. (P16)

Symptoms were divided into initial and persistent symptoms. Initial symptoms lasted between a few weeks and half a

year. Afterward, some participants felt that they had regained their general condition and health, thus considering recovery to be complete. At the same time, most participants described having overcome the most bothersome symptoms but conceded to not being fully recovered and described experiencing persistent symptoms for up to a year or longer after surgery. These symptoms became an integrated part of everyday life. The most frequent symptoms were problems with stool, odor, and reduced physical function and energy. It became difficult to know which bodily changes were due to physical decay related to increased age and which were due to the cancer treatment. The participants were confronted with their mortality when they began preparing for the future. Responsibilities had to be managed, and they reflected a great deal on not wanting to be a burden. However, their descriptions of events portrayed them as lonely and sometimes ashamed of their circumstances in their attempt to manage challenges in recovery, hindering them from seeking necessary help.

I sat down on the toilet when it exploded. It was horrible. I felt if I asked for help, they would most certainly throw up. I had to take care of it myself, which I did. I rinsed, dried and managed to clean up by myself.... It was embarrassing. You cannot ask someone else to come and clean up after you, at least not when you are of a clear mind. (P5)

Other health problems shifted focus away from recovery in the form of persistent symptoms of previous health problems, the occurrence of new health problems after the cancer surgery, or diseases uncovered during the CRC trajectory. This could take the form of existing or new symptoms such as dizziness, heavy breathing, a drop in blood pressure, pain, reduced energy, or lack of mobility. Alternatively, it could include physical injuries such as trauma to the extremities or back or an additional cancer diagnosis. The need to undergo treatments, procedures, and surveillance for new health problems affected the participants' physical functioning and mental strain. Regardless of origin, the experience of symptoms related to old or new health problems could impair their capability to engage in rehabilitation and health-promoting activities.

It is not the cancer that troubles me the most. If it had just been it (the cancer), I think I would have been able to do more. If my legs worked right and I had a good back, I would have been better, I could have accomplished more.... I have trouble walking, but I try to go for a walk nearly every day, but it hurts.... Yes, of course, it has a negative effect. (P15)

## Subtheme 2: External Support Systems Facilitate and Impede Colorectal Cancer Recovery

This subtheme concerns the impact of external support systems on the recovery of older persons after surgical CRC treatment. The external support system consisted of the patient's family, support from home care nursing in the municipality, and, in a few cases, close friends. The support system could compensate for the needs and care that the older patients were unable to fulfill and provide for themselves. However, problems in recovery could arise when they experienced discrepancies between their expectations of home care nursing and reality.

#### CATEGORY: HEALTHCARE SERVICES AND SOCIAL NETWORK PROVIDE SUPPORT FOR UNMET NEEDS IN RECOVERY

Having a supportive network of family or close friends was a vital resource for recovery. The interviews contained descriptions of practical and psychosocial support from family members when needed. The older participants had few expectations of support from family but appreciated the assistance immensely. Family members provided help with practical tasks such as housework, shopping, and transport in addition to visits. Municipality services lacked facilities for these practical everyday tasks. Consequently, if the participant's social network was sparse, these tasks were described as challenging and could remain unfulfilled. An intimate partner often assisted with personal hygiene otherwise covered by home care nursing. Furthermore, support from home care nursing consisted of assistance in performing procedures such as wound care, rehabilitation, stoma care, stitch removal, and the administration of medication. In addition, home care nursing provided assistance in acute situations, for example, if the participant had fallen, felt unwell, or experienced stoma leakage. The participants were more dependent on help initially in recovery and managed successively more as their general condition improved and symptoms subsided. They gradually regained strength or learned how to perform the procedures themselves, thus eliminating the need for help from home care nursing.

There are days that are difficult with (stoma) leakage and such. However, now I know what to do.... Now I manage. In the beginning, I had to call and get help from home care nursing, but now it is fine. (P15)

Some participants mentioned the importance of calling healthcare personnel if something happened during recovery. General practitioners, home care nurses, and specialist nurses at the stoma outpatient clinic were mentioned as good supporters to make them feel safe at home.

You always have to know from where you can receive help, yes. It is that communication that makes you feel like you are not isolated. That someone says you can call...just as in the hospital with the stoma nurse whom you can call and ask—Is this normal? It is very important that you don't need to wonder and feel (so you can abandon the feeling) that you cannot get the help you need. I think that means a lot. (P14)

## CATEGORY: HEALTHCARE SERVICES MAY CREATE PROBLEMS IN RECOVERY

Some aspects of follow-up care may become barriers to recovery, such as an imbalance in anticipated and provided support or the occurrence of unrealistic expectations of the older person's capacity for management of healthcare activities.

Discrepancy sometimes occurred between the expected and provided support, resulting in unmet needs in recovery. Throughout recovery, several participants described needing support from healthcare services. A few participants reported that their requests for assistance or aids were denied by the healthcare service, such as a request for assistance with food preparation because of reduced energy or installment of a door opener because of reduced physical function. The rejection made the participants feel worthless and resulted in everyday life being more challenging. Miscommunication and lack of collaboration within and between the specialist healthcare service and the primary healthcare service could ultimately affect the assistance provided to the participants; many did not receive the services promised. This could be help from home care nursing, as promised by nurses in the hospital, or follow-up from the hospital, as described by their general practitioner. One participant described consulting her general practitioner after experiencing bleeding per rectum months after surgery; however, she did not receive a directive for further testing from the hospital, contrary to instructions from the general practitioner, and had to pursue this herself.

But I did not hear anything. Time passed and then I thought I had to make an appointment with my general practitioner to ask about it.—I have not heard anything from the hospital, I said (to the general practitioner).—Oh! Good of you to come, he said, I will call them at once. He was surprised. I got an appointment a week afterwards.... I was nervous for several months and thought it (the cancer) had come back again. (P13)

The expectations of the healthcare service regarding the participant's ability and capacity to manage became visible. There was an expectation from healthcare services that the participant could use e-health services when communicating with some healthcare services. However, several participants did not manage e-health services because they were not digitally competent, resulting in a feeling of helplessness. Furthermore, the follow-up surveillance offered to the participants varied in addition to the responsibility for the follow-up schedule. Several were enrolled in a systematic 5-year follow-up program with regular blood tests and different diagnostic tests, whereas others had no follow-up. One participant wanted more follow-up as a reassurance of the cancer being gone, whereas another trusted the doctor's judgment regarding what was needed in terms of follow-up.

In a few instances, the general practitioner took the initiative to organize the follow-up appointments. Otherwise, and most often, the participants themselves were responsible for arranging the follow-up appointments by contacting their general practitioner, who organized the appointments. When the participants were responsible for the follow-up schedule, they often felt burdened with having to be in control of the follow-up schedule. Management of the follow-up program by participants initially resulted in some missed appointments in the schedule. The responsibility of managing follow-up care could be an extra burden, especially when considering that the participants often had other diseases also in need of healthcare surveillance.

There were quite a few appointments for a while. One day, I started to cry when I thought—Ugh, cardiologist, clinic for skin disease, gynecologist...But then I calmed down a bit and looked at the appointments and sorted out the ones I could not attend since I was going into town (outpatient clinic for skin disease) on Monday, Wednesday and Friday. It was a bit much. (P4)

## Discussion

This study explores the experience of recovery after curative CRC treatment among the old in the first 2 years after surgery. Our findings illustrate that recovery among the oldest old is a complex process. They described experiencing issues over which they had little control—such as other health issues, the presence of symptoms and complications, and insufficient collaboration with healthcare services—and how this ultimately affected daily life. Given the SOC concept, the issues experienced can affect the older person's comprehensibility and understanding of the situation. Consequently, they can challenge the older person's coping capacity. However, these participants also described supportive factors in recovery, such as their inherent resilience and supportive environments, which helped them manage challenges.

This study found that recovery at home varied between the participants in relation to recovery time, functional status, the occurrence of symptoms, severity, and duration. The participants described recovery as being a challenging time in terms of managing symptoms and complications, most frequently in the beginning, although some symptoms persevered. Experiencing symptoms and complications required the older person to take responsibility for the required medical treatment and necessary care at home. Long-term physical effects and adverse events after medical treatment were seen to be an extra burden in recovery<sup>29</sup> and possibly have a profound impact on functional outcomes.<sup>30,31</sup> Furthermore, receiving a stoma can be a specific burden related to CRC treatment. Having a stoma and being older than 85 years increased the probability of experiencing a higher frequency of symptoms up to 2.5 years into recovery.<sup>32</sup>

The participants in this study were concerned with physical function, symptoms, and returning to a normal life beyond 1 year after surgery. The participants experienced reduced physical function compared with the preoperative status and felt like a burden to others because they experienced limitations in everyday life. These findings are in accordance with the results of previous research, which found that older CRC patients experienced decreased physical functioning up to 28 months after surgery.<sup>10</sup> The limitation in physical functioning affected the participants' ability to perform everyday tasks and health-promoting activities, have an active social life, and regain autonomy. This shows that individualized follow-up care is an important aspect of the cancer trajectory in older cancer patients.<sup>33</sup> Promoting resource-oriented follow-up care could improve their health<sup>18</sup> and ability to manage recovery. This agrees with the theory of salutogenesis. By screening older patients for SOC through the Orientation to Life Questionnaire, healthcare personnel can identify problem areas and the resources that patients still possess. This information will enable them to identify areas needing health-promoting activities and identify and use the person's strength in these. Although no cutoff points are provided for the questionnaire, a higher score equals better SOC.17 Older individuals with low SOC could be identified and provided targeted initiatives to improve their SOC<sup>34</sup> and optimize individual recovery.

Some participants in this study did not necessarily ask for help from home care nursing when needed because of the shame they felt in the situation, such as situations involving uncontrollable bowel function. Fear of recurrence, feeling ashamed, and having problems discussing the issue with others can be a result of uncontrollable bowel function as a consequence of cancer treatment.<sup>35</sup> It can be difficult to talk about and impair participation in social life.<sup>36,37</sup> To be mentally prepared and able to cope in recovery with the potential challenges and responsibilities, in addition to asking for help when needed, the quality of perceived information before discharge is important.<sup>14</sup>

This study found that several participants were enlisted in a 5-year follow-up program, although national guidelines do not recommend the systematic follow-up of patients 80 years and older but rather encourage them to keep in contact with the general practitioner.<sup>3</sup> On the basis of the findings of this study, the decision to enroll old patients in the systematic follow-up program should be made on an individual basis because most old patients with metachronous metastases will not be eligible for treatment or cure. This study found that they need individually tailored follow-up care to manage their symptoms and complications. Another important finding was that chronic illnesses and other health issues increased the participants' burden of organizational responsibility. The participants found the responsibility in terms of healthcare follow-up to be demanding and sometimes incomprehensible, which could hamper follow-up adherence. Besides a few general practitioners who took responsibility for the follow-up appointments, the participants did not describe any assistance from healthcare services in lifting this organizational burden. Increased healthcare utilization among the old naturally follows increased health problems and encompasses the coordination of treatments and appointments for multiple health problems in some cases. For older people who recover after CRC surgery, this involves not only dealing with their recovery but also having to manage other health problems in addition to normalizing everyday life.<sup>38</sup> This burden of recovery is an aspect of recovery from CRC surgery among the oldest old that up until now has been little explored.

We also found in this study that chronic illness and other health problems shifted focus away from recovery and hindered health-promoting activities among the old. Comorbidities have received a lot of attention in research on CRC patients, especially in older patients, where the focus has been on the prognostic value of treatment outcomes.<sup>39,40</sup> However, the effect of comorbidities and other health problems on recovery after discharge has received less attention. A large population-based study found that older people after cancer treatment had on average 5 comorbidities, with 2 emerging after the cancer treatment.<sup>41</sup> Complex health problems in older patients have been shown to disrupt all aspects of everyday life and were seen in this study to further hamper the ability to take part in health-promoting activities.<sup>42</sup>

Furthermore, having a supportive network, that is, family or close friends, was seen to be a vital resource in CRC recovery among the old, concurrent with earlier research.<sup>14,15,43,44</sup> Social support can positively influence an individual's SOC by shaping a perception that can boost the individual's meaningfulness. By providing meaning and aid to their situation and defining challenges, social support contributes to disease management and is therefore considered to be a health-promoting resource.<sup>17,45</sup> Studies

have shown that social support is an important resource for older people to maintain functioning, physical health, and quality of life.<sup>46,47</sup> Our findings show that older patients appreciate help, but they were, to some degree, afraid of becoming a burden.<sup>14,15</sup> The finding that participants sometimes abstain from asking for help is an aspect that healthcare personnel need to be aware.

However, despite experiencing challenges in recovery, they managed well. They exhibited an inner strength through their descriptions of how they have experienced challenges and managed them through recovery. This is in accordance with previous findings on older persons' recovery after CRC treatment evalu-ated closer to the surgery.<sup>15</sup> The salutogenic theory proposes that through former encounters with challenging situations, the older person learns coping strategies and insights that promote adjustment to negative life events.<sup>48</sup> The older participants have accumulated life experiences through other stressful situations and management of them. This experience strengthens their SOC and shapes their perception of the cancer trajectory to make cognitive, behavioral, and motivational sense, thus allowing for the application of appropriate resources to manage the situation<sup>18</sup> that could make the cancer trajectory seem less daunting. Patients of higher ages seem to adjust better to cancer<sup>49</sup> and be psychologically less affected.<sup>50</sup> This also enables older people to adapt to the process of recovery from cancer and its challenges.

#### Limitations

This study has some limitations that must be addressed. Because of the convenience sampling, the sample may represent people with greater resources and a stronger SOC who experienced fewer challenges in recovery than the general population, which may introduce a selection bias. Consequently, challenges in recovery may be more prevalent in the general population of the old compared with the study population. However, the sample was recruited from an unselected patient population of a single institution offering surgical treatment. It represented a heterogeneous group of people with varying age, gender, cancer location, and living area. Because of the qualitative nature of the study, the results cannot be generalized to all older people recovering from CRC surgery.

The interviews were conducted up to 2 years after surgery, which could have affected the participants' ability to recall information. The interviews were conducted during the COVID pandemic, which could have affected recruitment, with fewer volunteers because of the potential fear of contamination because data were collected through face-to-face interviews. This could have limited the findings. The interviews were performed during periods when society was open, with few restrictions. However, the recovery included periods with stricter restrictions and societal lockdowns; thus, the findings regarding the ability to function in society may, to some extent, be masked because of this general barrier.

An aspect of CRC recovery that does not appear in our findings is the financial burden of cancer treatment and follow-up. In Norway, cancer treatment is free of charge and available to all Norwegian residents. In countries with other healthcare systems, the financial burden can be an aspect of recovery and should be taken into consideration.

#### **Implications for Practice**

Modern medicine allows more people to live with cancer in old age, wherein their cancer trajectory extends beyond discharge from the hospital after treatment. Our findings illustrate that older persons can experience complex healthcare conditions that can affect their coping capacity. The study illustrates a need for improvement of the care provided for the oldest old after curative CRC, addressing individual needs throughout the entire recovery process. Therefore, an understanding of older persons' experiences throughout the recovery process and the challenges they encounter and identifying health-promoting resources are essential to optimize follow-up care. Healthcare personnel in contact with this group of patients must be aware of the challenges the latter might encounter to be able to facilitate the older person's environment to promote their coping capacity. They should also make efforts to preserve and optimize the older person's physical function and independence in today's practice of follow-up care after CRC surgery. Furthermore, measures to reduce the burden of other healthcare problems and symptom management should be included in addition to actions to ease organizational responsibility when needed.

## Conclusion

Our findings suggest that older people recovering from CRC treatment are a vulnerable group with complex healthcare conditions that can influence and sometimes hamper their recovery. The older persons' inner strength and support from family and healthcare services were important resources in recovery after CRC treatment. At the same time, their general health and other health problems could hamper and prolong their recovery. We identified challenges they experienced in recovery that could be rectified to improve the care of older people after CRC surgery.

#### ACKNOWLEDGMENTS

The authors are very grateful to all individuals who willingly participated in the study.

#### References

- Sung H, Ferlay J, Siegel RL, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin.* 2021;71(3):209–249.
- Cancer Registry of Norway. Arsrapport Nasjonalt Kvalitetsregister for tykk- og Endetarmskreft 2021 [Annual Report for Colorectal Cancer 2021] Oslo: Cancer Registry of Norway; 2022.
- 3. The Norwegian Directorate of Health. Nasjonalt Handlingsprogram Med Retningslinjer for Diagnostikk, Behandling og Oppfølging av Kreft i Tykktarm og Endetarm [National Action Program With Guidelines for Diagnosis, Treatment and Follow-up of Patients With Colorectal Cancer] Oslo: The Norwegian Directorate of Health; 2021.
- Li LT, Barden GM, Balentine CJ, et al. Postoperative transitional care needs in the elderly: an outcome of recovery associated with worse long-term survival. *Ann Surg.* 2015;261(4):695–701.
- Aldwin CM, Igarashi H, Gilmer DF, Levenson MR. *Health, Illness, and Optimal Aging: Biological and Psychosocial Perspectives*. New York: Springer Publishing Company; 2017.
- 6. Forsmo HM, Erichsen C, Rasdal A, Körner H, Pfeffer F. Enhanced

recovery after colorectal surgery (ERAS) in elderly patients is feasible and achieves similar results as in younger patients. *Gerontol Geriatr Med.* 2017;3:2333721417706299.

- van Leeuwen BL, Påhlman L, Gunnarsson U, Sjövall A, Martling A. The effect of age and gender on outcome after treatment for colon carcinoma: a population-based study in the Uppsala and Stockholm region. *Crit Rev* Oncol Hematol. 2008;67(3):229–236.
- Couwenberg AM, de Beer FSA, Intven MPW, et al. The impact of postoperative complications on health-related quality of life in older patients with rectal cancer; a prospective cohort study. *J Geriatr Oncol.* 2018;9(2):102–109.
- Ommundsen N, Nesbakken A, Wyller TB, et al. Post-discharge complications in frail older patients after surgery for colorectal cancer. *Eur J Surg Oncol.* 2018; 44(10):1542–1547.
- Rønning B, Wyller TB, Jordhøy MS, et al. Frailty indicators and functional status in older patients after colorectal cancer surgery. *J Geriatr Oncol.* 2014; 5(1):26–32.
- O'Gorman C, Stack J, O'Ceilleachair A, et al. Colorectal cancer survivors: an investigation of symptom burden and influencing factors. *BMC Cancer*. 2018;18(1):1–10.
- Manceau G, Karoui M, Werner A, Mortensen NJ, Hannoun L. Comparative outcomes of rectal cancer surgery between elderly and non-elderly patients: a systematic review. *Lancet Oncol.* 2012;13(12):e525–e536.
- Rønning B, Wyller TB, Nesbakken A, et al. Quality of life in older and frail patients after surgery for colorectal cancer—a follow-up study. J Geriatr Oncol. 2016;7(3):195–200.
- Samuelsson KS, Egenvall M, Klarin I, Lökk J, Gunnarsson U, Iwarzon M. The older patient's experience of the healthcare chain and information when undergoing colorectal cancer surgery according to the enhanced recovery after surgery concept. *J Clin Nurs*. 2018;27(7–8):e1580–e1588.
- Eriksen KS, Eikeland Husebø SI, Kørner H, Lode K. Experiences of recovery from colorectal cancer surgery after hospital discharge among the oldest old: a qualitative study. *Nord J Nurs Res.* 2021;4(3):140–148.
- Williams GR, Pisu M, Rocque GB, et al. Unmet social support needs among older adults with cancer. *Cancer.* 2019;125(3):473–481.
- Antonovsky A. Unraveling the Mystery of Health: How People Manage Stress and Stay Well. San Francisco: Jossey-bass; 1987.
- Antonovsky A. The salutogenic model as a theory to guide health promotion. *Health Promot Int.* 1996;11(1):11–18.
- Eriksen KS, Lode K, Husebø SIE, Kørner H. Exploring variables affecting sense of coherence and social support in recovery after colorectal cancer surgery among the oldest old. *Geriatr Nurs.* 2022;47:81–86.
- Boeckxstaens P, Vaes B, De Sutter A, et al. A high sense of coherence as protection against adverse health outcomes in patients aged 80 years and older. *Ann Fam Med.* 2016;14(4):337–343.
- 21. Sim J, Wright C. Research in Health Care: Concepts, Designs and Methods. United Kingdom: Nelson Thornes; 2000.
- Polit DF, Beck CT. Nursing Research: Generating and Assessing Evidence for Nursing Practice. 11th ed. Philadelphia: Lippincott Williams & Wilkins; 2020.
- Kvale S, Brinkmann S, Anderssen TM, Rygge J. Det Kvalitative Forskningsinteruju [The Qualitative Research Interview]. 2nd ed. Oslo, Norway: Gyldendal Akademisk; 2015:50–60.
- Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today.* 2004;24(2):105–112.
- Graneheim UH, Lindgren B-M, Lundman B. Methodological challenges in qualitative content analysis: a discussion paper. *Nurse Educ Today*. 2017;56: 29–34.
- QSR International Pty Ltd. NVivo Qualitative Data Analysis Software, Version 12. QSR International Pty Ltd; 2018. https://www.qsrinternational.com/ nvivo-qualitative-data-analysis-software/home. Accessed December 10, 2022.
- 27. Lincoln YS, Guba EG. *Naturalistic inquiry*. Thousand Oaks: SAGE; 1985:289-327.

- Ponterotto JG. Brief note on the origins, evolution, and meaning of the qualitative research concept thick description. *Qual Rep.* 2006;11(3): 538–549.
- Sav A, McMillan SS, Akosile A. Burden of treatment among elderly patients with cancer: a scoping review. *Healthcare (Basel)*. 2021;9:612.
- Sav A, Salehi A, Mair FS, McMillan SS. Measuring the burden of treatment for chronic disease: implications of a scoping review of the literature. *BMC Med Res Methodol.* 2017;17(1):1–14.
- Norlyk A, Harder I. Recovering at home: participating in a fast-track colon cancer surgery programme. *Nurs Ing.* 2011;18(2):165–173.
- Downing A, Morris EJ, Richards M, et al. Health-related quality of life after colorectal cancer in England: a patient-reported outcomes study of individuals 12 to 36 months after diagnosis. *J Clin Oncol.* 2015;33(6):616–624.
- 33. Moser A, Melchior I, Veenstra M, Stoffers E, Derks E, Jie KS. Improving the experience of older people with colorectal and breast cancer in patient-centred cancer care pathways using experience-based co-design. *Health Expect.* 2021;24(2):478–490.
- Dietscher C, Winter U, Pelikan JM. The application of salutogenesis in hospitals. In: Mittelmark MB, Bauer GF, Vaandrager L, Pelikan JM, Sagy S, Eriksson M, Lindstrøm B, Magistretti CM, eds. *The Handbook of Salutogenesis*. Switzerland: Springer Open; 2017:277–298.
- Reinwalds M, Blixter A, Carlsson E. Living with a resected rectum after rectal cancer surgery—struggling not to let bowel function control life. *J Clin Nurs.* 2018;27(3–4):e623–e634.
- Thong MS, Koch-Gallenkamp L, Jansen L, et al. Age-specific health-related quality of life in long-term and very long-term colorectal cancer survivors versus population controls—a population-based study. *Acta Oncol.* 2019; 58(5):801–810.
- Norton C. Nurses, bowel continence, stigma, and taboos. J Wound Ostomy Cont Nurs. 2004;31(2):85–94.
- Sav A, King MA, Whitty JA, et al. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expect.* 2015;18(3):312–324.
- 39. Boakye D, Rillmann B, Walter V, Jansen L, Hoffmeister M, Brenner H.

Impact of comorbidity and frailty on prognosis in colorectal cancer patients: a systematic review and meta-analysis. *Cancer Treat Rev.* 2018;64:30–39.

- Simonds P, Best L, George S, Baughan C, Buchanan R, Davis C. Surgery for colorectal cancer in elderly patients: a systematic review. Colorectal Cancer Collaborative Group. *Lancet.* 2000;356:968–974.
- Leach CR, Weaver KE, Aziz NM, et al. The complex health profile of long-term cancer survivors: prevalence and predictors of comorbid conditions. J Cancer Surviv. 2015;9(2):239–251.
- 42. Skilbeck JK, Arthur A, Seymour J. Making sense of frailty: an ethnographic study of the experience of older people living with complex health problems. *Int J Older People Nurs*. 2018;13(1):e12172.
- Jakobsson J, Idvall E, Kumlien C. The lived experience of recovery during the first 6 months after colorectal cancer surgery. *J Clin Nurs.* 2017;26(23–24): 4498–4505.
- Stuhlfauth S, Melby L, Hellesø R. Everyday life after colon cancer: the visible and invisible challenges. *Cancer Nurs*. 2018;41(6):E48–E57.
- Wiesmann U, Hannich H-J. A salutogenic analysis of healthy aging in active elderly persons. *Res Aging*. 2010;32(3):349–371.
- 46. Sherbourne CD, Meredith LS, Rogers W, Ware J. Social support and stressful life events: age differences in their effects on health-related quality of life among the chronically ill. *Qual Life Res.* 1992;1(4):235–246.
- 47. Drageset J, Eide GE, Nygaard HA, Bondevik M, Nortvedt MW, Natvig GK. The impact of social support and sense of coherence on health-related quality of life among nursing home residents—a questionnaire survey in Bergen, Norway. *Int J Nurs Stud.* 2009;46(1):66–76.
- Averill PM, Beck JG. Posttraumatic stress disorder in older adults: a conceptual review. J Anxiety Disord. 2000;14(2):133–156.
- Cohen M, Baziliansky S, Beny A. The association of resilience and age in individuals with colorectal cancer: an exploratory cross-sectional study. *J Geriatr Oncol.* 2014;5(1):33–39.
- Hernández R, Calderon C, Carmona-Bayonas A, et al. Differences in coping strategies among young adults and the elderly with cancer. *Psychogeriatrics*. 2019;19(5):426–434.